ARV COMMUNITY KNOWLEDGE, AWARENESS, ACCESSIBILITY & THE POLICY ENVIRONMENT

A Compendium Report of Tanzania, Mozambique & Burkina Faso

Acronyms

ACORD	Agency for Co-operation and Research in Development
ART	Anti-retroviral Therapy
ARVs	Anti-retroviral Drugs
DDH	District Designated Hospital
EAC	East African Community
HASAP	HIV and AIDS Support and Advocacy Program
IEC	Information, Education and Communication
IGA	Income Generating Activity
MoH	Ministry of Health
NGOs	Non Governmental Organizations
PLHA	Persons Living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
PEPFAR	United States Presidential Emergency Plan for AIDS Relief
SADC	Southern African Development Community
TAWOLIHA	Tanzania Women Living with HIV and AIDS
TRIPS	Trade Related International Property Rights
TWG	Technical Working Group
UNAIDS	The Joint United Nations Program of HIV and AIDS
UNGASS	United Nations General Assembly Special Session on AIDS
VCT	Voluntary Counselling and Testing
WAMATA	Walio Katika Mapambano dhidi ya Ukimwi Tanzania
WHO	World Health Organization
WTO	World Trade Organization

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Executive Summary

Introduction

In 2006, the Agency for Co-operation and Research in Development (ACORD) through its HIV and AIDS Support and Advocacy Program (HASAP) undertook Anti-retroviral drugs (ARVs) studies in Burkina Faso, Tanzania and Mozambique. The overall objective of the three studies was to generate information to be used for advocacy by ACORD, as well as other relevant actors, for increased equitable accessibility to AIDS care and treatment services in African countries. The specific objectives of the studies included, among others, to:

- Find out peoples' knowledge and understanding of ARV treatment as well as sources of information for ARV treatment,
- Assess ARV accessibility and use by the population in the three countries,
- Find out the impact of ARV use,
- Analyse the national and international policies[1] and
- Make recommendations aimed at addressing identified gaps in the provisioning of ARVs related services.

All the three studies adopted a combination of qualitative and quantitative methodologies. ARV recipients were the primary study participants. A total of 103, 58 and 176 ARV recipients were interviewed in Tanzania, Mozambique and Burkina Faso respectively. Other study participants included non-users of ARVs (eligible PLHAs not on ARVs by own choice), members of the general community, and household members of ARV beneficiaries, health workers and district officials. Technocrats in the Ministries of Health, the National AIDS Control Program (NACP), WHO, UNAIDS, and associations of PLHAs.

Key Results

Profiles of ARV Recipients

In all the three countries, the majority of ARV recipients were female and basically resided in urban areas. Most of the ARV users in Tanzania

and Mozambique were heads of households and had attained low levels of formal education i.e., primary education and were generally poor as reflected by their main occupation. Almost a quarter (18%) of the ARV users' households in Tanzania had an estimated monthly income of less than US $10 per month and slightly over a tenth (12%) earned between US $ 25-40 per month.

Knowledge and Awareness of ARV Treatment

Overall, people's knowledge about eligibility to use ARVs including those currently on ART was limited. More than two-thirds (67.9%) and almost all (89.5%) ARV recipients in both Tanzania and Mozambique respectively believed that all PLHAs should be on ARVs. A significant proportion of ARV users shared the view that ARVs can be used in prevention of infection with HIV and AIDS. Glaring gaps in knowledge about ARVs, especially on who qualifies to take the drugs and the circumstances warranting a complete discontinuation of use of the drugs, existed. Comparatively, ARV users in Mozambique were less knowledgeable compared to those in Tanzania. The knowledge gap was also evident in the perceived reasons for taking ARVs whereby over a third of the sample in Tanzania, and a quarter in Mozambique, believed that taking ARVs would prevent HIV and AIDS. ARV knowledge gaps were not only confined to ordinary community members, but health workers as well.

Study findings revealed varying degrees of popularity of the different sources of information on ARV treatment and services. For instance, in Tanzania and Burkina Faso, Health providers/counsellors at the ARV dispensing site were reported as the main source of information on ARVs, whereas in Mozambique, they were among the least cited sources instead the commonly cited source of information about ARV treatment was the radio. In all the study areas, the commonly cited type of information received from the various modes of communication was on "access to ARV treatment centres". The major aspects

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[1] This aspect of the study was not covered in Burkina Faso

of ARV treatment were not being disseminated outside the ARV dispensing sites in all the study countries.

ARV Availability, Accessibility and Use

Though availability of ARVs showed signs of increase, it was still inadequate in all the three countries especially for those residing in rural areas. Accessibility to ARVs was therefore not universal to all in need in the three countries. Various barriers to use of and access to ARVs including facility based, policy, awareness, and transport related, as well as nutritional, were cited in almost all the three countries. In Mozambique and Tanzania ARVs are freely provided and hence no direct cost is incurred by the beneficiaries, but in Burkina Faso government does not provide universal access to treatment, although some people are able to access the drugs free through organizations such as SOS-SIDA, but others have to pay.

At the health facility, the commonly cited barrier to use and access to ARV treatment services was the inadequacy of personnel at the ARV dispensing site. All countries visited acknowledged having challenges with health workers trained to provide specialized AIDS care. The other facility related barrier was inadequacy of premises and other facilities.

Existing policies are also potential barriers to access ARV treatment. Apparently, some guidelines inadvertently constrain access to services. Further, ARV users, non-users and potential users alike wanted to be assured that ARVs would always be available and the free ARV program sustainable. Lack of clear information on the ability and readiness of the governments to sustain the supply of free ARVs was reportedly causing worry and discomfort, leading to non-use of ARVs.

Low awareness due to lack of appropriate and adequate information on ARVs was cited widely as a key barrier to use of ARV treatment services. Cases of PLHAs refusing to enrol for ARV treatment services due to fear of side effects were underscored in these studies. Overall, transport related barriers owing to the costs involved were the most frequently cited obstacles in Burkina Faso.

Impact of ARV use and Barriers to Accessibility

Overall, the positive and negative impact of ARV use on the individual beneficiaries was yet to be experienced since ARV use was relatively recent in the study sites. Nonetheless, the individually realized benefit of improved health was cited by almost all the users in the three countries, ranging from energized hope to live; being able to resume work and commercial activities, planning for their families, and to contributing to the wider struggle of combating HIV and AIDS.

In most instances, the use of ARVs had not resulted into adverse effects on family relations. Instances of family members showing a positive and more caring attitude were reported in all the three countries, although isolated instances among spouses and members of extended family who developed hostile attitudes were also reported.

With regard to the impact of provision of ARVs on other health services, the major problem in both public and private health facilities is the associated enormous running costs essential for a sustainable program. No doubt, successes in treating PLHAs increases demand on the health system. This is both in terms of personnel and infrastructure. What is very important to note in the three countries, was the reassurance and expressed commitment from the governments to address the constraints in the ARV program.

National and International Policies

Tanzania and Mozambique have comprehensive National Strategic Frameworks for HIV and AIDS—i.e., Tanzania has a National HIV and AIDS Care and Treatment Plan which specifically guides the implementation and management of the ARV program in the country, and similarly Mozambique a "National Health Sector Strategic Plan to Combat STIs and HIV and AIDS". Both countries have developed other policy guidelines and frameworks to promote provisioning of ARVs. What is common is that the policy guidelines on care and treatment are not explained in ample detail. Other issues such as the mechanisms for monitoring and follow-up of people on ARVs, plans for rolling out to address the equity problems, inbuilt sustainability mechanisms for availability of ARVs and accessibility, incentive plans for manufacturers of ARVs etc., are also not well

articulated by the policy's goal and objectives in the countries studied. In both Tanzania and Mozambique there was no evidence adduced by the studies that the policies in place are disseminated to those mandated to implement them.

Like all developing countries, changes in the global policies regarding ARVs such as policies on patent rights have affected Tanzania, Mozambique and Burkina such as the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) that was introduced in 1995. With India complying with the TRIPS Agreement effective March 2006, the ARV expansion programs have been under threat in least resourced countries.

Recommendations for National Action
A number of recommendations for national action have been made. These include the following:
- Poverty reduction efforts targeting PLHAs on ARVs
- Addressing the equity problems between the urban and the rural areas regarding access to ARVs as well as information about the same
- Evolving a multi-faceted IEC strategy for disseminating factual information on ARV treatment
- Mounting campaigns targeting stigma and discrimination
- Scaling up of ethical and effective VCT Services
- Provisioning of nutritional and food support to the most vulnerable PLHAs on ARV treatment
- Targeting and increasing the proportion of males using ARVs
- Improvement of the general health care system and human resources

Wider recommendations at Regional and Pan African level

The wider recommendations at regional and Pan African level entail the involvement of African governments in a concerted effort together with civil society organizations to engage in global policies and debates. Part of which involves intensive advocacy and lobbying around the following areas:

- Funding for health services and resource mobilisation
- Operationalization and harmonization of national and regional policies
- Expediting the legislation of TRIPS flexibilities and enhanced engagement in global policies

1.0 Introduction

1.1 Introduction

In 2006, the Agency for Co-operation in Research and Development (ACORD) through its HIV and AIDS Support and Advocacy Program (HASAP), undertook Anti-retroviral drugs (ARVs) studies in Burkina Faso, Tanzania and Mozambique. The studies focused on community accessibility to ARVs, knowledge and awareness of ARVs, and also examined the policy environment within which the ARV Program was being implemented. As part of disseminating findings that arose from the three studies, HASAP decided to abridge the reports into this single popular version i.e., the Compendium Report (CR). The immediate objectives of this CR were largely fourfold, namely:

- To situate the CR in a clear ARV background and context
- To provide an analytical summary of the three reports
- To identify the various similarities and or differences in the findings of the three countries
- To compile the recommendations for policy makers and implementers at national and international levels

1.2 Background of the Studies

It is over two and a half decades since HIV and AIDS emerged on the world scene as one of the most devastating human calamities of the 20th century. With the onslaught of HIV and AIDS claiming thousands of lives, governments world over devoted resources to combat its spread in their general populations—prevention interventions. As prevention interventions took root in several countries, the need to care and treat people living with HIV and AIDS (PLHAs) emerged, posing a big challenge to poorly resourced countries such as Tanzania, Mozambique and Burkina Faso where ACORD has programs. Thus, in the last couple of years, the issue of extending access to ARVs has increasingly dominated the policy agenda at the international and national levels with civil societies more than ever before increasing their advocacy efforts regarding increased and universal accessibility to ARVs.

Advocacy for increased access to ARVs in Tanzania, Mozambique and Burkina Faso has to a large extent been precipitated by the '3 by 5' initiative of WHO that aimed at reaching 3 million people in need of ARV treatment by 2005, as well as other large-scale initiatives, such as the United States Presidential Emergency Plan for AIDS Relief (PEPFAR) Fund, various World Bank initiatives, such as the Regional Treatment Acceleration Programme and other United Nations supported initiatives. Resultant from the UN commitments, most countries in the sub-Saharan Africa region came under pressure to set and meet targets in relation to ARV access by the year 2005, which targets seemed to have been highly unrealistic. For example, the target for some of the countries where ACORD operates such as Burkina Faso in West Africa is 20,000, but only 2,000 people are currently receiving treatment. In the case of Tanzania in East Africa, the target is 200,000, but currently only 19,000 have been reached. The situation is not any different in Mozambique, it was estimated that 210,000 HIV+ people in need of ART should have access to ARVs by October, 2005 but only 25,465 were on ART (IRIN, January 2006). It is partly in view of this situation that actors in the area of HIV and AIDS such as ACORD are increasingly becoming interested in the issue of ARV provisioning and accessibility.

ACORD's interest in the issue of access to ARVs relates directly to one of the three key aims of its HIV and AIDS mission, namely to "*promote equal access to information, services and treatment by challenging all forms of discrimination and social exclusion*". Guided by this mission, ACORD commissioned the studies, which covered, among others, remote and marginalized communities in the three countries.

1. 3 The Study Problem and Justification

ARV provisioning is a relatively recent initiative in developing countries such as Tanzania, Mozambique and Burkina Faso. Due to limited resources, current efforts to provide ARVs to the nationals have been characterised with a lot of inequities—largely reaching the elite, the affluent categories in the general population and a few individuals in the urban areas. Thus, universal accessibility to ARVs in poor countries is yet to be achieved. All this is happening amidst lack of empirically documented experiences with regard to ARVs accessibility and the implications it has on the individuals, households and communities. There has been limited research on consequences and dimensions of ARV program implementation at community level and hence the compelling reasons and justification for ACORD to undertake these studies.

1. 4 Objectives of the Three Studies

The overall objective of the three studies was to serve as an advocacy tool for ACORD and other actors involved in advocating for increased equitable accessibility to AIDS care and treatment in African countries. The specific objectives included:

1. To find out peoples' knowledge and understanding of ARV treatment as well as sources of information for ARV treatment
2. To assess ARV accessibility and use by the population in selected communities in the three countries
3. To investigate barriers to ARVs access and adherence such as stigma, distance to services, attitude of service providers, inadequate information about correct use, cost of ARVs and/or related services
4. To analyse potential threats to ARVs treatment including threats posed by food security and nutrition
5. To analyse the impact of ARV use on the population, including gender relations and household income levels as well as on other health services, in particular primary health care services as a result of introducing ARVs
6. To analyse the extent relevant national and international policies and frameworks facilitate and/or, constrain access to ARV treatment

7. To seek the views of service providers on the quality and coverage of the ARV programme with a view to identifying the strengths and weakness and thus make recommendations aimed at addressing the identified gaps in the provisioning of ARV related services, including access and use

1.5 Scope of the Studies

Unlike Burkina Faso, the studies in Tanzania and Mozambique put particular emphasis on "community knowledge and awareness regarding ARVs as well as the policy environment within which ARVs are dispensed. In Burkina, the focus was on access to and benefits of ARV treatment.

1.6 Methodology and Approach

A combination of qualitative and quantitative methodologies was employed in conducting these studies. Quantitative methods helped to investigate individuals' knowledge and awareness, accessibility and use of services, barriers encountered by the ARV recipients, and impact on household relations. On the other hand, qualitative data complemented quantitative data, and largely helped in exploring the context within which ARV treatment is accessed in greater detail. However, the scope of study for Burkina Faso was restricted to assessing quality and coverage of the ARV programme.

1.6.1 Study areas

Study areas in the three countries were purposively selected based on the presence of operations and interventions by ACORD, existence of organized associations of people living with HIV and AIDS (PLHAs) and presence of functional ARV sites. Selection of the study sites was also cognizant of the rural – urban divide. For instance in Tanzania, the study was carried out in Mwanza area with both urban and rural characteristics and Sengerema District, which is basically rural. In Mozambique, Maputo province and Maputo City represented the typical urban setting while the districts of Panda and Maxixe in Inhambane province represented the rural areas. In Burkina Faso, Pô and Ouagadougou represented the rural and urban study areas respectively. Coverage of the rural and urban areas enabled the studies to identify differences in the level, quality and accessibility of ARV services in the different geo-economic areas. National capitals in the

three countries were included in the studies to capture views of the national policy-makers and planners—technocrats and other stakeholders.

1.6.2 Study participants/sample

In all the three countries, ARV recipients were the primary study participants. The procedure of selection varied. For instance, whereas in Tanzania ARV recipients were captured mainly during the clinic days where a total of 103[2] recipients were subjected to exit interviews, in Mozambique snowball[3] sampling techniques were used to trace 58 ARV recipients in their communities. In Burkina Faso, a total of 176 PLHAs affiliated to prominent AIDS care organizations in the two areas of study and 66 service providers were randomly selected.

Other study participants included non-users of ARVs (eligible PLHAs not on ARVs by own choice), members of the general community, and household members of ARV beneficiaries, health workers and district officials. Technocrats in the Ministries of Health, the National AIDS Control Program (NACP), WHO, UNAIDS, and associations[4] of PLHAs were also reached.

1.6.3 Data collection methods

Quantitative data was collected through personal interview using a structured questionnaire which was administered to ARV recipients and other community members[5]. The tool was administered by trained survey personnel fluent in the local languages of the three countries.

Interviewers in Mozambique undergoing a training session

Qualitative data was collected through literature review of various documents on HIV and AIDS care and treatment; the key policies and planning frameworks. Key documents included HIV and AIDS National Policy on HIV and AIDS, National Health Strategic Framework for STI/HIV and AIDS (2004-2008) in the case of Mozambique and the National Multi-Sectoral Strategic Framework on HIV/AIDS (2003-2007) for Tanzania, Ministry of Health Care and Treatment Guidelines (2004), documents by the UNAIDS and WHO.

Other sources of qualitative data were key informants at district and national levels, health workers in ARV sites and leaders/representatives of associations of PLHAs and AIDS service organizations especially those that were on ARV treatment, and local leaders), direct observation and in the case of Burkina Faso, use of a checklist for assessing organizational capacities of service providers.

1.6.4 Data management

All the dully filled questionnaires were edited and entered into the computer using the Epidemiological Software package (EPI-INFO) and further analysis was conducted using the Statistical Package for the Social Scientist (SPSS). The analysis was mainly descriptive with some cross-tabulations, to establish the causal-effect relationships between significant variables. For the qualitative data, thematic and content approach was used for analysis. Dominant themes were developed on the basis of study objectives under which data was analysed and presented.

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2 Out of the 103 beneficiaries of ARVs from Tanzania; 89.3% (n=92) were from Mwanza, while slightly over a tenth (10.7%; n=11) were from Sengerema District
3 Bureaucratic hurdles relating to clearing of the research team by the directors of hospitals and absence of ARV recipients at the sites made it impossible to conduct exit interviews
4 PLHA Associations included Social and Health Development for PLHAs (SHDEPHA+) and Tanzania Women Living with HIV and AIDS (TAWOLIHA); UTOMI, WONA-NDLELA in Inhambane Provincial capital, TINHENA and RENSIDA in Maputo City as well as AJUDECO in Panda district.
5 Only covered in the Mozambique to bridge the gap in the Tanzania and Burkina Faso studies

2.0 Profiles of ARV Recipients

2.1 Introduction

Profiles of ARVs recipients are very important to appreciate in any policy debate regarding accessibility and utilization of ARVs. The socio-demographic characteristics are particularly important due to their potential to influence the extent to which beneficiaries access ARVs, use them and adhere to ARV use.

2.2 Socio-demographic Profiles of ARV Recipients

The findings of the three studies revealed that the majority of the ARV recipients were females and basically residing in urban areas. Thus, in the three countries, there were great disparities in access to ARVs by locality of usual residence. See Table 1 for more details.

The gender disparity in access to treatment with ARVs is partly a reflection of the openness exhibited by females who are living with HIV and AIDS compared to men, and also a demonstration of better health seeking behaviour by females than males. In several group discussions, female users whose partners were also using ARVs commented that they started using ARVs before their partners did.

Findings further showed that most of the ARV users in Tanzania and Mozambique were heads of households. By implication in the African context, household heads are breadwinners. A high dependency ratio at the household level (i.e. several household members depending on the household head), in cases where the majority

Table 1: Socio-demographic profiles of ARV recipients

| Characteristic	Tanzania	Mozambique	Burkina Faso[1]
	% (N=103)	% (N=58)	% (N=176)
Locality			
Rural	8.8	9.0	22.7
Urban	91.2	91.0	77.3
Sex			
Male	31.1	28.0	30
Female	68.9	72.0	70
Marital status			
Single/Never married	10.7	62.1	25
Married/cohabiting	42.7	20.7	38
Widowed	31.1	8.6	24
Divorced/Separated	15.5	8.6	12
Education level			
Never attended school	6.8	10.0	29
Primary level	73.8	45.0	35
Secondary Level	17.5	35.0	28
Post Secondary	2.0	3.0	3.4
Others	0.0	7.0	0.0
Relationship with the head of household			
Himself/herself head	66.0	56.9	-
Son	2.9	10.3	-
Daughter	1.0	24.1	-
Uncle	5.8	0.0	-
Aunt	1.0	1.7	-
Grandparent	2.9	0.0	-
Others (Specify	20.4	6.9	-

of breadwinners are living with HIV and AIDS, can represent an uncertain future for the entire household.

Most of the ARV users had attained low levels of formal education i.e., having attained only primary education. More than a half of the ARV recipients in the three countries had attained primary level education.

2.3 Economic Profiles of ARV Users

Most of the ARV beneficiaries in the three countries were generally poor as reflected by their main occupation, which at the same time was the main source of income for many except for students and housewives. For instance, in Tanzania, majority earned a living through petty trading (47%) while in Burkina Faso, over a third were house keepers. In all the three countries with exception of Mozambique, chances of finding civil servants and wealthy people among ARV recipients were minimal. See Figure 1.

Figure 1: Distribution of ARV recipients in 3 countries by occupation
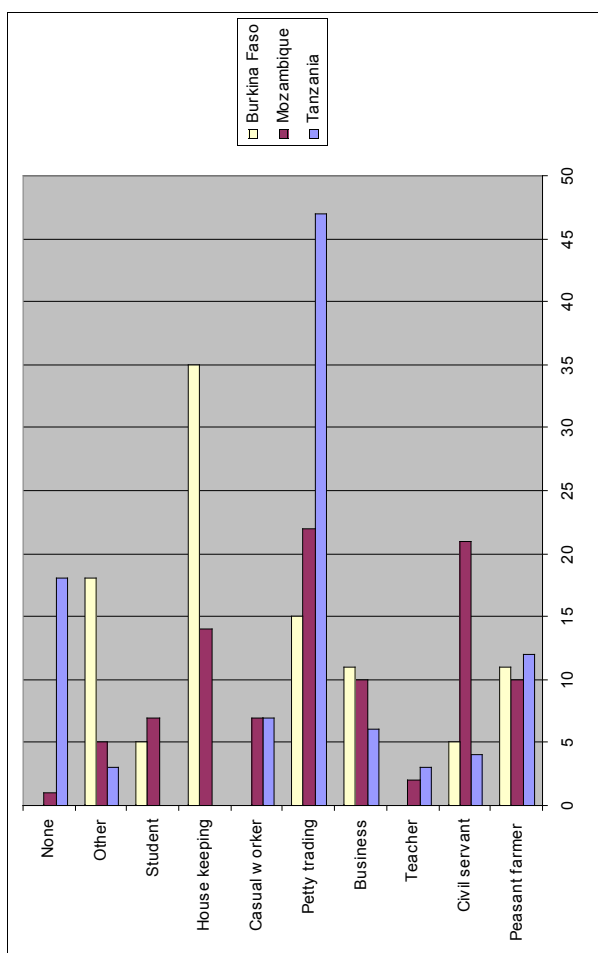
Interviews with key informants revealed that most of the civil servants and wealthy people prefer to remain anonymous when it comes to accessing and using ARVs. It was noted that these rarely disclose their HIV status for fear of being stigmatized and discriminated. Majority of such people have not had the courage and will to go for VCT.

Related with the occupation of ARV users were the levels of income and household headship status; both of which can potentially affect ARV accessibility, use and adherence. For instance, almost a quarter (18%) of the ARV users' households in Tanzania had an estimated monthly income of less than US $10 per month and slightly over a tenth (12%) earned between US $ 25-40 per month.

Further analysis of the economic profiles of ARV beneficiaries revealed that majority of households were living above their income bracket - estimated monthly household expenditure far exceeded income earned per month. The over and above expenditure in such households was reported to be made possible by some income handouts from relatives and or friends, borrowing, selling off some household items; all of which are not sustainable and can easily plunge a household into a vicious cycle of poverty especially in a situation where the family member using ARVs is at the same time the head of the household and a breadwinner.

In most cases (specifically for Tanzania and Mozambique) the ARV users were heads of their households and breadwinners. This situation could be exacerbated by the fact that the biggest proportion of ARV users had children of their own—hence the burden of care.

The above findings in the three countries therefore underscore the challenging livelihood conditions that ARV users have to cope with. It is possible to deduce that it would be unlikely for such poor people to start antiretroviral therapy (ART) if they were to pay for them.

3.0 Knowledge and Awareness of ARV Treatment

3.1 Introduction

The level of awareness and knowledge an individual has on a particular aspect determines how he/she relates to that aspect. In this case, knowledge of what constitutes ARVs, their utility, and problems associated with taking them were issues deemed pertinent to using ARVs. This section, therefore, presents a synthesis of the study findings on the levels of awareness and knowledge about ARVs including such intricacies as understanding of ARV treatment, the sources and means of information on ARVs.

## 3.2 Knowledge and Understanding of ARV Treatment

Figure 2: ARV Recipients' first time to hear ARV treatment in Mozambique
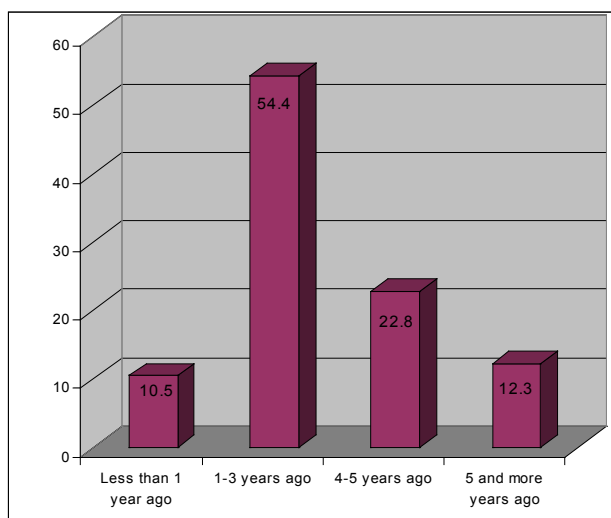
The study findings revealed that knowledge about ARVs was very recently acquired in all the three countries. Most of the study participants in the different countries had heard, for the first time, about ARV treatment in a period of between less than one year and three years preceding the studies. Variations across the different countries under study existed but were not quite significant. For instance, in Tanzania the bigger proportion (38.2%) compared to 10.5% in Mozambique and 34% in Burkina Faso reported that they first heard about ARV treatment less

than one year ago. Further, only about a tenth (11.8% and 12.3%) in Tanzania and Mozambique respectively reported their first time to have heard about ARV treatment as being over 5 years ago, while 15% in Burkina Faso had heard about ARV treatment 4 years back. See Figures 2 and 3.

Figure 3: ARV Recipients' first time to hear of ARV treatment- Tanzania
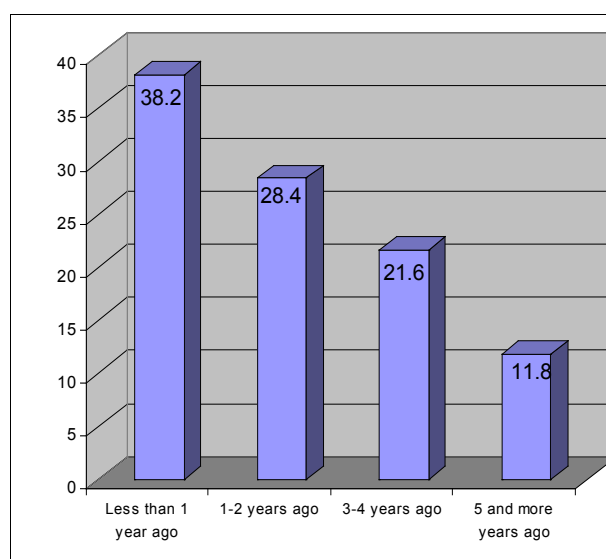
The findings further confirm that knowledge of ARVs especially in developing countries; a category, in which the three countries of Tanzania, Mozambique and Burkina Faso fall, is relatively recent.

3.3 Knowledge on Eligibility of ARV Treatment

Various proxy indicators on levels of knowledge about ART and ARVs, in general, were tested in the study countries. Overall, people's knowledge about eligibility to use ARVs including those currently on ART was limited. The study results revealed insignificant variations across the three countries. For instance, more than two-thirds (67.9%) and almost all (89.5%) ARV recipients in both Tanzania and Mozambique respectively believed that all PLHAs should be on ARVs. This implies that only a third of ARV users in Tanzania

and about a tenth of users in Mozambique had correct knowledge regarding who should be on ARVs, i.e. only PLHAs that are recommended and advised by a doctor should start or take ARVs i.e. (after taking a CD 4 test count as well as undergoing professional clinical diagnosis).

Findings on knowledge on eligibility to ARV use further revealed that a significant proportion of ARV users shared the view that ARVs can be used in prevention of infection with HIV and AIDS. See Table 2.

It is also important to note, that factual information about ARVs and their utility constitute part of the content of counselling. Glaring gaps in knowledge about ARVs, especially on who qualifies to take the drugs and the circumstances warranting a complete discontinuation of use of the drugs, existed in all communities visited. Comparatively, ARV users in Mozambique were less knowledgeable compared to those in Tanzania; high levels of treatment illiteracy were more evident among users in Mozambique.

Table 2: Knowledge on who is eligible to use ARVs

Knowledge Aspect	Tanzania	Mozambique
	% (N=103)	% (N=204)
Category of persons perceived to (who should) be on ARV treatment*		
All PLHAs	67.9	89.5
Only PLHAs who have been recommended by a medical doctor	32.1	49.1
Other categories	0.0	1.8
Perceived reason for taking ARV treatment *		
To prevent HIV and AIDS	35.3	22.8
To treat AIDS	1	64.9
To treat opportunistic infections related to HIV and AIDS	31.4	22.6
To strengthen the immune system	37.3	24.6
To treat pain	19.6	12.3
Perceived length of time for one to stay on ARV treatment		
All the time	97.1	60.7
Always except when the medical doctor recommends otherwise	1	35.7
Don't know	2	3.6
When to stop ARV treatment		
No circumstance	70.6	50.9
On the recommendation of a doctor	-	52.6
When he/she gets better	1	0
If there are side effects	14.7	1.8
If ridiculed by family/community members	1	3.5
Don't know	5.9	5.3
Problems associated with not taking ARV medication as prescribed by the doctor*		
None	11.7	26.3
Developing resistance	50.5	24.6
Resurfacing of pain	4.9	5.3
Developing of side-effect	11.7	3.5
Developing full blown AIDS	29.1	15.8
Others	1.9	26.3

*** Multiple Responses were allowed*

The knowledge gap was also evident in the perceived reasons for taking ARVs whereby over a third of the sample in Tanzania and a quarter in Mozambique believed that taking ARVs would prevent HIV and AIDS. This can particularly undermine the effectiveness of HIV and AIDS prevention campaigns especially the "Abstinence, Be Faithful and Use Condoms"

(ABC) campaign. For, people can start indulging in sexual behaviours and practices that can potentially expose them to the risks of HIV infection hoping that ARVs will be a solution. All these knowledge gaps need to be addressed. People need information on ARV services including information on HIV testing.

"Dissemination of correct knowledge on ARVs both in urban and rural areas is very important in promotion of ARV use... the community has to be prepared and be informed that treatment is available. We need to begin with community mobilization and sensitization about ARVs before we think of rolling out"

- Key Informant, MoH - Mozambique

ARV knowledge gaps are not only confined to ordinary community members, but health workers as well. Although the studies did not cover health workers in terms of assessing their knowledge of ARVs, other studies that preceded this one e.g., in Mozambique concluded that the level of knowledge on AIDS was very low in all ranks of health workers as evidenced by the big number of health workers who were neither able to give good information to patients and the public in general, nor able to treat opportunistic infections (OIs) properly (Conjumba, 2003). This then means that ARV knowledge campaigns need to be all embracing covering the health workers as well especially those in the low cadre.

Segregation of data on ARV knowledge by sex of the respondent generally revealed little difference between men and women users of ARVs. Only in Mozambique were slight differences noted; male respondents were found to have a slight edge over the female counter-parts. Many more female respondents (88.8%) were of the view that every person living with HIV and AIDS should be on ARV medication as compared to 78.1% male respondents. But overall, female ARV users seemed to be more exposed to sensitization and counselling regarding AIDS care.

Table 3: Sources of Information on ARV Treatment

Source of learning about ARVs ***	Tanzania	Mozambique
	% (N=103)	% (N=204)
Sources of information on ARV treatment		
Radio messages	36.0	65.9
Television messages	14.0	7.1
Billboard Advertising	1.0	1.2
Posters/brochures/fliers	5.0	0.6
Newspapers	6.0	0.6
Drama show	1.0	2.4
Friends/ Relatives	17.0	4.7
Counsellor/health provider	58.0	11.2
Local leaders/village meeting	7.0	0.6
NGO staff	9.0	0.6
Type of information on ARV treatment currently received		
Access to ARV treatment centres	46.5	61.2
Services offered at ARV treatment Centres	6.9	31.9
Correct use of ARVs/adherence to ARVs	33.7	44.0
Side effects of using ARV	4.0	15.5
Advantages of using ARVs	35.6	38.8
None	6.9	0.9
ARV treatment site has information on ARV treatment		
Yes	93.2	62.4
No	3.9	12.1
Don't know	2.9	25.4
ARV information delivery means		
Leaflets	3.1	33.3
Brochures	2.1	32.4
Posters	6.3	11.1
Booklets	1	12.0
Oral sessions	91.7	64.8

*** *Multiple Responses were allowed*

3.4 Sources of Information on ARV Treatment

Findings revealed varying degrees of popularity of the different sources of information on ARV treatment and services. For instance, whereas in Tanzania and Burkina Faso[6], Health providers/counsellors at the ARV dispensing sites were reported as the main source of information on ARVs, in Mozambique they were among the least cited sources instead the commonly cited source of information about ARV treatment was radio. See Table 3.

3.4.1 Most Popular/Common sources of information on ARVS

In Tanzania, findings revealed that the most popular means of delivery of information about ARV treatment were the oral sessions held by health workers/counsellors on site. The situation in Mozambique was slightly different, whereas oral sessions featured most as the popular means of delivery of ARV information, there were other means that were notable such as brochures and leaflets. What all this implies is that in Tanzania, outside the ARV dispensing sites, not much information is disseminated to the community. Further, it implies that information about ARVs is not disseminated for the sake of informing people and raising their awareness about ARVs, but to prepare intending users to take and adhere to ARV use. In Burkina Faso, some respondents noted that they had heard of ARVs when they travelled to neighbouring countries, such as Ivory Coast.

3.4.2 Types of information received about ARVs

With regard to the type of information that was being received by the population from the various sources of information, findings showed no differences across the different countries. In all the study areas, the commonly cited type of information received from the various modes of communication was on "access to ARV treatment centres", i.e. where the ARV sites were located. Information on correct use or adherence to ARVs, although not as significant, was notably received. As can be seen in Table 4 above, the major aspects of ARV treatment were not being disseminated outside the ARV dispensing sites in all the study countries—Tanzania and Mozambique. It has to be noted that for people to be motivated to seek ARV treatment, they need to be provided with information on several aspects including advantages of using ARVs, possible side-effects, types of services that are offered at the ARV treatment centres and on the significance of adherence once a person has started taking ARVs on the recommendation of a qualified medical doctor. All these represent the knowledge gaps that have to be bridged.

3.4.3 Disparities in Information access

Segregation of data by gender, age and levels of education revealed no variations in sources of information and access to information on ARVs. However, significant differences existed between ARV users in urban areas and those in typically rural settings in all three countries.

3.4.4 Recommendations

For the general community, much more information is needed, especially on HIV testing, before a person can start thinking of ARVs. Availability of ARVs potentially acts as a motivating factor for people to seek testing services. This means that as ARV literacy is promoted, the governments and other stakeholders in the three countries where the studies were conducted have to ensure equitable provisioning of HIV testing facilities. Once this is done, then the population needs to be sensitized and provided with information on the availability of HIV testing and counselling services.

Regarding the disparities in access to information about ARVs, it can be noted that awareness raising and sensitization on ARVs ought to widen to include all sections of the society; the rich and the poor, users of ARVs and non-users, PLHAs and those that are HIV negative, i.e., reaching everyone. This strategy seeks to arouse social support for PLHAs to use ARVs, but also goes hand in hand with strategies for eliminating stigma and discrimination, which also undermine the use of ARVs and adherence. Methods which reinforce highly interpersonal, customised, individualised means of delivery of information need to be promoted.

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6   Study respondents in Burkina Faso reported to have heard most about ARV treatment from associations like SOS-SIDA – an association where PLWHA access ARV treatment from. But no quantitative data was collected.

4.0 ARV Availability, Accessibility and Use

4.1   Introduction

Availability of ARVs denotes the situation of users' ability to get the drugs (ARVs) anytime they need them. On the other hand, accessibility also implies users being able to reach with relative ease the ARV dispensing site and, obtain ARV treatment and services. This Section focuses on these aspects of ARV provisioning.

2.2   Availability of ARVs

Availability of ARVs, though improving, is still inadequate in all the three countries of study.

4.2.1 Availability of ARV dispensing/ distribution sites

In Mozambique, literature shows that only 34 health facilities in the whole country were providing Highly Active Antiretroviral Therapy (HAART) by end of 2005. The situation is much the same in Burkina Faso. Of the three countries, it is only Tanzania with a sizable number of ART treatment sites i.e. 204 sites. In Burkina Faso, quite different from Mozambique and Tanzania, service providers had a very low opinion of the availability of ARVs nationally with almost all (98%) observing that ARVs were not widely available, and hence not easy to access—a clear demonstration of equity problems.

4.2.2 Disparities in availability of ARVs dispensing/distribution sites

The issue of equity in distribution of ARV provisioning sites across communities in the different countries featured prominently. That there is more concentration of ARV treatment sites in urban areas and little in rural areas is not debatable. For instance, in Mozambique, Maputo city had 10 ARV dispensing sites by end of 2003 compared to 3 sites in Inhambane – a typically rural province. Distribution of sites in Tanzania was not any different either; Mwanza City had 2 sites dispensing ARVs while Sengerema district; a rural area had only one site. In Burkina Faso the situation was similar to that in the other two countries as the following quote illustrates.

> *"One of the weaknesses of the current programme is that ARVs are not available in most of the health districts….I have to go to the capital Ouagadougou every month to get my ARVs"*
>
> - Male ARV beneficiary from Nahouri, Burkina Faso

4.2.3 Distribution of ARV dispensing sites

As is mentioned in the above section, this inequitable distribution of health facilities that dispense ARVs implies that majority of the persons on ARVs are concentrated in typically urban settings as opposed to rural areas where over 80% of the population resides in most developing countries.

> *"There are about 40,000 people on ARVs in Mozambique, but most of these are in Maputo because that is where most of the health centres are concentrated and hence the services available…"*
>
> -Key Informant, UNAIDS - **Mozambique**

4.2.4 Ongoing initiatives to increase availability of ARVs

On a positive note though, Governments of the three countries with support from donors and other stakeholders are taking initiatives to ensure that free ARVs are always available in the few sites which have been accredited. For instance, the free ARV regime in Tanzania started in Mwanza in October 2004 and a year later it spread out to cover Sengerema District and no cases of failure to get replenishments were reported. Virtually all respondents (98%) revealed that they got ARV treatment whenever they visited the ARV dispensing units. Similarly, in Mozambique, almost all the respondents who were taking ARVs - 50 out of 58 noted that they always got ARVs at their respective health facilities. However, cases of erratic drug supplies were more common in Burkina Faso.

4.2.5 Sustainable availability and provision of ARVs

Although issues of availability are generally taken care of, continuity in access has not been guaranteed. Reassurance that free ARVs are there to stay is lacking hence the uncertainty – even government officials were not certain of the future. For instance, a government official in Sengerema District, Tanzania in response to the issue of the future of the ARV programme had this to say; *"we assume the supply of free ARVs will continue"*. Even UNAIDS (March 2006) acknowledges that the lack of secure funding for most national ART programmes beyond 2008 remains a concern. This highlights a need for advocacy to urge African governments to consider budgeting for ARV programmes instead of heavily relying on donor support.

The uncertainty of sustainable supply of ARVs was discouraging potential ARV users particularly in Tanzania where non-users noted that they were better off not to start on ARVs than starting on them and then default, which would be disastrous for their lives.

4. 3 Access to ARVs

From secondary sources, it emerged that accessibility to ARVs was not universal to all in need in the three countries. Of the three countries, Tanzania had achieved notable accessibility - by mid July 2006 there were 83,000 people enrolled with 42,000 on ARVs; though encouraging, the figure was still far off the national target of reaching 100,000 people with ARVs by end of December 2006. The situation in Mozambique was much worse; about 260,000 Mozambicans were recorded as being in need of ARVs, but only about 37,000 were accessing ARVs by end of October 2006 (MoH; NAC). Similarly, in Burkina Faso out of an estimated 45,000 PLHAs in need of ARV treatment, only 5,200 was accessing ARVs as of end of 2005.

4.3.1 Access to ARV dispensing / distribution sites

With regard to geographical accessibility to ARV treatment services, study findings showed low levels of access, especially for people residing in typical rural settings. In all the three countries, majority of the people accessing ARVs were in urban areas. For instance, Panda in Mozambique had less than a tenth of the sample of ARV recipients. Transport was reported as the main factor that affected accessibility to ARVs. The distances travelled were long; the average estimated distance from the ARV recipient's home to the site was 9.8km and 10.5km in Tanzania and Mozambique respectively. In citing key problems relating to access and availability by service providers in Burkina Faso, distance of support structures and lack of transport facilities to access services feature prominently. See Table 4 for computed data of Tanzania and Mozambique.

Table 4: Geographical access to ARVs

Access	Count	
	Tanzania	**Mozambique**
Estimated distance from ARV beneficiary's home to ARV site		
Average (Mean)	9.8km	10.5km
Nearest	0.5km	1km
Farthest	70km	28.3km
Estimated time taken to travel from home to source of ARVs		
Average/mean	54min	56min
Minimum/shortest	3min	6.7min
Maximum/longest	500 min [8hrs]	120min (2hrs)
Means of transport to ARV Treatment Centre		
Walking on foot	38.2%	67.9%
bicycle/motorcycle	7.8%	-
vehicle	59.8%	32.1%
train	1%	-

Given that before one starts using ARVs, s/he has to visit the site for a minimum of 3 times, including testing for CD4 cell count and undergoing adherence counselling, such distances are a hindrance to the poor but potential users. Important to note, all ARV dispensing sites were located in urban centres, which constrains access to ARVs by the rural based users and intending users, due largely to transport problems. Even in rural districts such as Sengerema and Inhambane in Tanzania and Mozambique respectively, the dispensing sites were located in the main urban centres of the districts. One of the few cases of non-adherents, was reported to have failed to raise the transport fare and decided to quit the ARV program altogether.

Overall, however, accessibility to ARV treatment services has tremendously improved over the years, but the numbers are still far below achieving UNAIDS desired universal access. Apparently, there is limited access compared to the need in all the communities studied and it is reportedly more skewed against the rural based ARV users. Plans to roll-out to lower level health facilities including rural based facilities are underway in all the three countries. But for such localization of ARV dispensing services to be relevant, it ought to go hand in hand with promotion of VCT and activities aimed at eliminating stigma and discrimination. The little, but significant incident that happened in Sengerema illuminates this point. The hospital nurse who helped the study team to trace users in their residences, had to first remove her identifying gown before approaching the home of the user for fear of arousing unnecessary

suspicion from neighbours who would start speculating that the household had a PLHA that would culminate into stigmatization and discrimination of the occupants forthwith.

4.4 ARV Use/Utilization of ARV Treatment Services

Among users of ARVs, high adherence levels were reported in all the study communities. PLHAs who had taken the decision to start using ARVs were still determined to ensure maximum adherence. However, it should be noted that ARV use is a relatively new practice in these countries, although Burkina Faso and Mozambique had a slightly longer history of ARV use compared to Tanzania. Slightly over a quarter (26.9%) of ARV recipients in Mozambique and 8.3% in Burkina had started taking ARVs before 2003. In Tanzania, provisioning of ARVs became more prominent in 2005. The difference was that in Tanzania ARV provisioning to the nationals was much more an initial government initiative and donors just bought in compared to Mozambique and Burkina Faso, where the initial initiative originated from outside—donors.

Segmentation of data on ARV users according to gender, attests to the fact that ARV use has a gender dimension. Findings revealed that female persons account for the biggest proportion of ARV users. For instance, in Mozambique, almost three-quarters of the ARV beneficiaries were females compared to slightly over a quarter who were men—72.4% and 27.6% respectively. Almost equal proportions of female and male ARV beneficiaries were reported in Burkina

Faso– 73.6% and 26.4% respectively. In Tanzania there were also more female than male users. For instance, over 70% of the registered PLHA benefiting from the services of AIDS Outreach Nyakato were females.

ACORD Staff with research team and participants during the project participatory action research study in Mwanza, North Western Tanzania, May 2006

In Inhambane provincial capital- Mozambique, members of WONA-NDLELA; an association of PLHAs, it was noted that out of the 60 members, 43 were on ARVs and majority were women. In another association of PLHAs in Maputo city, TINHENA with a total of 285 members, over 90% were women.

This gender dimension does not in any way connote that it is mainly women who are in need of ARVs. Most women tend to visit health centres than men where they access information on ARVs, and for expecting mothers, they are often counselled to take an HIV test, and if found positive are encouraged to enrol on the "prevention of mother to child transmission (PMTCT) program. Discussions with members of various associations of PLHAs revealed that often men do not disclose their status to the extent that even when they are on ARV treatment, it is more of a private matter—they keep it to themselves compared to women who find it easy to disclose and join associations of PLHAs for psychosocial and material support.

5.0 Impact of ARV Use and Barriers to Accessibility

5.1 Introduction

This Section presents synthesized findings on the impact of ARVs on the individual recipient, their households, the community and impact on other health services. It also highlights barriers to ARVs accessibility.

"I came to learn about my HIV sero-status in 2005, after several episodes of sicknesses. Given the shock of the HIV results and the battle with TB, I was hospitalized for 6 months. At the time of hospitalization, my CD4 count was 30 and I was weighing 28-30 kilograms. I started on ARVs, which I attribute my life and current good health to.

I was very sick, I could not talk, but ARVs made me regain my life and health."

Sophia, whose CD 4 count at the time of this study was around 220, was weighing 58 Kgs had become an HIV Activist running HIV and AIDS related programs on Television (TV) to sensitize the population on the epidemic and to promote the use of ARVs. Sophia who had started being discriminated in society especially after leaving hospital due to her

clear example of what ARVs can do to one's life if taken consistently.

This case of Sophia, a Mozambican, brings the point home that use of ARVs can lead to improved economic productivity and hence family welfare as a result of reduced episodes of illnesses and

physical looks, has now become a TV star, and is now looking after her young siblings, which could not have been possible had she not started on ARVs.
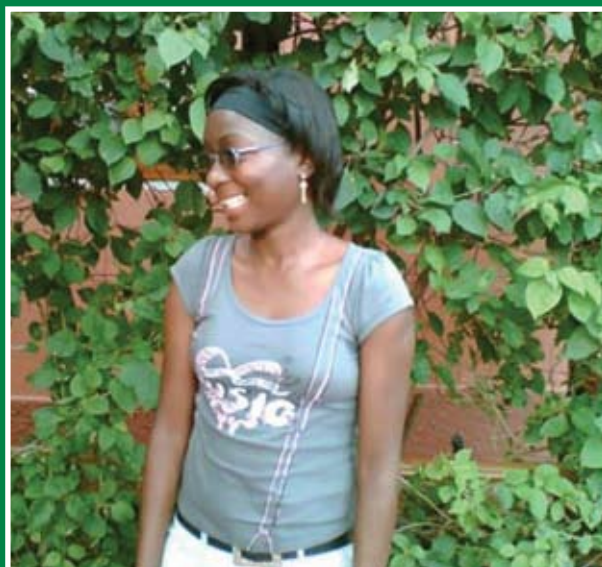
5.2 Impact of ARV Use

5.2.1 Impact on the individual and household levels

Overall, the positive and negative impact of ARV use on the individual beneficiary is yet to be felt since as indicated earlier, ARV use is relatively recent in the study sites. Nonetheless, the individually realized benefit of improved health was cited by almost all the users in the three countries ranging from energized hope to live; ability to resume work and commercial activities, planning for their families, and to contributing to the wider struggle of combating HIV and AIDS. A real life case of Sophia[7] is a

reduction in family costs on frequent medical care for a PLHA.

5.2.3 Impact of ARV use on family and community behaviour

In most instances, use of ARVs had not resulted into adverse effects on family relations. Instances of family members showing a positive and more caring attitude were reported in all the three countries, although isolated instances were reported among spouses and members of extended family who developed hostile attitudes. In Burkina Faso it was found out that 45% of the ARV beneficiaries reported significant improvement in relations with family members since taking ARVs, only in 10% of the

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7 Sophia consented to have her real name and picture used in this report. She was also a member of the research team that conducted the study in Mozambique.

cases reported no change in relationship while a fifth of the beneficiaries reported improved relations with neighbours and other community members.

However, outside the social circle of users, and their immediate family, there were indications that use of ARVs had not been given a good reception by some community members. In some of the communities visited, an air of resentment towards ARV treatment was evident [with a possibility of increasing unless checked by sensitization campaigns]. Their disapproval was more inclined on the likely compromise on risk averting approaches; they argued that users lose all the symptoms associated with AIDS and some even engage in unprotected sex with unsuspecting people. This finding highlights the need to move beyond focusing on the rights of PLHAs to include their responsibilities in protecting the rights of others (in prevention of HIV spread).

5.2.4   Impact of ARVs on other health services

The major problem with ARV provisioning in both public and private health facilities is the associated enormous running costs essential for a sustainable program. No doubt, successes in treating PLHAs increases demand on the health system. This is both in terms of personnel and infrastructure; most of the ARV dispensing sites did not have all the required facilities such as CD4 count machines hence hospital funds were expended to get the tests done. In effect, the private facilities had to subsidize the running costs for ARVs and yet majority of ARV recipients did not pay for services. The in-charge of Sengerema hospital, a mission facility in Tanzania, lamented that providing ARVs was too big a burden on the hospital.

> *"The laboratory technicians at Sengerema are too few to handle all the cases…the programme is taking our best personnel; highly qualified and experienced. We don't have enough people…we have only three counsellors who can competently provide counselling services in addition to other designated duties,   yet counselling for ARV beneficiaries and those coming to test is becoming a daily service*
>
> -Medical in-charge, Sengerema Hospital, Tanzania

Challenges of personnel were also rife in Burkina Faso and Mozambique. A case of Panda Health facility in Mozambique succinctly summarizes the prevailing situation.

PANDA HEALTH FACILITY - MOZAMBIQUE

Whereas Panda Health facility now provides ARVs, no more staff have been recruited. What one notes is that the most qualified health worker, i.e. the health centre director, is the one in-charge of the ARV program assisted by other staff that underwent the training. Although, not mentioned, the ARV program is taking the best of the best at the centre. In addition, people who come for HIV testing, line up with patients of routine medication, which often slows down the process. The time of waiting is therefore prolonged, which impacts on quality of services provided.

What is very important to note in the three countries, is the reassurance and expressed commitment from the governments to address the constraints in the ARV program. For instance, in Tanzania, it was revealed that government was in the process of working out a Memorandum of Understanding to be signed between government and private providers clearly spelling out the commitment of either party once they (private facility) have been designated to run an ARV program.

5.3 Barriers to ARV Use

Various barriers to use and access ARVs including facility based, policy, awareness, and transport related, as well as nutritional, were cited in almost all selected communities in the three countries.

5.3.1 Direct costs for ARVs

In Mozambique and Tanzania ARVs are freely provided and hence no direct cost is incurred by the beneficiary to access ARVs. However, in Burkina Faso government does not provide universal access to treatment, although some people are able to access the drugs free through organizations such as SOS-SIDA, but others have to pay.

The only category of people in Burkina Faso that have free access to ARVs are those on low income and/ or no income linked to associations, national and regional hospitals who are identified by a doctor, pharmacist and social services agent or association officer. This selection criterion could be so stigmatizing and demeaning to the extent of putting off potential ARV users.

5.3.2 Facility related barriers

At the health facility, the commonly cited barrier for using and accessing ARV treatment services was the inadequacy of personnel at the ARV dispensing site. Increased accessibility to ARVs is not only a function of the availability of drugs and health facilities, but also availability of qualified health personnel. All countries visited acknowledged having challenges with health workers trained to provide specialized AIDS care. For instance in Mozambique, the situation was more pathetic compared to the rest of the Southern Africa Development Community (SADC) region as revealed by the following:

- There were 17,000 health workers of which 11,000 were trained and that quality of care was being hampered by the minimal qualification of health personnel.
- Only 6% were medical doctors of the 11,000 health workers, and consequently less than 50% of the district hospitals had a doctor
- The number of nurses per patient was 1:5,000 — the lowest in the SADC region i.e., compared to South Africa (1:125); Botswana (1:457); Zambia (1:610); Malawi (1:1298) and Zimbabwe (1:704).

- There was a limited number of counsellors and pharmacists
- High turnover of trained health workers with an annual loss of 7% due to transfers or death of the district health staff.
- By March 2004, the country had an estimated 240 doctors that had been trained to deliver ART.

Key informants in all the countries visited concurred that their national health systems were constrained by lack of human resources. UNAIDS (March 2006) in particular noted that scaling up treatment highlighted critical weaknesses in health systems that needed to be addressed, notably infrastructure and human resources. Although training of health workers to provide specialised AIDS care had been done, it had not solved the human resource problem.

The other facility related barrier was inadequacy of premises. In all health facilities visited, it was reported that the number of ARV recipients had been on the increase which had inadvertently led to congestion. For instance, in Tanzania when the study team visited Sekou Toure, PLHAs had jammed the corridors where counselling, testing and dispensing of ARVs was being done. The study team had to squeeze through the crammed corridor. It was revealed at Sengerema that on ARV clinic days, there was always a scramble for facilities such as seats/benches between routine patients and beneficiaries of ARVs. Laboratory capacity was a major weakness in all the three countries and additional resources and expertise would also be needed to assure the quality of laboratory infrastructure over the long term.

Tanzania at the time of this study was trying to recruit more people to handle ARVs. The recruited and trained persons were to be sent to all ARV dispensing facilities both private and public. Likewise, Mozambique planned to train 2000 intermediate-level healthcare professionals. Burkina was also seeking to broaden its list of people qualified to prescribe ARVs.

5.3.3 Policy related barriers

Existing policies are potential barriers to access ARV treatment. Apparently, some guidelines inadvertently constrain access to services. In Tanzania for example, the restriction on where an ARV recipient gets[8] drugs, was cited among

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8   ARV beneficiaries are not allowed to be served in any other site

constraints to access or barring any other person from collecting ARVs on behalf of the recipient from the dispensing site, which could contribute to non-adherence. This certainly poses particular challenges to users who are bed ridden and those with transport problems. This calls for innovations and flexibility in policy guidelines so as to help increase adherence as well as convincing non-users to enrol. In Burkina Faso, the plan was to decentralize drug dispensing sites to ensure easier access for users in rural areas.

Other policies which were nutritional related were cited in some communities as a barrier, but only specific to Tanzania where intending ARV users were required to sign a compliance form declaring that they would adhere to correct use of ARVs. Among the conditions was the ability to afford special diet, a steady source of income, clean water etc. Consequently, importance of food becomes an essential element of the continuum of care for PLHA.

> *"I attended several seminars on ARVs and they emphasize that one must take six meals a day, but I can hardly afford a single meal, so I could not start taking ARVs"*
>
> - Male ARV non-user, Mwanza, Tanzania

Lastly, ARV users, non-users and potential users alike wanted to be assured that free ARVs were there to stay and the program was sustainable. Lack of clear information on the ability and readiness of the governments to sustain the supply of free ARVs was reportedly causing worry and discomfort, leading to non-use of ARVs.

5.3.4 Awareness related barriers

Low awareness due to lack of appropriate and adequate information on ARVs was cited widely as a key barrier to use of ARV treatment services. As earlier indicated, the major aspects of ARV treatment were not being disseminated outside the ARV dispensing sites. The commonly heard messages in the media were on places where ARVs could be accessed. Apparently, this left many with little or no knowledge of ARVs. There were even claims that ARVs were introduced without prior preparations of PLHAs to dispel

the fear driven by myths and misinformation. In Tanzania for instance, it was noted that the focus of the government was reportedly on ensuring enough supplies of ARVs on the assumption that free supplies of ARVs would be enough to attract PLHA to use the drugs. Cases of PLHAs refusing to enrol for ARV treatment services due to fear of side effects were underscored in these studies.

> *"Some people out rightly decline the idea of starting on ARVs that their condition might worsen…they fear the possible side-effects"*
>
> - District Home-Based Care Coordinator, Sengerema, Tanzania

> *"A donor gave us free ARVs for 3 years; we were 5 people but only 2 agreed to take the ARVs. Although the donor said the drugs were brought because of me, I refused because I was not ready. Unfortunately, the 2 who took the drugs died because of drug reactions. I nursed one of them before she died; I still remember the side effects, even up today I cannot take ARVs; I have told the doctors"*
>
> - ARV non-user, Mwanza City, Tanzania

5.3.5 Transport related barriers

Transport related barriers to access and use of ARVs were the most frequently cited obstacles in Burkina Faso. Transport as a barrier to ARV use is double edged. It constrains the users and potential users and also makes it difficult for health service providers to make follow-up visits. As earlier indicated, access to ARV dispensing sites was poor – the average estimated distance from the ARV recipient's home to the ARV dispensing sites is long, which translates into high travel fares that discourages users and leads to non-adherence. One such case was cited in the islands of Lake Victoria which is about 70kms from the ARV site in Sengerema – the user defaulted due to high travel fares.

6.0 National and International Policies

6.1 Introduction

Issues relating to the policy environment in which ARV programmes are being implemented were not covered in Burkina Faso as they were in Mozambique and Tanzania. None the less, it should be noted that both national and international policies can either promote or constrain accessibility to and use of ARVs as well as program rolling out.

6.2 National Policies and Frameworks

The policy environment in the two countries provided a favourable environment for implementation of ARV programmes. Both Tanzania and Mozambique have comprehensive National Strategic Frameworks for HIV and AIDS—i.e., Tanzania has a National HIV and AIDS Care and Treatment Plan which specifically guides the implementation and management of the ARV program in the country, and similarly Mozambique a "National Health Sector Strategic Plan to Combat STIs and HIV and AIDS". For the later, the policy direction for the provisioning of ARVs and rolling out is embedded in that Plan. It is the national overall reference point and framework upon which HIV and AIDS interventions and guidelines are based including those for ARVs as compared to Tanzania where the "National HIV and AIDS Policy (2001)", is the supreme and reference document to guide the HIV and AIDS response.

It is important to note that both countries have developed other policy guidelines and frameworks to promote provisioning of ARVs such as the "Policy on HIV Testing and Treatment", The ART Guidelines (2004) and the "The Nutritional Guidelines" for Mozambique and the "National Guidelines for the Clinical Management of HIV and AIDS (April 2005)" in the case of Tanzania. Tanzania also has The National Multi-Sectoral Strategic Framework on HIV and AIDS (NMSSF) 2003-2007 which operationalizes its National HIV and AIDS Policy. This framework, among others, provides for the treatment of common opportunistic infections, including ARVs, and recognises that the provision of appropriate care including access to highly effective anti-retroviral treatment is one of the corner stones of every national strategy.

What is common to both countries is that their policy guidelines on care and treatment are not explained in ample detail. For instance, whereas Tanzania's policy goal and objectives are very clear on HIV prevention, it provides a general and cursory attention to the issue of treatment under its third specific objective-"Care for PLHAs". Advocacy for increased access of PLHAs to medical care mainly ARVs is not well articulated. Other issues such as the mechanisms for monitoring and follow-up of people on ARVs, plans for rolling out to address the equity problems, inbuilt sustainability mechanisms for availability of ARVs and accessibility, incentive plans for manufacturers of ARVs etc. are also not well articulated by the policy's goal and objectives. All these need to clearly come out in the country's National policy on HIV and AIDS.

In the case of Mozambique, the challenge is mostly on the content in the National strategic plan document. This overarching national framework is divided into parts; the "Strategic Component—Situational Analysis and the "Operationalization". The Strategic Component itself is a detailed document that presents a situational analysis, among others, on indicators for disease assessment, drivers of the epidemic, IEC activities, prevention activities, treatment, mitigation of the impact etc. But being a situational analysis, it does not provide a comprehensive analysis to the aspect of ARVs. It largely provides background information which has since been overtaken by events. Most of it is centred on prevention of the infection and hence needs to be reviewed to cater for ARV provisioning and accessibility.

6.3 International Policies and Frameworks

Like all developing countries, changes in the global policies regarding ARVs such as policies on patent rights have affected Tanzania, Mozambique and Burkina. According to UNAIDS report (March 2006) patents have become one of the most hotly debated issues in essential medicines since the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) was introduced in 1995. This was followed by the Doha Ministerial Declaration on the TRIPS Agreement and Public Health of 2001, which clarified that the Agreement contains flexibilities that allow countries to import and produce generic versions of antiretroviral drugs under patent to protect public health. This, in turn, provided a mechanism for increasing competition among pharmaceutical manufacturers, reducing drug prices and expanding access to antiretroviral therapy. UNAIDS has, however, warned that the public health impact of the TRIPS flexibilities will depend on how effectively countries implement and use them within their national systems. In the same report it is observed that low and middle-income countries often lack the capacity to effectively administer policies governing intellectual property rights and also lack information about the status of patents on essential medicines, which is needed to make use of the TRIPS flexibility. Given this situation, countries such as Tanzania, Mozambique and Burkina could be better off dealing with these aspects in their regional groupings.

All the three countries i.e. Tanzania, Mozambique and Burkina are members of a number of regional bodies such as SADC, the East African Community (EAC) and ECOWAS. These aim at harmonizing member States' HIV and AIDS Policies, Strategies and Treatment Protocols. Member states in EAC have even been urged to consider joint procurement of ARVs based on the harmonized EAC ART Protocols in order to further reduce cost of the drugs and increase access.

In the particular case of Tanzania, all the partner states in the EAC have established programs for scale up and distribution of ARVs to patients in their jurisdiction. This has happened in the last two-three years using cheap generic products mainly from India. However, with India complying with the TRIPS Agreement effective March 2006, these expansion programs are under threat. India shall not be able to produce cheap generic ARVs through reverse engineering. The option EAC member countries have is to manufacture the drugs themselves.

As of now developing countries including Tanzania, Mozambique and Burkina Faso and other partner states in the regional bodies need to pass legislation that can enable them to exploit positively the flexibilities provided in TRIPS, and also vigorously produce generic drugs for their nationals. But overall, the three countries where these studies were conducted are all recognized as having enabling national policies that can potentially accelerate availability and accessibility of ARVs.

7.0 Conclusions and Recommendations

7.1 Introduction

This final Section of the Report draws the conclusions and suggestions arising out of the study findings. The suggestions are synthesised from the views of study participants on what they considered to be the role of civil society, ACORD inclusive in this era of ARVs—HIV and AIDS care and treatment.

7.2 Conclusions

Overall, provisioning of ARV treatment services is a recent initiative in all the three countries of Tanzania, Mozambique and Burkina Faso. There are still daunting challenges with regard to ARV availability, accessibility and utilization. Universal accessibility of ARVs especially of free ARVs will take a while to be realised in all the countries. Inequity in distribution of ARV dispensing sites is more skewed for the typically rural settings – even in rural areas, ARV dispensing sites are located in the urban parts of the community. As of now, most ARV sites in the three countries are located in urban centres. This is an equity problem that characterises the ARV programmes and requires attention. It is even a bigger problem in Burkina Faso where ARVs are not provided freely.

Availability of ARVs does not easily translate into accessibility and use, unless the general poverty situation is addressed. As is typical of all poverty-stricken households, the expenditure of households captured in this study exceeded the estimated monthly income. This kind of situation threatens ARV accessibility, use and adherence; implying that programs aimed at expanding ARV accessibility should go hand in hand with poverty eradication programs.

On a positive note though, it is worthy noting that even within such a short time of introduction of the ARV programmes, the masses have a more than average knowledge and understanding of ARV treatment. The information on ARVs is basically provided at ARV sites/health facilities by health workers and counsellors, which implies that other members in the community who do not or rarely visit the ARV sites or health facilities hardly get information on ARVs.

Every health program has its impact—negative or positive, so is the ARV program. Although it is still too early to take stock of the long term impact of the ARV program due to the short time it has been implemented, the study has nevertheless revealed a few aspects of impact. The positive impact on the individual beneficiary has been improved health and increased productivity, but the negative impact is increasingly being reflected in the costs associated with accessing ARVs such as transport costs and forfeiting some household needs among others.

7.3 Recommendations

The recommendations are categorized into two; those which are for national action, and those which require regional and Pan African concerted approach. In fact, there may be need for more in-depth research at the regional and Pan African level.

1.1.1 Recommendations for national action

Poverty reduction efforts: - The socio-demographic and economic profiles of all the ARV users revealed that majority are poor. These conditions of poverty double as barriers to ARV accessibility and use, which require action. Two scenarios are suggested (i) that PLHA on ARVs and whose health is deteriorating should be targeted with safety-nets—e.g., direct nutritional support, and any other support as deemed critical, and (ii) for PLHA whose health has not been greatly compromised, their households should be targeted with micro-credit support.

Addressing the equity problems:- The study findings showed that ARV sites were almost a preserve of urban areas, which created imbalances in access to information and service provision between the urban and the rural areas, and yet majority of the people stay in rural areas. It is therefore recommended that alongside stimulating demand for ARVs, government

should decentralize dispensing of ARVs to lower health units to ease accessibility, and promote use. This implies rolling out the ARV program in "hard to reach" rural communities or those at the margins of society. Treatment and related services need to be availed freely to all those who need them especially in Burkina Faso where the ARV program is not entirely free.

Regarding the disparities in access to information about ARVs, it can be noted that awareness raising and sensitization on ARVs ought to widen to include all sections of the society; the rich and the poor, users of ARVs and non-users, PLHAs and those that are HIV negative, i.e., reaching everyone. This strategy seeks to arouse social support for PLHAs to use ARVs, but also goes hand in hand with strategies for eliminating stigma and discrimination, which also undermine the use of ARVs and adherence. Methods which reinforce highly interpersonal, customised, individualised means of delivery of information need to be promoted.

Multi-faceted IEC strategy for factual information: - The study findings revealed low levels of ARV knowledge and awareness in the general population—both in urban and rural areas. Secondary data also pointed to lack of adequate ARV knowledge among the health providers to disseminate factual and appropriate ARV information. The study findings also revealed that health providers/counsellors at the ARV dispensing sites were the main source of information on ARVs. It is recommended that a multi-faceted strategy of the radio, print media, community-based health educators, health workers and civil society organizations be used to disseminate knowledge and information on ARVs—i.e., to increase ARV literacy and dispel myths and fears that are barriers to ARV use.

Campaigns targeting stigma and discrimination: - Although stigma and discrimination were reportedly on the decrease, there was evidence that they still existed in some sections of the communities, which undermined ARV uptake. It is therefore recommended that Governments with support of other stakeholders such as the civil society should sustain the campaign against stigma and discrimination, which undermines social support for taking ARVs.

VCT Services: - Study findings indicated that for localization of ARV dispensing services to be relevant, it ought to go hand in hand with promotion of ethical, effective and sustainable VCT services. Ethically and effectively delivered VCT services can contribute greatly towards eliminating stigma and discrimination.

Nutritional and Food support: - There is no doubt that appropriate nutrition constitutes the first line in treatment of AIDS related illnesses. Therefore nutritional programs and availability of adequate food to people on ARVs need to be financed by government and other players in the field as part of the ARV program. This will, among others, contribute to adherence, and attract potential users to embrace the program. Indeed, the issue of nutritional and food support is at the centre of ARV utilization in Mozambique.

Increasing the proportion of men using ARVs
The findings revealed that more females than males were using ARVs, which highlights the need to reach out to the males. One of the main intervention points to encourage the men to use ARVs is through reduction and eventual elimination of stigma and discrimination. Sustained awareness raising, sensitization and counselling of the community al large would realize impressive changes in the number of men using ARVs.

Improvement of the general health care system and human resources: - Before rolling out ARV provisioning in all the three countries, deliberate efforts must be made to improve the general health care system. There is an urgent need for more training of health personnel in both public and health facilities, and also to advocate for improved terms and conditions of service for enhanced recruitment and retention.

Support for structures of and for PLHAs:- PLHA associations play a vital role in identifying people in need of treatment and supporting them with essential information and counselling. These associations must be supported and strengthened through increased financial support and capacity building.

7.3.2   Wider recommendations at Regional and PAN African level

Funding for health services and resource mobilisation:- The issue of limited resources has been documented as a barrier to equitable accessibility to ARVs. This constraint affects all

the three countries. This study recommends increased advocacy for enhanced funding for health services and other components for managing HIV and AIDS to meet current needs. It is therefore important that resource mobilization and advocacy efforts are supported. Similarly, focus should be placed on efficient allocation of resources along the different interventions to the public and private providers, improving collaboration and partnerships, strengthening central government and districts to ensure that the resources are used in efficient delivery of services to the target groups.

Operationalization of national policies and frameworks:- Although the ARV program is still relatively new, the study revealed a rich and conducive national HIV and AIDS policy and framework. The limitation is the translation of this policy environment or policies into concrete programs on the ground. There is therefore need for increased lobbying and advocacy, and to mobilize resources so that these policies can be translated into sustainable funded programs aimed at enhancing ARV accessibility and use in the region and sub-Saharan African countries.

Expediting the legislation of TRIPS flexibilities and enhanced engagement in global policies:- The study revealed a possible difficultly in sustaining the supply of ARVs to nationals in the region as India, which used to be the main source of ARVs for the region, has complied with TRIPS. Countries in sub-Saharan Africa need to sustain their engagement with international bodies and powerful governments in the world that are setting the agenda for ARV manufacturing and supply.

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(Footnotes)
1   The sample includes both PLHAs and service providers but the figures in the table are for only PLHAs

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