

ARVs and Rural Communities: A solution or a dilemma?

by

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Introduction:

To date (2004), globally the HIV/AIDS pandemic has infected 60 million people .A disturbing factor is that of all the AIDS cases in the world, 50% are in only 15 countries i.e. Botswana, Côte de Voire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Zambia and Vietnam. (PEPFAR Presentation, September 2004). Specifically on Tanzania, with a population of 34.2 million people (2002 census) there is an HIV prevalence rate of 9.6% among the adult sexually active population (15-49 years). This situation has led the national leadership in 1999 to declare the pandemic a national disaster and:

‘called on the entire nation, including the government, political, religious and civil leaders and non-governmental organisations, on the importance of taking new measures to put the nation on a war footing against HIV/AIDS’ (President Benjamin W. Mkapa, National Policy on AIDS , 2001).

In response to the Tanzanian President’s call and the continuing spread of the virus, the country, in collaboration with all partners is intensifying its efforts in fighting the pandemic. To date, the pandemic ranks among the top priorities in government plans (CARF, 2003).

Fighting the HIV/AIDS epidemic:

In Tanzania the fight against HIV/AIDS has centred on prevention, care, treatment and support as well as impact mitigation. The balance among the three approaches has been a dilemma. Where should one place emphasis in terms on resources: money, men, materials and time? During the 2002 International AIDS Conference in Barcelona, Spain, it was strongly recommended that prevention and care, treatment and support must be accorded equal importance. The Action Treatment Campaign of the Republic of South Africa made history when it took the government to court and won the case for free access to anti-retroviral therapy for those in need of them. As already shown by successful local and community responses to HIV/AIDS, prevention and treatment are synergistic: access to HIV treatment enhances the effectiveness of prevention as well as voluntary counselling and testing (VCT) programmes. Prevention or reduction of new infections in the sero-negative population should not be pitted against care

for those who are already HIV-infected. The idea that prevention could be more effective than treatment ignores their interdependence and indivisibility of the two categories. Assuming that 20 –25% of the HIV-infected persons worldwide are symptomatic and/or in an advanced stage of Immuno-deficiency, 7.5 to 9 million living in developing countries are in urgent need of ARVs. In Tanzania, the majority of them in rural areas and hence difficult to access urban based ARV services. In contrast, a total of only about 200,000 HIV-infected persons, of whom 100,000 live in Brazil, use these treatments. In most industrialised countries, AIDS mortality has plunged sharply due to the advent of ARVs (Farmer, 2001). This is less than 3% of those in need. (Declaration for the Framework for Action Improving Access to HIV/AIDS in Developing Countries, 2004). To crown it all, women and girls bear the brunt of the epidemic through being the primary caregivers for the sick and hence the need to ensure that they in turn must have equitable access to health services and support, including ARV treatment as it becomes available, Sida: Eyes on AIDS, 2004)

The Tanzania case:

It is estimated that in Tanzania the national HIV prevalence rate among adults is 9.6% thus translating to 2.2 million Tanzanians. Twenty per cent of these people living with HIV/AIDS, i.e. 400,000 people are estimated to be in need of treatment with anti-retroviral therapy (ARVs). There are pockets of high cumulative reported AIDS cases (1993 –2003) found across the country e.g. Mbeya, Dar-Es-Salaam Kagera and Kilimanjaro, (HIV/AIDS/STI Surveillance report, No.18, 2004) yet Kagera was for years the topmost area with the highest HIV prevalence! Should equity values be adhered to during provision of ARVs, if so, then those in greatest need should be given priority in accessing the drugs.

If 400,000 PLWHA are already in need of ARVs, how many are getting the drugs? By 2003, only two thousand Tanzanians had accessed ARVs through the private sector. What can be assumed as the results for this group?

- Service providers were not trained
- Clients were not given adequate and correct health education related to ARVs
- No monitoring and evaluation mechanisms were in place
- ARVs bought in the private market were not regular neither were the clients regular in purchasing drugs
- The drugs were/are expensive hence unsustainable to many
- The importance of adherence was not as well emphasised as it needs to be

The results can be anticipated. A high rate of the emergence of drug resistant HIV strains and hence posing the danger of wide spread infectivity of the same hard-to-control strains. Why did such a small but economically able sub-population choose to get ARVs? It was unfortunate that the problem of access to treatment has focussed on provision or rather the non-provision of ARVs. The value of medication as treatment should not be underestimated in that for many this is a symbolic way of demonstrating care and valuing the lives of others. However treatment and care of PLWHA involves much more than the provision of medication. (AIDS Consortium, 1998) Nutrition is a key part of care. It is also true that arrival of ARVs has also raised the issue of access to treatment into the focus

of the media and international debate and has been a useful focus of activism. The use of ARVs is beneficial but it has also raised unrealistic expectations in that provision alone is not the sore answer without consideration being given to the complexities, which are:

- i. Difficulties of compliance
- ii. Difficulties of sustaining a continuity of supplies
- iii. Need to link ARVs and Nutrition
- iv. Need for continuous and accurate health education on ARVs

Tanesa and Kisesa Ward, Magu District:

Since 1990, Tanesa has been working in Kisesa ward of Magu district in Mwanza Region. The ward leadership and the community have been very cooperative. There are 28,000 residents, mostly of one ethnic group, Sukuma, 98% and mostly agricultural in their economic activity. Tanesa has carried out unlinked anonymous sero-status HIV testing since 1994, 1997, 2000 and 2003. The results of the first three rounds have been reported widely and were 6.2; 6.6 and 7.3% respectively while the 2003 are being analysed. Until 2003, there are 1018 PLWHA. According to National estimates, there are nearly 200 people who need ARVs. Of those 28,000 residents, there are people who have requested for voluntary counselling and testing and of those who attended, 160 were found sero-positive.

If we discuss those 200+ that are eligible for ARVs, what is the delivery vehicle in Kisesa ward?

There is one health centre, 4 government dispensaries and 3 private ones. In the health centre, there is 1 Assistant Clinical Officer (formerly RMAs), 1 Nurse Midwife, one Health officer, 1 Health Assistant, and four nurse auxiliaries. This is the human resource supposed to deliver ARVs to the eligible 200 clients. The nationally approved human resource for health quota needed to successfully deliver ARV services per site is:

- 1 Clinician
- 1 Nurse
- 1 Pharmacist
- 1 Laboratory technologist
- 1 Community-Based Home Carer
- 1 Voluntary Counsellor (and for testing)

The nearest referral centers are the Regional Hospital at Sekou Toure and the Bugando Medical Centre. The bus fare from Kisesa to the two sites is 1,400/- per one return trip. Yet in the same community, borrowing 200/- from a neighbour has to be witnessed by the ten-cell leader to assure re-payment. When/if ARVs start, these are the facts to be considered. But most important of all, can health centres become ARV delivery points in the near future? They are the very units closest to the clients. In the coming years, the enhanced performance of the overall health system may prove to be a critical cornerstone for new initiatives in health care, as countries like this, Tanzania, adopt new therapies and treatment for HIV/AIDS. It is obvious that good management, motivated health workers and functional networks of communication and transportation are required for such new

treatments to reach the people who need them and for those treatments to be used effectively Savigny, D.; Kasale, H.; Mbuya, C and Graham Reid, 2004).

The rollover plan for ARVs and what the mass media says:

In the Health Sector Strategy for HIV/AIDS, 2003-2006 (2003) under the chapter on Care, Treatment and Support, there are three groups of activities. Under activity (iii) the document mentions 'to scale up access to HAART stepwise from tertiary centres in the first instance to potentially include district health facilities in the context of training establishing and strengthening laboratory services and drug availability'. And the following opportunities are given, i.e.

- the presence of an accessible network of health care system from National to community Primary level that includes public, private and NGO run services
- the presence of National guidelines on the management of HIV/AIDS using ARVs
- a strong collaboration between public private NGO health care systems
- availability of a small but skilled expertise of various categories that can be utilised for training and scaling up services
- the existence of the MSD that can be restructured/improved to be able to procure, store and distribute ARVs
- willingness of the Government sector to invest and support the management of HIV/AIDS
- willingness of international partners to support various initiatives in the expanded management of HIV/AIDS for example Global Fund; Clinton Foundation, Diflucan initiative, e.t.c.

Hence the above situation forms the basis for the scaling up of the use of ARVs in Tanzania. As 80% of Tanzanians are in rural areas, the first opportunity hits the target. Yet the very introduction of the drugs while the public still has to be educated even more than the professional providers, raises a triple dilemma: to the providers, to the beneficiaries and to the government. Yet each of the three parties is engaged in the debate of the deaf. The mass media headlines bring the situation even more dramatically. Is it for better or for worse? I let you to decide. Here are samples. For example:

- Daily News 9 December 2004: Un envoy calls for action on AIDS with the main message being 'the Zanzibar government must do the needful in ensuring that it provides ARVs to orphans some of whom are living with HIV/AIDS
- Guardian December 2, 2004: AIDS: Basic issue ignored and went on to state that 'unless the country tackles gender inequality and curb unequal distribution of resources, Aids will continue to burden us for years to come'
- Daily News, December 2, 2004: Swaziland's queen takes up spear in AIDS battle' and Queen Inkhosikati LaMbikiza gave a famous male Swazi quote of a man: Yewela Make and stated that it is what a Swazi man says

to a woman when he wants sex i.e. 'I'm ready, come here'. without asking the woman are you OK? The word of the Swazi man is final' she said

- Hilary Benn, UK Secretary of State for International Development, Guardian 2 December 2004 in a titled interview stating 'How can the world overcome Aids? And he went on to state that that 'much of the work has to deal with issues which go way beyond Aids itself. The challenges of Aids are the challenges of education, of health services, of women rights, of business and economic development, of peace and stability'.
- Daily News 2 December 2004: China faces worsening AIDS situation: ...China for years denied AIDS was an issue and only started seriously addressing the problem in the past two years. Even so, ignorance about AIDS remains rife, with sufferers routinely facing widespread discrimination by local police, health authorities and the public'. In an effort to bring the problem into the open, President Hu Jintao yesterday publicly shook hands with AIDS patients and called for an end to discrimination!
- The Economist, November 27 2004 in an article titled 'The new face of AIDS' went on to report the following story: 'Women will soon be a majority of those infected with HIV. Male chauvinism is largely to blame. Charlene Smith a South African woman, who was raped in 1999, has since then campaigned against sexual violence and for the free provision of ARVs to prevent rape victims contracting HIV, the virus that causes AIDS. Neither of these stances you might imagine would be controversial. But both have enraged South Africa's President, Thabo Mbeki, who accuses Ms Smith, who happens to be white, of spreading the racist myth that African men are 'rampant sexual beasts, unable to control our urges, unable to keep our legs crossed, unable to keep it in our pants!' as he told the country's Parliament last month.

One is left to recall the famous phrase, 'we should be fighting the virus and not one another. The media of all types and colours should help in educating the masses for behaviour change and all communications should be geared towards that approach.

This presentation is addressing ARVs in rural Tanzanian communities.

In an article in the Mtanzania Jumanne Novemba 30, 2004: Mpango wa dawa za Ukimwi walalamikiwa: Serikali imelaumiwa kwa kutowapa haki watu wanaoishi na virusi vya Ukimwi katika mpango wake wa kutoa dawa za bure za kupunguza makali ya virusi hivyo!

'the government (of Tanzania) is blamed for not giving PLWHA priority in the freely available ARV programme'

It is heartening to learn that TACAIDS is soon to create a specialised cadre of journalists who will address the AIDS pandemic with accurate and informed articles in order to speak with one voice which are not contradictory. More

importantly to inform the public the dilemma inherent in ARVs. They do not work for all situations nor do they CURE AIDS!

ARV rollover in Tanzania:

'The sites and number of services to be covered during the financial year 2004/05 for the ARVs are 91 for Tanzania mainland. Of those sites the breakdown is as follows:

- 4 Referral Hospitals
- 22 Regional Hospitals
- 34 District Hospitals
- 30 Faith-Based/NGOs/Private Hospitals
- 1 Lugalo Military Hospital

Delivery plan for ARVs in Tanzania

It has been planned that 32 health care delivery facilities will commence delivering ARVs as from October 2004 and there will be a rollover plan such that in the first cycle 92 facilities will have been covered. Those most involved with HIV care and treatment at facility level have been listed above.

The trainers of all these cadres will be drawn from the same specialities. Until now the sub-district level has been left out for the time being. Is enough being done to explain why? The fear among many health workers is the potential interference and blame from an uninformed public. Why? Not all know that:

- ARVs are not for all those who have tested HIV +
- Only 20% of PLWHA and who have tested positive are due for ARVs
- The strong need for client education to accept taking the drugs for life
- The very strong need for an over 95% adherence or else the drugs do more harm than good

It has now been stated that the introduction of HAART will create an enormous burden on the health care delivery system. The National Care and treatment plan estimates that there is need for an additional 10,000 health workers while the actual need for health workers in order to achieve the millennium development goals is estimated to be 68,000! Compared to the current workforce of 43,000 only. There is a human resource 'crisis' which is irresolvable (Hales, et al, 2003). The brunt of the inadequacy of the health care human resource is born by the rural areas!

What has happened to those who had already received the ARVs prior to the current programme?

There are close to 2,000 clients who had started ARVs privately. The prescribers had not been trained nor the clients. Since it was the private sector, there was no accountability in terms of assuring continuity of drug supplies nor distribution let alone rational drug use. There were numerous reported cases of prescribers who had given their clients ARVs written 1BD for 7 days! The new climate has been

defined in the NACP/MOH document (2003) where it is planned that care, treatment and support will cover the following areas: training; CHBC; management of OI; improving access to HAART; nutrition and integrated HIV/AIDS/TB care. . Furthermore policy makers and programme managers to be aware that there is need to clearly define the systems and processes for scaling up care and treatment without compromising the overall general health systems issues (Bertozzi, et all, 2004; Hutton, 2004).

The case studies below demonstrate the position in the field:

Case Studies:

Case 1:

TD is a 36-year-old nurse at a District hospital in the Lake Zone. She had been married but now separated from her husband. She had found the husband with a girl friend and decided to test for her HIV sero-status. It was reactive. On requesting her husband to test, he refused. They were transferred to another district where the husband decided to marry a second wife. Since then he has again been transferred but left TD in the last station and he has re-married again. She was seen at Bugando Medical Centre where after a workout she was put on ARV (Triomune 40), which she had to buy from her meagre salary.

It did cost her 45,000/- per monthly dose. When she was seen she had abandoned treatment since the choice was to either bur the ARVs or pay the fees for her only son!

Case 2:

MW is a seamstress who tested HIV positive six years ago. She then saw a Clinical Officer who put her on locally grown Artemisa (powdered leaves and powder from the 'Miracle tree: Moringa Oleifera-natural nutrition for the tropics (Fuglie, 2001). When she was first seen by the author she was on Combivir, 1 BD that had been bought by her brother in Dar-Es-Salaam. There was no evidence of CD4 count and no any other clinical workout let alone her body weight. She was advised to not start on the drug until she has been assessed correctly. She now is on triple ARVs, which is being bought by the same brother. However last time she was seen she had 2 days supply of ARVs left and the brother had gone to Europe on duty travel and his return had been delayed! The free ARVs at BMC could not be accessed due to logistics problems.

Discussion:

There is need for a holistic approach to ARVs at community level. At that level the ratio for traditional healer to population is 1:300 while the equivalent ration for doctors is 1:15,000 at a very conservative estimate. Traditional healers are trusted and see many more clients at an even early stage that we do in hospitals. (Munthali, 2002). Are they enemies or co-workers? Have we brought them into the fold as far as ARVs are concerned? There is a great potential of conflict

between confidentiality and the community leaders who have not taken any oath of confidentiality and yet we expect them to support clients when it comes to ensuring they attend hospitals and get regular supplies of ARVs as well as adherence. Unlike other diseases, the adherence rates for ARVs must be 95%+ for any beneficial effect to be felt. When first line ARVs fail due to poor compliance, we are in a mess! Worse still most health learning materials on ARVs are in English and the majority of clients are non-English readers/speakers. As seen in the mass media publications, there is a lot of work to be done in public education. We need to involve PLWHAs in the planning of ARVs and even in the very criteria on who qualifies and who does not qualify for getting ARVs and why? It will be a hard sell but given political support there will be a greater chance of success and less interference from non-health workers as well as protecting ourselves from unwarranted accusations of corruption.

Has the choice of the health facilities for delivering ARVs adhered to equity considerations? i.e. are those with the greatest needs getting priority in service delivery for ARVs? The very cornerstone of the plan is the learning by doing. Training the trainers through allowing them to start the delivery and then teach those below them on how to operationalise the plan. The public need to be prepared to see the rationale of such an approach. The benefits of ARVs have been proven and they include: restoration and/or preservation of immunologic function; improvement of quality of life; reduction of HIV-related morbidity and mortality and restoration and/or suppression of viral load. (NACP/MOH 2004)

Conclusion:

In this very venue, in the 2002 Tanzania AIDS Society conference, there was an ARV parallel session, which had a presentation from a Swedish Professor. His advice was 'don't wait, start right away. There is no way you can learn without trying and making mistakes. We did the same thing'. It is very expensive to make clinical mistakes in ARVs but then no one is perfect including clinicians. That is why a team approach has been designed by the NACP/MOH to countercheck potential pitfalls. The challenge to the health workers is to change this dilemma into a solution to the PLWHA as others have done. Furthermore policy makers and programme managers to be aware that there is need to clearly define the systems and processes for scaling up care and treatment without compromising the overall general health systems issues.

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