

# Pharmalink

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## HIV programming in Church institutions



## Challenges & responses

## About Ecumenical Pharmaceutical Network (EPN)

Ecumenical Pharmaceutical Network (EPN) is an independent, not-for-profit, Christian organization whose mission is to support churches and church health systems provide and promote just and compassionate quality pharmaceutical services for all. In addition, the work of EPN is aimed at working towards services that allow no discrimination and guarantee equal access to all.

## About the cover image

At a Sisters of Charity hospice for AIDS patients in Haiti, a Sister supports a patient as she walks.

Credit: Paul Jeffrey / Ecumenical Advocacy Alliance.

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## Editorial

Have we learnt enough about stigma? Jesus was stigmatized, especially the closer he got towards his execution. Although the availability of antiretroviral medicines has increased over the last decade and HIV/AIDS is treated like many other chronic diseases, the stigma that infected people do experience is not overcome. Church leaders are highly respected and therefore are seen as a role model by their communities. How should we deal with people infected? All of us, if we claim to be faithful, should act as a role model and can make a difference to overcome stigma.

Christian health organizations give examples of being reliable partners for international organizations with huge HIV/AIDS programmes. CHAZ, CHAK and UCMB are excellent success stories to be reflected in this issue.

If we draw a balance of people receiving antiretroviral treatment and those without any medication, the situation is far from acceptable. The financial crisis affecting the funds for programmes is scary. Looking at the most vulnerable group of a society, the children, the lack of adequate medicines for them is even more shameful. Let us raise this issue, when we get in contact with donors and stakeholders.

A chronic disease requires continuous treatment. Adherence to antiretroviral therapy is key for keeping down the virus load in the patient. Every effective medicine can cause side effects. This applies also to antiretrovirals. The more a patient knows about the side effects to expect and what to do about it, the more likely she or he will still adhere to the medication. It is the responsibility of all personnel who are involved in the treatment and dispensing process to address this issue with the patient.

We know who is our role model, whom to follow. Isaiah 58, 7 reminds us what to do. We have medication to treat HIV/AIDS, we are involved in different roles in the health system and/or community. Let us be a role model!

Andreas Wiegand

## Letters to the editor

Inquiries or comments about this edition of Pharmalink should be directed to: [communications@epnetwork.org](mailto:communications@epnetwork.org). The editor also welcomes author's initiatives for future editions.

# CHAZ HIV programmes: Supporting humanity's resilience

Josephat Kakoma

Back in the mid/late 1980s, HIV and AIDS was a ravaging monster; a deadly disease the very mention of which elicited debilitating fear of inevitable death coupled with the shame of contracting a disease largely associated with illicit sexual activity. The ghostly appearance of its victims sent cold shivers along the spines of even the strongest of men and women. Being diagnosed with HIV back then meant slow but certain death, but perhaps the worst bit was the social death - stigma and discrimination – that a person with AIDS experienced. HIV simply became to mean death - shameful death - and even the men and women of collar were caught off balance in their initial response to this deadly disease. Because HIV was widely associated with immorality, many, including the clergy, responded with condemnation of its victims – hence the widespread stigma and discrimination. HIV and AIDS was not just a medical condition but it also ravaged entire communities economically by claiming the health and lives of many breadwinners. Stigma and discrimination often kept its victims from seeking medical attention when they needed it the most.

## The cradle of CHAZ's HIV and AIDS programmes

The story of the Churches Health Association of Zambia's (CHAZ) HIV and AIDS programming is a story of humanity's resilience against a ravaging enemy. Given the high HIV prevalence rate which was around 16% at the time, the bed occupancy at most health facilities soon shot up with HIV

and AIDS related cases. This situation became acute around 1987/1988 and most health facilities were failing to cope with the ever rising number of HIV and AIDS related admissions particularly as they also did not have medication to manage AIDS at the time. Eventually, most health facilities began discharging AIDS patients, feeling helpless and hopeless as they could do little to keep the patients alive.

Given this situation, Churches, out of their compassion for the sick, began making visits at the homes of their members who were sick but could not be admitted at the health facilities. These visits gained momentum as time went by and increasingly came to be known as home-based care (HBC). With increasing HBC visits, CHAZ member facilities began to coordinate their efforts to replicate these services where not yet introduced. A referral system linking these "community health services" to the nearest health facilities was created. This was also to ensure that the lay community "HBC" providers were provided with mentoring and help on approaching terminally ill patients. Soon the need to appoint coordinators was identified.

Facing the problem at hand, coupled with a lack of knowledge about HIV and AIDS, most of these groupings started to organize themselves to "train" community and family "care-givers" on how to take care of their "clients". Soon, efforts began to sensitise their members about

*CHAZ's experience with HIV and AIDS programming has seen the organization transition from relatively isolated and unorganized efforts in remote areas to well-coordinated efforts spread throughout the country.*



A home-based care visit by CHAZ staff (credit: CHAZ)



Community members conducting a drama performance during a behavioural change communication campaign. (credit: CHAZ)

“HBC” and also eventually on HIV and AIDS. Before long, CHAZ members recognized the need to coordinate these efforts at a broader level. CHAZ raised resources and set up a formal HBC programme in 1990/1991. Over time, the disease resulted in a high number of deaths leaving behind children with single or no parents. The groups responded by organizing themselves, raising resources to ensure orphaned children be able to continue with their education and have food on the table. This was an important milestone given that AIDS was commonly a disease of bread winners. Hence, most families were failing to cope as AIDS soon took on an economic dimension.

The CHAZ’ supported HIV/AIDS initiatives were formally developed into a programme around 1992/3, which came to be known as the CHAZ AIDS Care and Prevention Programme (CACPP) and was funded by DanChurchaid. The programme was initially implemented in four (4) Church Health Institutions (CHIs). After four

years, the successful programme was further introduced to four other CHAZ health facilities. By the year 2000, the CACPP became very popular and CHAZ was increasingly being seen as a key player in the country’s effort to fight the HIV and AIDS epidemic.

During this period, some members of CHAZ, Chikankata Mission Hospital in particular, began training health workers and a limited number of community workers in HIV and AIDS management. They also started Care and Prevention Teams (CPT). CPTs were a mechanism designed at the community level championed by the health facility to harness communities’ involvement in fighting HIV and AIDS. CPTs comprised community traditional leaders, care-givers, clients, opinion leaders, teachers, etc. in the community and they planned the community HIV/AIDS prevention initiatives and how to care for AIDS patients and also the children affected by HIV and AIDS. These CPTs soon spread among CHAZ member facilities and the model also gained prominence even among secular efforts to fight HIV and AIDS.

#### Scaling up the response

In 2002, the Global Fund started to fight AIDS, TB and Malaria (GFATM). Under this initiative, CHAZ was appointed by key stakeholders in the health sector in Zambia to be a Principal Recipient (PR), along with the Ministry of Health (MoH), the Ministry of Finance and National Planning (MoFNP) and the Zambia National AIDS Network (ZANAN). Under this arrangement, CHAZ was mandated to sub grant funds to Faith-Based Organizations (FBOs).

This development saw CHAZ extend its umbrella role from its traditional CHIs to FBOs in general. The organization’s influence in no time became nation-wide as it implemented a 5 year US\$20 million comprehensive HIV/AIDS programme that focused on prevention, impact mitigation, care and support initiatives. Under this programme, CHAZ subgranted to over 50 CHIs and 16 subrecipients (SRs) with the latter in turn subgranting funds to nearly 400 FBOs countrywide! When cheap Antiretroviral Treatment (ART) became available globally, the GFATM introduced a treatment Round (R4) and CHAZ began treating people living with HIV/AIDS (PLWHAs) in its health facilities.

#### Lessons learned

1. **It is all the grace of God:** We have “planted the seed” and God has been faithful to water it and grant success to our efforts.
2. **Programmes must be grounded on national policies, frameworks and guidelines:** CHAZ operates within and buys into the national policies and plans. The Association’s Strategic Plan is therefore within the national framework. This has made it much easier for the organization to partner with the Government and the MoH in particular.
3. **Continuous capacity building is key:** Our experience is that there is no substitute for enhanced capacities among service providers, be it at the national, sub national and the community levels. The Association ensures that staff at the various levels are kept abreast with know-how to enhance their performance. Even more so with the high attrition levels experienced at the CHIs.
4. **Know your epidemic, know your response:** Knowledge of the various dynamics of the epidemic is central to ensuring that the strategies that are developed are in line with the situation on the ground. Knowledge of the epidemic is particularly key to targeting and scheduling of interventions.
5. **Programmes must be anchored on community participation:** Community participation is the cornerstone of any initiative that CHAZ implements at the community levels. When communities are involved in planning, implementing and making decisions on the programme, community ownership is enhanced and this is critical even for the acceptability of interventions and the sustainability of the project(s).
6. **Address key affected communities or most at risk populations:** HIV has in most cases thrived due to certain social, physical, biological and environmental factors. For instance, transmission of HIV in Zambia is closely linked with women’s poor socio-economic status in society. The aspect of gender needs to be incorporated in HIV and AIDS programming. Other key affected communities may include youth (girls in particular), sex workers, men who have sex with men, injecting drug users, among others.
7. **Strengthen organizational accountability systems:** Accountability is another cornerstone of HIV and AIDS programming. Strengthened financial and grants management systems that ensure that risks are minimized, Monitoring and Evaluation (M&E) systems, etc. are critical to the success of any programme.
8. **Evidence-based programming:** Evidence-based practice is a buzz word in the scientific world and this is no exception in the HIV and AIDS sector. Evidence-informed interventions ensure that investments for preventing or mitigating HIV and AIDS are put to the best possible use.

During 2003 – 2006, CHAZ was also implementing a couple of other key HIV and AIDS programmes alongside the Global Fund programme, such as the Local Community Competence Building (LCCB) programme (2003 – 2005). It was implemented in five CHIs and co-funded by the European Union (EU) and DanChurchaid. This programme focused on creating HIV/AIDS competences in local communities and had a thrust on HIV/AIDS prevention interventions. New to CHAZ was the rights-based HIV and AIDS programming approach and the gender perspective. The Facilitating Community to Community Transfer of HIV/AIDS initiative (FCCT) programme (2005 – 2007) was funded by DanChurchaid. This was a comprehensive HIV/AIDS programme that focused on spreading CHAZ’s “social vaccine” against HIV and AIDS. The premise of the programme was the evaluation of a previous phase of the programme

which established that the evaluation of CACPP had proven huge milestones in HIV and AIDS programming and the new programme aimed to extend the benefits to other CHIs and their communities.

#### Current HIV and AIDS programmes

Currently (2011-2012), GFATM and the Country Coordinating Mechanism (CCM) in Zambia have temporarily dropped ZNAN and MoFNP as PRs and have requested CHAZ to be the PR for their grants at least for the next 2.5 years. What this has meant is that CHAZ’s mandate has been extended to subgrant to CSOs and also to manage the grant for Government line Ministries with the exception of the Ministry of Health.

CHAZ is currently implementing two large comprehensive HIV and AIDS programmes funded by the Global Fund and a basket funding initiative

called Joint Funding Arrangement (JFA). Under CHAZ's 2011 – 2015 Strategic Plan, the goal of the Association's HIV and AIDS programme is "To contribute to the prevention of HIV incidence and mitigate the social-economic impact of the HIV/AIDS epidemic in rural Zambia".

### Challenges

Though seemingly a rosy story, CHAZ's HIV and AIDS programming has not been without its down turns and challenges. The following are the main challenges faced in the Association's HIV and AIDS programming:

- 1. Resource constraints:** This may come as a surprise seeing that CHAZ handles millions of US\$ on an annual basis. But the fact of the matter is that the resource envelope is limited and there is only so much we can do.
- 2. Poor infrastructure:** Most mission health facilities were built in the colonial era and are thus in desperate need of facelifts. Most CHIs are working with old buildings, run-down and archaic equipment, inadequate supplies of medical products, etc.
- 3. Human Resources for Health (HRH) crisis:** While the HRH crisis is a global phenomenon, African countries are hardest hit. CHAZ' CHIs are mostly located in rural areas where it is extremely challenging to retain trained health care workers. This results in available staff being too stretched across a variety of responsibilities hence they may not adequately implement HIV and AIDS programmes, particularly providing mentoring to community providers. Staff who have benefited from diverse trainings become very attractive to other NGOs and consequently leave the health facilities, thereby the programmes "lose" their investments and new people have to be trained all over again.
- 4. Poor record keeping:** FBOs have generally been accused of poor record keeping and some of the implementing partners CHAZ works with are fit recipients of this accusation. Poor record keeping may cost the implementation of initiatives as information is not readily available and reports cannot be produced in time or if at all. In the end, accurate and timely decision making is inhibited.
- 5. Limited sustainability of initiatives:** While some investments poured into programmes enhance sustainability, a significant amount of interventions have very



CHAZ staff distributing materials to raise awareness (credit: CHAZ)

limited sustainability. Training of community health workers ensures that AIDS competence is enhanced but most initiatives such as income generating activities, while helpful in the short term cannot be said to be sustainable. Other initiatives with limited sustainability include Behavioural Change Communication.

### Conclusion

CHAZ's experience with HIV and AIDS programming has seen the organization transition from relatively isolated and unorganized efforts in remote areas to well-coordinated efforts spread throughout the country. The programme has also transformed the Association from a small insignificant organization to a key and influential public institution nationally with important influences abroad. All this has been achieved by the grace of God! The message to other CHAs is that in spite of the threatening challenges, it is possible to make key contributions to the nation's fight against HIV and AIDS and, by extension, to other critical areas in the health sector. CHAZ is grateful to the Government of the Republic of Zambia for the mutual and cordial partnership that exists between the two institutions, making this contribution possible. 🌱

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# Situation, market dynamics & challenges of paediatric ARV supply in sub-Saharan Africa



Dr Edwine Barasa, Dr Andreas Wiegand

Each day, 1000 children are newly infected with HIV/AIDS and an alarming 700 die due to AIDS-related complications<sup>1</sup>. The burden of paediatric HIV/AIDS is highest in developing countries, and sub-Saharan Africa specifically, where it is estimated that HIV/AIDS is responsible for 5% of deaths in children under the age of five<sup>2</sup>. To achieve millennium development goals 4 (Reduce child mortality), 5 (Improve maternal health) and 6 (Combat HIV/AIDS)<sup>3</sup>, there is need for scaling up and increasing access to cost-effective interventions<sup>4</sup>. Antiretroviral therapy (ART) has been identified as an effective and cost-effective intervention in reducing the morbidity and mortality due to HIV/AIDS in children<sup>5</sup>. For example, a landmark trial demonstrated that early antiretroviral therapy reduced infant mortality by 76% and HIV progression by 75%<sup>5</sup>. It has also been observed that without treatment, one third of children born with HIV die before their first birthday, 50% die before they turn two<sup>1</sup>.

Increasing the access to and availability of ARVs will have an impact on the child mortality caused by HIV/AIDS. The church health sector plays a major role in the provision of health care in developing countries. In Kenya for example, church health facilities account for about 40% of health care delivery<sup>6</sup>. It is therefore imperative that church health facilities are at the forefront of improving access to HIV/AIDS care and treatment, including care for children. The provision of Paediatric ARVs by church health services, similarly to the public health sector, is however affected by a number of realities in the market for paediatric ARVs.

### Paediatric ART supply situation

Despite the evidence that antiretroviral treatment is effective in reducing mortality and morbidity due to HIV/AIDS, as of the end of 2010, less than one third of children who needed antiretroviral therapy globally were receiving it<sup>1</sup>. Of the 1,270,000 children in need of ART globally, 1,140,000 (89%) live in sub-Saharan Africa<sup>7</sup>. However, the estimated coverage for paediatric antiretroviral therapy in sub-Saharan Africa is only 26% (table 1). Accessing quality treatment and care therefore remains an uphill battle for families of children living with HIV/AIDS especially in resource-poor settings such as Africa<sup>1</sup>.

Geo-graphical location	Estimated number of children needing ART, 2009 (range)	Number of children (0-14 years) receiving ART, Dec 2009	ART coverage among children, Dec 2009 (range)
Eastern and Southern Africa	790,000 (530,000-1,000,000)	254,900	32% (25%-48%)
Western and Central Africa	350,000 (180,000-510,000)	41,000	12% (8%-22%)
Total sub-Saharan Africa	1,140,000 (710,000-1,500,000)	296,000	26% (19%-42%)

Table 1: Coverage of Paediatric Antiretroviral Therapy in sub-Saharan Africa  
Source: WHO, UNAIDS, and UNICEF, Towards Universal Access: Scaling up priority interventions in the health sector. 2010

A study was conducted by the Ecumenical Pharmaceutical Network (EPN) in 2010 in Kenya, Uganda and Chad to determine the availability and pricing of selected paediatric ARV

formulations. This was a cross-sectional survey conducted in health facilities managed by church health services across the 3 countries, as part of a larger study on the availability of paediatric medicine formulations in church health facilities. Church health facilities were classified into 3 strata: hospitals, health centres and dispensaries. Table 2 shows the selected facilities.

Table 2: Facilities included in EPN's study on availability of medicines

Country	Total facilities	Hospitals	Health facilities	Dispensaries
Kenya	79	30	23	26
Uganda	61	17	44	0
Chad	30	7	24	0

In Kenya, availability of paediatric antiretrovirals (any paediatric antiretroviral) was lowest in dispensaries at 11.6% and highest in hospitals at 74.4%<sup>8</sup>. Overall availability among the different formulations ranged from 7.5% for Efavirenz 50mg capsules to 53.8% for Nevirapine tablets 200 mg (table 3).

Table 3: Availability of paediatric ARVs in Kenya

Formulation	% availability in hospitals	% Availability in health centres (95% CI)	% Availability in dispensaries (95% CI)	% Availability in all facilities (95% CI)
Abacavir solution (100mg/5ml)	77 (57.7-90.0)	4 (0-20.4)	4 (0.1-23.4)	31.2 (21.3-42.6)
Efavirenz oral liquid (30mg/5ml)	13 (3.8-30.7)	9 (0.1-26.0)	0	7.5 (2.8-15.6)
Efavirenz capsules (50mg)	57 (9.9 - 42.3)	4 (0-20.4)	4 (0.1-23.4)	23.75 (14.9-34.6)
Lamivudine oral solution (10mg/ml)	83 (65.3-94.4)	35 (14.9-53.4)	12 (2.5-31.2)	45 (33.8-56.5)
Lamivudine tablets (150mg)	83 (65.3-94.4)	35 (14.9-53.5)	12 (2.5-31.2)	45 (33.8-56.5)
Nevirapine syrup (50mg/5ml)	93 (77.9-99.2)	35 (14.9-53.6)	23 (9.4-45.1)	52.5 (41.0-63.8)
Nevirapine tablets (200mg)	93 (77.9-99.3)	39 (18.0-57.5)	23 (9.4-45.1)	53.8 (42.2-65)
Zidovudine syrup (10mg/ml)	93 (77.9-99.4)	43 (21.1-61.3)	15 (4.5-36.1)	52.5 (41.0-63.8)
Zidovudine capsules (100mg)	77 (57.7-90.0)	17 (4.5-36.1)	8 (0.1-26.0)	36.5 (25.8-47.8)

In Uganda, the average availability of paediatric antiretrovirals among the different formulations ranged from 0% for Abacavir solution 100mg/5ml to 53% for Nevirapine solution 50mg/5ml and Nevirapine tablets 200 mg (table 4)<sup>9</sup>.

Table 4: Availability of ARVs in Uganda

Formulation	% availability in hospitals (95% CI)	% Availability in all facilities (95% CI)
Abacavir solution (100mg/5ml)	0	0
Efavirenz oral liquid (150mg/5ml)	5 (0.1-24.9)	2 (0-8.9)
Efavirenz capsules (50mg)	47 (23.1-68.5)	15 (7.1-26.6)
Lamivudine oral solution (10mg/ml)	19 (3.2-37.9)	5 (1.0-13.9)
Lamivudine (30mg) + Nevirapine (50mg) + Zidovudine (60mg) tablet	42 (19.1-63.9)	15 (7.1-26.6)
Nevirapine oral liquid (50mg/5ml)	53 (27.2-73.9)	26 (16.1-39.6)
Nevirapine tablets (200mg)	53 (27.2-73.9)	26 (16.1-39.6)
Zidovudine oral liquid (10mg/ml)	32 (11.9-54.3)	12 (4.8-22.6)
Zidovudine capsules (100mg)	26 (8.7-49.1)	8 (2.8-16.8)

In Chad, the availability among the different formulations ranged from 0% for Efavirenz 50mg capsules and Abacavir 100mg/5ml to 71% for Zidovudine syrup 10mg/ml (table 5)<sup>9</sup>.

Table 5: Availability of ARVs in Chad

Formulation	No of hospitals with medicine n=7	% Availability (95% CI)
Abacavir solution (100mg/5ml)	0	0
Efavirenz capsules (50mg)	0	0
Lamivudine oral solution (10mg/ml)	5	71 (9.0-96.3)
Nevirapine syrup (50mg/5ml)	6	86 (42.1-99.6)
Lamivudine tablets (150mg)	2	29 (3.7-70.9)
Nevirapine tablets (200mg)	3	43 (9.9-81.6)
Zidovudine syrup (10mg/ml)	5	71 (29.0-96.3)

The availability was generally found to be higher in hospitals than in peripheral health facilities (health centres and dispensaries). This can be explained by the fact that most peripheral facilities are not qualified to provide HIV/AIDS treatment and care. In Chad for example, antiretroviral care is only provided at the hospital level. Given that peripheral facilities such as health centres and dispensaries have a greater coverage and access to the population, perhaps efforts should be undertaken to use these facilities to provide ART services. Challenges such as lack of skilled personnel will however have to be addressed if these facilities are to provide ART services to children.

The availability was generally found to be higher for first line antiretrovirals such as Lamivudine and Zidovudine and much lower and sometimes missing all together for second line medicines such as Abacavir. It is likely that most children who need to be put on alternative therapies do not get access to these medicines.

#### Financing and procurement of paediatric ARVs

The major actors in the financing of paediatric ARVs in sub-Saharan Africa are UNITAID<sup>10</sup>, the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM)<sup>11</sup> and the United States' President's Emergency Plan for AIDS Relief (PEPFAR)<sup>12</sup>. Given the substantial overlap of funding in some countries by UNITAID, GFATM, and PEPFAR, agreements were made with countries and major donors that UNITAID would initially be the primary source of funding for paediatric ARVs in those countries. Such coordination allows for optimization of resources and avoidance of service duplication. The Clinton Health Access Initiative (CHAI)<sup>13</sup> and the Supply Chain Management System (SCMS)<sup>14</sup> conduct large-scale purchasing on behalf of UNITAID and PEPFAR, respectively. In countries where UNITAID and PEPFAR are not active, GFATM supported HIV/AIDS programmes to procure their ARVs independently.

Changes in the funding and procurement landscape for paediatric ARVs are however likely to reverse the gains made in access to paediatric ARVs. UNITAID/Clinton Health Access Initiative (CHAI) is phasing out its funding of HIV medicines and commodities<sup>15</sup>. In line with the initial overall timeframe of UNITAID funding through

CHAI, funding and procurement for paediatric ARVs was planned to officially end in September 2010<sup>15</sup>. However, a two year multi-country transition extension was granted by UNITAID, while transition to other donors is explored<sup>15</sup>. In countries supported by the Global Fund and/or PEPFAR, these donors will take up this funding role<sup>15</sup>. This change over from UNITAID/CHAI to the Global Fund is likely to lead to supply gaps during the transition period. While CHAI's procurement mechanism involves the pooling of country orders and joint procuring, countries funded by the Global Fund procure independently. Given that paediatric ARV orders are usually small, independent country procurement is likely to erode gains from economies of scale, result in increased pricing and offer a disincentive to manufacturers to produce paediatric ARVs. As the Global Fund takes over the financing of paediatric ARVs in countries therefore, considerations need to be given to pooled procurement. The fact that funding cycles for country programmes financed by the Global Fund are often not aligned is likely to pose a challenge to pooled procurement. This means that, additionally, funding cycles need to be aligned.

#### Paediatric ARV market dynamics

Pharmaceutical companies have numerous disincentives to develop and produce paediatric ARVs. For a market to be favourable, it has to generate sufficient demand to guarantee a return on investment to pharmaceutical companies<sup>16</sup>. Paediatric ARV markets are, however, always smaller and less attractive than adult markets. Even when paediatric ARVs are procured by large-scale purchasers like UNITAID, an unfortunate paradox comes into play in paediatric HIV/AIDS treatment: the more paediatric ARV formulations are tailored to the needs of specific sub-groups, the less demand there is for a given product<sup>16</sup>. This becomes particularly problematic in convincing companies to produce age appropriate strengths of fixed-dose combination ARVs in multiple formulations. The reduced demand also impedes the realization of economies of scale in production and distribution, making the unit cost of paediatric ARVs high<sup>17</sup>.

#### Challenges to scaling up paediatric ART coverage in sub-Saharan Africa

Despite evidence of the effectiveness of paediatric ART in resource constrained settings; scale-

up to the level of universal access has been limited for a variety of reasons.

#### Lack of trained health care workers

Scarcity of skilled human resource for health has been recognized as a health system challenge in developed countries. Specifically in the area of paediatric ART, efforts by public health facilities as well as the church health services to scale services are often hampered by lack of trained personnel to provide paediatric HIV/AIDS care. This is partly because paediatric ARV dosing and administration can be complex, requiring personnel with good training in the area.

#### High cost of paediatric medicines

Paediatric medicines, while having decreased in cost considerably, still cost significantly more than adult formulations of the same medicines. It is estimated for example that paediatric ARVs cost almost 75% - 90% more than adult versions per month of treatment<sup>18</sup>. Part of this cost is attributed to the diseconomies of scale as a result of the small market for paediatric ARVs. High costs are also attributed to the increased cost of production and packaging of paediatric formulations. In many parts of the world, twice as many adults could be treated with the same amount of funding<sup>18</sup>.

#### Paediatric labelling

Many available ARV medicines have not been tested or labelled for paediatric use; some that have been labelled are only suitable for limited subsets, such as for children above a certain age or weight limit. For example Lamivudine dosing information is indicated only for children above 2 years, and that of Tenofovir is indicated for children above 12 years (table 6). Only 12 of 20 AIDS medicines developed so far are labelled for paediatric use; and just 7 for children under the age of 2<sup>18</sup>.

#### Limited number of paediatric formulations

There is a limited number of age-appropriate paediatric ARV formulations. As children move through infancy, toddler, and childhood stages, the optimal dosage forms change as well. Liquids (syrups, suspensions, and solutions) are needed to treat younger children who cannot swallow solid dosage forms. As children get older and the necessary volumes of liquid ARVs become too large, they require other products, such as chewable tablets, until they reach an age when they can swallow solid tablets<sup>18</sup>. There are a number of ARVs for which appropriate paediatric formulations such as chewable tablets are still not available. The dilemma for the development of alternative formulations like oral dispersible tablets is the investment in development. For each dosage form, the manufacturer needs to prove quality of the manufacturing processes and the final product. The more different dosage forms, the smaller the batch sizes. A bigger variety may also result in more equipment needed for production and thus more investment.

#### Difficulty obtaining registration

To appropriately treat young children, it is necessary to get approval to sell all formulations of all necessary medicines within a country. Fixed dose combinations, particularly those referenced in national guidelines, are easier to register because there is clarity regarding need and intent to use. However, the registration of paediatric formulations is often slow and costly due to the greater number of requirements needed by regulatory authorities<sup>16</sup>. Information such as pharmacokinetic studies and safety studies are for example not always available for all paediatric age groups, yet this information is required for registration of these medicines<sup>16</sup>.

#### Awareness for paediatric formulation

It has also been shown that many countries are not yet using new, improved paediatric formulations<sup>18</sup>. There are some challenges associated with the uptake of new formulations which might explain this finding. For example, country-based staff may be unaware of recent developments and availability of new paediatric formulations. There may be reluctance to use new formulations, such as dispersible tablets, in regions where these types of medicines are not historically or currently used. The need to revise treatment guidelines and the need to retrain all pre-

scribers and caregivers may also contribute to under-utilization.

#### Impact on supply chain management

However, to change from currently used ARVs to the new paediatric solid formulations such as dispersible tablets may also create challenges in supply chain management. Forecasting demand is a challenging and complicated task. It is possible that in the transition phase from one set of ARVs to another, the number of paediatric products in warehouses and on facility shelves increases substantially, making demand forecasting more complicated for some period of time. Thus, such transitions need to be carefully planned and monitored in order to avoid wastage and stock shortages. Further, countries may be locked into long-term contracts that preclude them from switching to improved products or their demand may be too low to meet some suppliers' minimum purchase requirements.

#### Concluding thoughts

To get closer to the achievement of the millennium goals 4, 5 and 6, more children need to get access to ARV treatment. One key element to overcome the bottlenecks is the extension

of ART service provision. We need to give priority to the training of health workers on paediatric ART provision. Thus we will be able to increase the number of health facilities covering ART. Efforts should also be made to design procurement mechanisms that will improve the availability of paediatric ARVs. Key issues include careful planning for the transition of funding from UNITAID/CHAI to the Global Fund and/or PEPFAR, streamlining the procurement of ARVs, such as pooling procurement among countries to benefit from economies of scale such as reduced pricing. The procurement and supplies infrastructure (e.g. transport and storage) should also be improved to enhance capacity for supply of paediatric ARVs. There is also a need to develop better business models that would give an incentive to pharmaceutical companies to invest in the research and development of ARVs.

#### About the Authors

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Table 6: paediatric labelling of ARVs

ARV	Paediatric labelling
Abacavir	3 months and older
Efavirenz	3 years and older
Lamivudine	2 years and older
Lopinavir/ritonavir	14 days and older
Stavudine	From birth
Tenofovir	12 years and older
Zidovudine	28 days and older



Photo credit: CHAZ

# The burden of HIV disease, key sources and suppliers of ARVs in selected African countries

Dr Edwine Barasa, Vivian Atieno Ochollah, Dr Andreas Wiegand

HIV/AIDS remains the most important infectious disease with an enormous economic, social and human challenge to sub-Saharan Africa. According to the UNAIDS World AIDS Day Report 2011, 22.9 million people in the region are HIV-positive, and AIDS is the leading cause of premature death on the continent<sup>1</sup>. Two-thirds of all people infected with HIV live in sub-Saharan Africa, although this region contains little more than 12% of the world's population. AIDS has caused immense human suffering on the continent. The most obvious effect of this crisis has been illness and death, but the impact of the epidemic has certainly not been confined to the health sector: households, schools, workplaces and economies have also been badly affected<sup>2</sup>.

## Women and children

HIV/AIDS affects young people and women disproportionately. Young women are three times as likely to be infected as young men. Due to the pandemic, it is estimated that 14.8 million children under the age of 18 have lost at least one parent<sup>3</sup>. Its impact on households, human capital, the private sector and public sector undermines attempts to alleviate poverty. In sum, HIV/AIDS threatens the development goals in the region, unlike anywhere else in the world<sup>4</sup>.

With regard to life expectancy, AIDS is erasing decades of progress. In sub-Saharan Africa, life expectancy has fallen from 61 years (1990 – 1995) to 52 (2005 – 2010)<sup>5</sup>. In the worst affected countries, average life expectancy has in the same period fallen by twenty years because

of the epidemic. Life expectancy at birth in Swaziland, which has the highest HIV prevalence in the world, is just 48.7 years<sup>6</sup>.

During 2010 alone, an estimated 1.2 million adults and children died as a result of AIDS in sub-Saharan Africa. Since the beginning of the epidemic in 1981, more than 15 million Africans have died from AIDS<sup>2</sup>. Although access to antiretroviral treatment is starting to lessen the toll of AIDS, fewer than half of Africans who need treatment are receiving it. The impact of AIDS will remain severe for many years to come<sup>2</sup>.

## Implications of the financial crisis

The global response to the HIV/AIDS epidemic has been unparalleled. Among the key donors are PEPFAR, the World Bank, the Global Fund, and UNITAID (a consortium of different donors). In 2008, an estimated US\$ 13.7 billion was invested. The calculations published in 2009 for 2010 reported 25.1 billion US\$. For prevention 11.6 billion, for treatment and care (incl. palliative care) 7.0 billion, for orphans and vulnerable children 2.5 billion, for programme support costs 3.7 billion, and for prevention of violence against women 0.3 billion US\$ were estimated<sup>7</sup>.

In 2010, for the first time in the history of the response, international investments for AIDS decreased by 13% from 2009 to 2010, from US\$ 8.7 billion to US\$ 7.6 billion. In 2011, the Global Fund cancelled its next round of new funding proposals due to financial constraints arising

22.9 MILLION PEOPLE IN SUB-SAHARAN AFRICA ARE HIV-POSITIVE

MORE THAN 15 MILLION AFRICANS HAVE DIED FROM AIDS



Photo credit: Paul Jeffrey / Ecumenical Advocacy Alliance

largely from the failure of donors to meet their financial commitments to the Global Fund<sup>8</sup>. The current economic crisis and donor's decreasing budgets will have an impact on the success of the HIV/AIDS programmes. Even though the rate of new infections has dropped worldwide (19% from 1999 to 2010)<sup>3</sup>, still 2.7 million people got infected in 2010. That means the total number of infected people is rising year by year. Thus, more infected people need more treatment. Yet, today only a third of those infected have access to treatment<sup>3</sup>.

One can look at the financial picture of HIV/AIDS programmes and call it a paradox. The external assistance dominates HIV investment in most countries in Africa, to a much greater extent than for the health sector as a whole. More than two-thirds of overall health expenditure in Africa comes from domestic sources, whereas international sources account for two thirds of AIDS investments. The procurement of antiretroviral drugs is highly dependent on external funding. This is evident from the funding sources by country for ARVs as shown in the table on the next page.

## India, the source of ARVs

On a more positive note, over the past decade, the emergence of competition from generic manufacturers, and direct negotiation with pharmaceutical companies have all contributed to a dramatic drop in the price of certain drugs to treat HIV and AIDS in developing countries<sup>2</sup>.

The availability of cheaper antiretroviral drugs has been instrumental in treatment scale-up for resource-poor settings hard hit by the AIDS epidemic. Around 6.64 million people in low- and middle-income countries are currently receiving drugs to treat HIV/AIDS<sup>8</sup>. This would simply not have been possible without a reduction in the price of antiretroviral drugs (ARVs). Since 2006, Indian-produced generic ARVs have accounted for more than 80% of the donor-funded developing country market, and comprised 87% of ARV purchase volumes in 2008. By 2008, Indian generic ARVs accounted for 65% of the total value (US\$463 million) of ARV purchases reported, while non-Indian generic and innovator ARVs accounted for 13% and 22% of market value, respectively. The number of Indian generic manufacturers supplying ARVs to low- and middle income countries increased from 4 to 10 from 2003 to 2008, while the number of Indian-produced generic ARV products increased from 14 to 53 over the same period. In 2008, 96 of 100 countries reported ARV purchases from

*In the battle against HIV/AIDS, the demand of African countries is still exceeding the provision of measures in treatment and prevention.*

Indian generic producers, while only 29 countries reported purchases from non-Indian generic manufacturers<sup>9</sup>. A better understanding of the role that Indian generic medicines producers play in HIV/AIDS treatment in developing countries is illustrated in the table.

## Conclusion

During the last years, the commitment of different donor organizations has caused an impressive change in the battle against HIV/AIDS. However, the demand is still exceeding the provision of different measures in treatment and prevention. On the contrary, as funds are shrinking, there is doubt that the countries affected will be able to compensate it themselves. 🇰🇪

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**Table: HIV/AIDS burden of disease, major national ARV procurement and supply organizations and key funders of HIV/AIDS and/or ARV programmes in selected countries**

Country	Burden of disease <sup>3</sup>	No of adults (15+) on ART <sup>3</sup>	No of children (< 15) on ART	Procurement and suppliers of ARV	ARV sources	Funders of ARVs
<b>Cameroon</b>	<ul style="list-style-type: none"> <li>Overall Prevalence: 5.3%</li> <li>No of PLWHA: 610,000</li> <li>No of Children with HIV: 54,000</li> <li>Annual AIDS-related deaths: 37,000<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 29,153</li> <li>Females: 60,302 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 3,994 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>The National Essential Drug Procurement Centre (CENEME-Centre National d'Approvisionnement en Médicaments et Consommables Médicaux Essentiels)<sup>9,10</sup></li> </ul>	<ul style="list-style-type: none"> <li>Ranbaxy Laboratories Ltd / Cipla Pharmaceuticals Ltd</li> <li>Matrix Laboratories Ltd / Emcure pharmaceuticals Ltd</li> <li>Aurobindo Pharma Ltd / Micro labs</li> <li>Strides Arcolabs Ltd / Hetero Drugs Ltd</li> <li>Abbott / Actavis Pharma<sup>11,12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>The Government</li> <li>Clinton Foundation</li> <li>World Bank<sup>9,13</sup></li> </ul>
<b>Swaziland</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 25.9%</li> <li>No of PLWHA: 180,000</li> <li>No of Children with HIV: 14,000</li> <li>Annual AIDS-related deaths: 7,000<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 21,689</li> <li>Females: 38,113 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 5,718 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Central Medical Stores<sup>14,15</sup></li> </ul>	<ul style="list-style-type: none"> <li>Emcure Pharmaceuticals Ltd / Hetero Drugs Ltd</li> <li>Matrix Laboratories Ltd / Strides Arcolabs Ltd</li> <li>Aurobindo Pharma Ltd<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>PEPFAR</li> <li>The Government</li> <li>Italian Cooperation</li> <li>DFID</li> <li>JICA</li> <li>European Union</li> <li>United Nations agencies<sup>14,15</sup></li> </ul>
<b>Lesotho</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 24.5%</li> <li>No of PLWHA: 290,000</li> <li>No of Children with HIV: 28,000</li> <li>Annual AIDS-related deaths: 14,000<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 28,349</li> <li>Females: 48,138 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 4,801 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>National Drug Supply Organization (NDSO)<sup>16</sup></li> </ul>	<ul style="list-style-type: none"> <li>Aurobindo Pharma Ltd / Bristol Myers Squibb</li> <li>Barr Laboratories / Matrix Laboratories Ltd</li> <li>McLeods Pharmaceuticals Ltd / Hetero Drugs Ltd</li> <li>Cipla Pharmaceuticals Ltd / IDA Solutions<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>PEPFAR</li> <li>The Government</li> <li>Clinton Foundation</li> <li>Ireland Aid</li> <li>World Bank<sup>16</sup></li> </ul>
<b>Liberia</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 3.1%</li> <li>No of PLWHA: 37,000</li> <li>No of Children with HIV: 6,100</li> <li>Annual AIDS-related deaths: 3,600<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 772</li> <li>Females: 1,641 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 314 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>National Drug Services<sup>17</sup></li> </ul>	<ul style="list-style-type: none"> <li>Strides Arcolabs Ltd / Matrix Laboratories Ltd</li> <li>Hetero Drugs Ltd / Aurobindo Pharma Ltd</li> <li>Ranbaxy Laboratories Ltd<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>PEPFAR</li> <li>Clinton Health Access initiative<sup>6,18</sup></li> </ul>
<b>Central African Republic</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 4.7%</li> <li>No of PLWHA: 130,000</li> <li>No of Children with HIV: 17,000</li> <li>Annual AIDS-related deaths: 11,000<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 4,696</li> <li>Females: 10,591 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 825 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>The National Drugs Procurement Unit</li> <li>Centrapharm - A private organization</li> <li>Some international organizations e.g. UNICEF procure drugs and manage supply<sup>19,20</sup></li> </ul>	<ul style="list-style-type: none"> <li>Cipla Pharmaceuticals Ltd / UNICEF</li> <li>Centrale Humanitaire Médico Pharmaceutique (CHMP)</li> <li>Hetero Drugs Ltd / IDA Foundation</li> <li>Bristol-Myers Squibb / Aurobindo Pharma Ltd</li> <li>Matrix Laboratories Ltd / Shalina Ltd</li> <li>Abbott / Ranbaxy Laboratories Ltd</li> <li>Cipla Pharmaceuticals Ltd / Strides Arcolabs Ltd<sup>4,21</sup></li> </ul>	<ul style="list-style-type: none"> <li>World Bank</li> <li>Global Fund<sup>20</sup></li> </ul>
<b>Sierra Leone</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 1.1%</li> <li>No of PLWHA: 49,000</li> <li>No of Children with HIV: 2900</li> <li>Annual AIDS-related deaths: 2,800<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 1,805</li> <li>Females: 3,747 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 675 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>National HIV/AIDS Secretariat (NAS) outsources procurement to KPMG<sup>21</sup></li> </ul>	<ul style="list-style-type: none"> <li>Cipla Pharmaceuticals Ltd / Abbot</li> <li>IDA Foundation / Aurobindo Pharma Ltd</li> <li>Matrix Laboratories Ltd / Merk Sharp &amp; Dohme</li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>World Bank<sup>22</sup></li> </ul>
<b>Togo</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 3.6%</li> <li>No of PLWHA: 120,000</li> <li>No of Children with HIV: 11,000</li> <li>Annual AIDS-related deaths: 7,700<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 8,399</li> <li>Females: 16,236 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 1,357 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>The Essential Medicines and Generic Drugs Purchasing Central (French acronym, CAMEG-Togo)<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>Matrix Laboratories Ltd / Strides Arcolabs Ltd</li> <li>Ranbaxy Laboratories Ltd / Hetero Drugs Ltd<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>United Nations agencies<sup>23,24</sup></li> </ul>
<b>Benin</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 1.4%</li> <li>No of PLWHA: 60,000</li> <li>No of Children with HIV: 5400</li> <li>Annual AIDS-related deaths: 2,700<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 6,468</li> <li>Females: 8,933 (Dec. 09)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 1,300 (Dec. 09)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Benin Central Purchasing Office for Essential Drugs<sup>25</sup></li> </ul>	<ul style="list-style-type: none"> <li>Ranbaxy Laboratories Ltd / IDA Solutions</li> <li>Matrix Laboratories Ltd / Abbot</li> <li>Strides Arcolabs Ltd / Merk Sharp &amp; Dohme</li> <li>McLeods Pharmaceuticals<sup>4</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>USAID</li> <li>UNICEF</li> <li>Clinton Foundation<sup>25</sup></li> </ul>
<b>Chad</b>	<ul style="list-style-type: none"> <li>Overall prevalence: 3.2%</li> <li>No of PLWHA: 210,000</li> <li>No of Children with HIV: 23,000</li> <li>Annual AIDS-related deaths: 11,000<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Males: 11,888</li> <li>Females: 19,400 (Dec. 10)<sup>3</sup></li> </ul>	<ul style="list-style-type: none"> <li>Children: 976 (Dec. 10)<sup>22</sup></li> </ul>	<ul style="list-style-type: none"> <li>Central Pharmaceutical Purchasing Unit<sup>26</sup></li> </ul>	<ul style="list-style-type: none"> <li>Cipla Pharmaceuticals Ltd / Aurobindo Pharma Ltd</li> <li>Merck Sharp &amp; Dohme / Matrix Laboratories Ltd</li> <li>Ranbaxy Laboratories Ltd / A to Z Textiles Ltd</li> <li>Strides Arcolabs Ltd<sup>12,27</sup></li> </ul>	<ul style="list-style-type: none"> <li>Global Fund</li> <li>United Nations agencies</li> <li>Development bank<sup>26,28</sup></li> </ul>



# Adverse effects of ARVs – How to ensure treatment adherence

Dr Andreas Wiegand

An HIV infected patient has to take her/his antiretrovirals (ARVs) permanently. Generally, combinations of ARVs with a different type of effect on the virus replication are used. The synergistic effects keep the virus load down. This medication strategy increases the effectiveness of the therapy and reduces the development of drug resistance. However, anti-retroviral medication has a significant number of adverse effects. Cicconi (2010)<sup>1</sup> observed about 20% adherence failure in treated patients due to the burden of adverse effects. Beside adverse effects, other factors correlate with the rate of discontinuing the intake of ARVs, e.g. young age, alcohol consumption and poverty<sup>2,3</sup>.

*A side effect (adverse effect, also known as an adverse drug reaction) is defined in European legislation as “a response to a medicinal product which is noxious and unintended”. The USFDA defines: “An adverse event is any undesirable experience associated with the use of a medical product in a patient.”*

*As HIV/AIDS is a life-threatening disease, the benefit for the patient taking ARVs by living much longer is higher than the risk of experiencing adverse effects with some impact on the quality of life. Sometimes of course, adverse effects are not tolerable and the treatment needs to be changed.*

Health professionals who treat or counsel HIV-patients or dispense medicines to them, can have an impact on the adherence of their clients. The more the patient knows about the occurrence of adverse effects due to the medication, what they are like, and what to be done to tolerate or combat those adverse effects, the more likely a patient will continue with the treatment. Adverse effects may affect various organs such as liver or kidneys. The knowledge of certain adverse ef-

fects can prevent major damages to different organs of the body. Even if no complaints are brought forward by the patient, a routine check on different body parameters (where possible) may help to prevent damages.

## Gastrointestinal adverse effects

Gastrointestinal adverse effects are the most commonly recognised effects. They form the majority of causes to stop ARV intake<sup>2</sup>. They occur with almost all ARVs especially at the beginning of the therapy. Typical symptoms are a feeling of abdominal fullness, loss of appetite, diarrhoea, nausea or even vomiting, heart burn, abdominal pain, sometimes also constipation.

Beside the impact on the general wellbeing of the patient, dehydration and loss of weight can reduce absorption of the ARVs with a risk of reduced efficacy and increased risk of resistance.

Some changes in nutrition and life style may help to reduce the gastrointestinal symptoms:

- Eating more small meals or portions during the day instead of the traditional three meals per day.
- Some medicines should be taken without food. If this leads to a significant stomach discomfort, the patient might take it with a very small amount of bread. A small amount will not impair the uptake of the medicine into the body but may help to decrease the stomach reactions.
- Tea or sweets made from ginger, peppermint or camomile may help as well.
- Coffee, smoking, alcohol, aspirin, and very spicy food should be avoided.

- Medicines to reduce nausea and vomiting may also help: metoclopramide, dimenhydrinate, 5-HT<sub>3</sub>-antagonists, e.g. ondansetron. The doses should be chosen carefully because other adverse effects may additionally weaken the patient.

*The gastrointestinal adverse effects occur mainly during the first weeks of treatment. It is important to explain to the patient what kind of effects can happen. If the patient is suffering because of the occurring symptoms, he/she should rather go for assistance at the health institution but not stop the treatment on his/her own initiative.*

If the gastrointestinal adverse effects persist for more than two months, a possible alternative treatment should be taken into consideration. The longer these adverse effects persist, the more likely the patient is to stop the medication.

## Diarrhoea

If other reasons than the ARVs are excluded, the first priority is to replace the loss of minerals by using ORS (oral rehydration solution). If not available, an alternative can be to use five oranges, one teaspoon of salt, two table spoons of sugar and boiled water cooled to room temperature. If the diarrhoea is associated to the intake of protease inhibitors, taking two times 500 mg of calcium twice a day may help to reduce the diarrhoea. As they interact with the ARVs, calcium tablets should be taken at least two hours after or before the ARVs. If not, less ARV will be absorbed and the effect is impaired. Loperamide is a possible option if other measures cannot reduce the diarrhoea. In general, the food should not contain too much fat and sugar as they increase the likelihood of diarrhoea.

## Hepatotoxicity

An increase of liver enzymes can occur with any ARV and is a common adverse effect. However, liver failure rarely occurs. Patients with a pre-impaired liver are more likely to develop serious hepatic adverse effects. With nevirapine, ritonavir and tipranavir, more liver damage has been recognised, particularly in high doses. Reported cases do exist also for other ARVs. Risk factors are an increase of transaminases at the beginning of the therapy, chronic hepatitis B and C, the intake of other liver toxic medicines, therapy with protease inhibitors, elderly patients, high body mass index, female patients, thrombocytopenia, misuse

of alcohol, high virus load, and renal insufficiency. Protease inhibitors, e.g. atazanavir and indinavir lead to an increase of indirect bilirubin<sup>4</sup>. Even if it is not damage of the liver which caused this phenomenon, patients stop the therapy because of the icterus. If bilirubin is only slightly elevated,

3 to 5 times above the usual concentration, then the therapy does not need any change. Persisting increase of bilirubin levels (seen as yellowing of the eyes and skin) are of course not tolerable and alternative treatment has to be identified. Ritonavir and tipranavir are liver-toxic but this is dose-dependent. Higher doses are of much more risk.

## Renal toxicity

Tenovir is potentially nephrotoxic. An increase in serum creatinine due to a reduced glomerular filtration has been reported. This renal toxicity occurs after some months of treatment. At risk are patients with an already existing renal impairment before therapy, and patients of low body weight. Care should be taken if other medicines which are also potentially nephrotoxic are combined. Close monitoring and a review of therapy is advised.

## Polyneuropathia

Peripheral polyneuropathia (PNP) is a neurological adverse effect caused by the ARVs DDI, D4T, and AZT (see table). The symptoms of PNP are sensibility disorders in the hands and feet which may occur after some months of treatment. Even the HIV infection itself can cause PNP. Risk factors are a vitamin B12 deficiency, diabetes, misuse of alcohol, or the intake of other neurotoxic medicine like isoniazide. There is no specific therapy for PNP. Only a change of the ARV-treatment may help. In severe cases not all symptoms disappear after changing the medicines.

## Central nervous system disorders

Dizziness, sleep disturbances, nightmares, mood fluctuations, depression, changes of character, and thoughts of suicide are possible. They mainly occur at the beginning of the therapy and usually vanish with time. High blood concentrations of medicines can be a reason. The medications should be checked for interactions. Patients with a history of a neurological disease are more at risk.

**Metabolism of the bones**

HIV patients can have more disturbances of the metabolism of the bones. This leads to pain in the bones, most prominently in the hip (caused by non-vascular bone necrosis). This adverse effect is associated with treatment including protease inhibitors and steroids. Crutches to reduce the burden on the hip during walking can reduce the pain. Alcohol and nicotine consumption should be avoided. This applies also for reduced bone density, as observed in HIV patients.

**Allergy and changes of the skin**

Exanthema is a very common adverse effect. The NNRTI-allergy is a reversible, immunologically caused allergy. It mainly occurs on the torso and arms. Fever can be recognised before. Other symptoms are fatigue, myalgia, and mucosal lesions. If the mucosa is strongly involved, blisters and exfoliation (peeling of the skin) occur, a physician needs to be consulted because the treatment can get dangerous. Serious skin reactions have been seen with ART.

**Blood disorders**

ART can lead to anaemia. Fatigue can be a symptom of neurological influence of anaemia.

**Responsibility of the health professional**

Health professionals can have an impact on the success of their patient's treatment. A medicine can only have its desired effect if taken by the right person, in the right dose, in the right way, at the right time, and in the right frequency. Dispensing a medicine is so much more than handing over some tablets. The information given to patients is the key to make a medicine work.

**Abbreviations (see also table)**

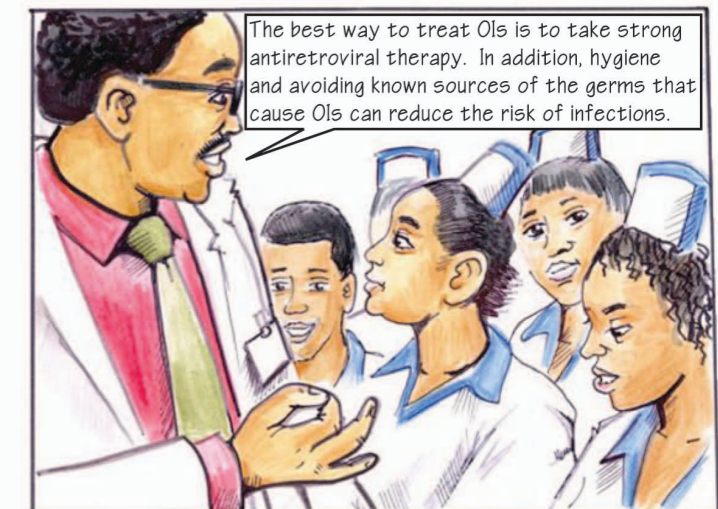
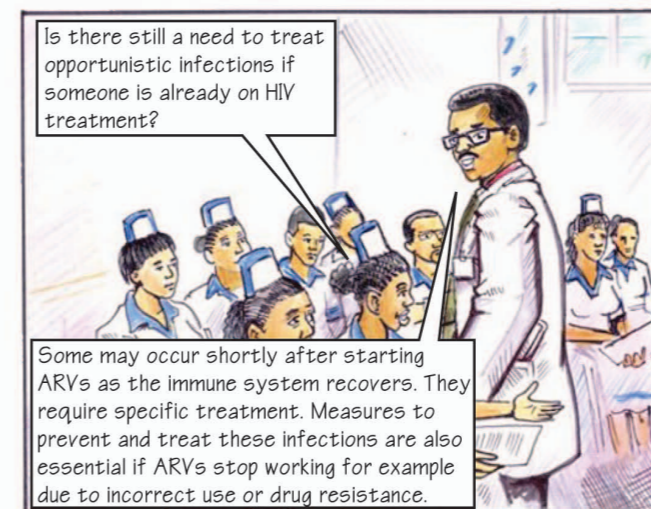
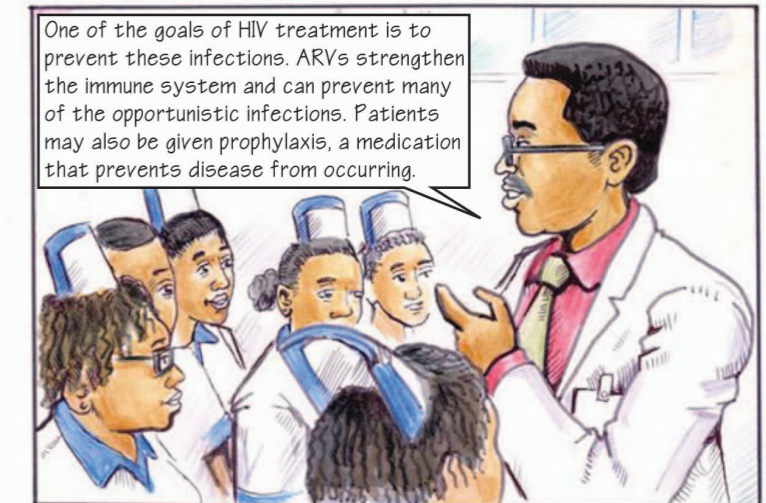
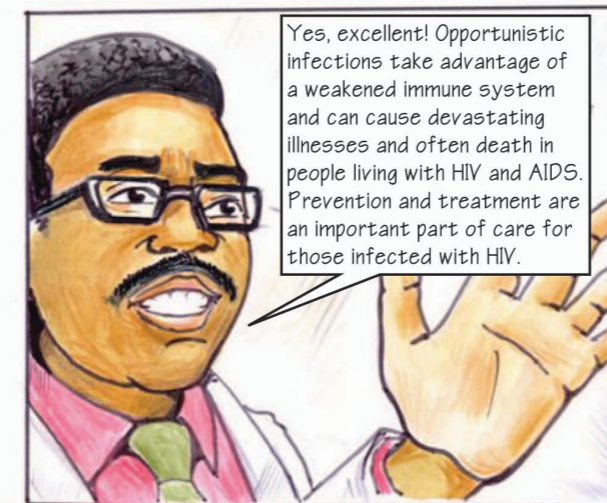
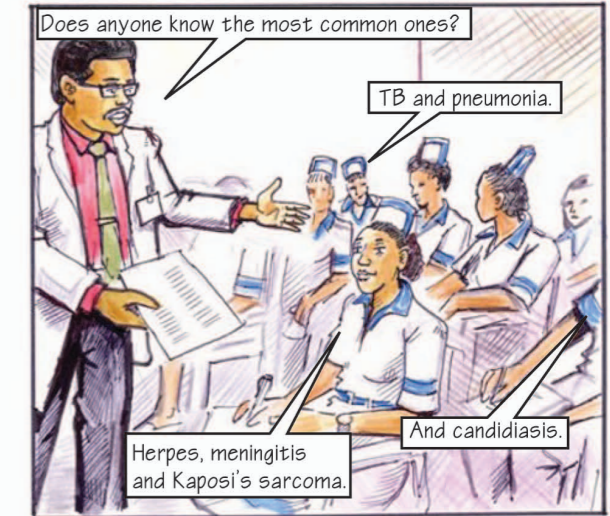
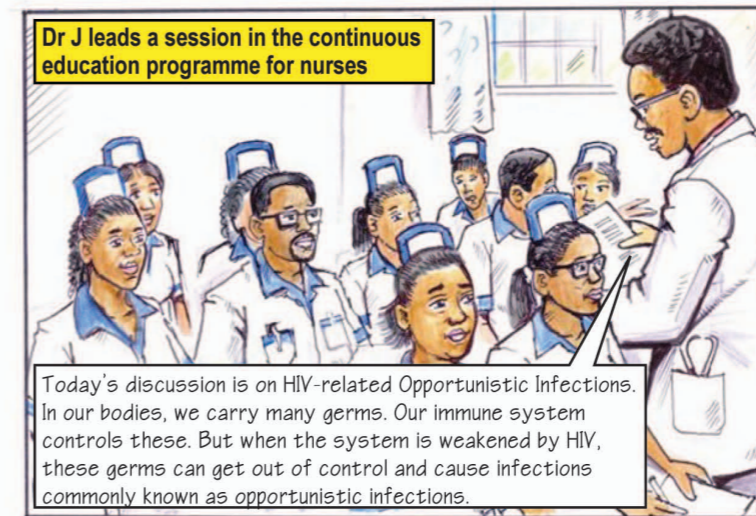
ART	Antiretroviral therapy
ARV	Antiretroviral
CPK	Creatine phosphokinase (enzyme)
FDA	Food and Drug Administration
GI	Gastrointestinal tract
ORS	Oral rehydration solution
PNP	Polyneuropathia

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**Antiretroviral medications and their adverse effects<sup>5</sup>**

ARV	Abbreviation	Most common adverse effect	Comments
<b>Nucleoside reverse transcriptase inhibitors (NRTIs)</b>			
Zidovudine	AZT	Nausea, headache, rash, anaemia, leukopenia, elevation of liver enzymes, elevation of lactic acid level, elevation of CPK level	Should not be combined with d4T.
Lamivudine	3TC	Neutropenia (rare)	
Didanosine	DDI	GI intolerance, pancreatitis, gout, reversible peripheral neuropathy	Should not be combined with ddC (Zalcitabine). Should be taken separately from food. Full daily dose can be given once daily.
Stavudine	D4T	Reversible peripheral neuropathy, lactic acid elevation (rarely fatal)	Should not be combined with AZT.
Tenofovir	TDF	GI upset, low phosphate levels	
Abacavir	ABC	Hypersensitivity reaction, which may be characterised by fever, rash, myalgia, arthralgia, malaise	Reaction may be fatal if medication is continued or patient is exposed to the substance again.
<b>Non-nucleoside reverse transcriptase inhibitors (NNRTIs)</b>			
Nevirapine	NVP	Rash, elevation of liver enzymes	Full daily dose can be given once daily.
Delavirdine	DLV	Rash	
Efavirenz	EFV	Central nervous system toxicity ("hangover", drowsiness), rash	
<b>Protease inhibitors</b>			
Saquinavir	SQV	Elevation of liver enzymes, GI toxic effects, elevation of liver enzyme levels	
Ritonavir	RTV	GI upset, diarrhoea, circumoral paresthesias, elevation of liver enzymes, hypertriglyceridemia	
Indinavir	IDV	Elevation of liver enzyme levels, nephrolithiasis, hypertension, ingrown toenails, benign hyperbilirubinemia	
Lopinavir/ritonavir	LPV/RTV	GI upset	
Amprenavir	APV	Rash, GI upset	
Nelfinavir	NFV	GI upset, mostly diarrhoea	



This comic strip was developed by EPN. Others are available on request. EPN has developed comic strips to raise awareness and spread important messages for the public and health professionals on topics such as HIV, hygiene, rational use of medicines and antimicrobial resistance.

# Community-based treatment services - Patients' health outcomes in 12 ACT facilities of the UCMB network

Robert Kayemba Mutebi

Community-based treatment services (CBTS) are a special component of the Uganda Catholic Medical Bureau (UCMB) - AIDS Care and Treatment (ACT) programme and a public health model, which aims at provision of comprehensive community-based HIV/AIDS treatment and support.

Through the implementation of the ACT programme that commenced in March 2012, UCMB has been providing comprehensive HIV/AIDS care in 12 health care facilities of its network. CBTS are running in all the 12 facilities located in Northern, Central and Western parts of Uganda as part of the ACT programme. The CDC funded ACT programme is targeting to provide counselling and testing for HIV to 36,000 individuals, provide 36,343 clients with Prevention with positives (PWP) minimum service package, circumcise 8,200 males and maintain 36,934 clients in general care by September 2012. Community Based Treatment Services are key in the realization of the above targets; they have contributed to and will continue to play a pivotal role in the provision of comprehensive HIV/AIDS care in the ACT programme.

Community based treatment services at the community level aim at increasing retention in

care while reducing on lost-to-follow ups and deaths of patients. The areas of focus include:

- Early recognition of treatment complications and effective communication between community health workers, village health teams (CHWs/VHTs) and community nurses.
- Increased use of People Living with HIV (PLHIV) for training and continuous support of other patients as peer educators. Most of the CHWs/VHTs are PLHIV and they use a home visiting tool for supporting patients and recording of findings.
- Community mobilization and sensitization activities that target religious leaders, traditional healers, community officials and the general public, e.g. on HIV counselling and testing (HCT), voluntary counselling and testing (VCT), safe male circumcision (SMC), and prevention of mother-to-child transmission (PMTCT).
- Formation of Community support groups for children, mothers, couples and post-test clubs and rural and "Para-urban" communities and individuals with problematic access to care are the communities of focus.

The community based treatment services model at health care facility (HCF) aims to ensure that maximum treatment benefits are realized.

*Community-based treatment services aim at increasing retention in care while reducing lost-to-follow ups and deaths of patients.*



A training of community health workers in Western Uganda (credit: UCMB)

The area of focus is thorough treatment preparation for patients, family and other treatment supporters (Treatment Buddies). This activity entails:

- A thorough patient assessment and individualized and/or group patient education on the basic HIV/AIDS information, understanding drugs (ARVS) and side effects, and nutrition. The HCF counsellors document this activity on the ART readiness checklist and patient agreement forms.
- Assessment of social factors that influence patient adherence to medication (disclosure, geographical distance, income levels, etc.). The patient readiness checklist and counsellor-patient encounter form/checklist is used to document the assessment.
- Inclusion of patient support network in the patient treatment preparation (i.e. preparation of patient family, support system, guardians and significant others) to ensure long-term treatment support and continuity of care within the community.
- Extensive emphasis on prevention and reduction of risky behaviours. This includes prevention among positives which is achieved best when we use other PLHIV within the programme and in the community.
- Continuous patient education and comprehensive counselling of patients using the counsellors' checklist as a guide.
- Managing HIV-positive pregnant mothers (PMTCT and Early Infant Diagnosis).

- Continuous follow-up and support of HIV-positive patients using the counsellors' checklist and Ministry of Health blue card as guides.
- On-spot check home visits targeting patients and other family members.

#### CBTS data at a glance:

Lost-to-follow up of patients in ACT programme was 6% by end of June 2012. The 2011 cohort that was studied for six months showed that 89% of patients took their medicines and adhered to levels above 95%. Currently, the adjusted retention is 85% in the ACT programme. This is the acceptable adjusted retention rate by the UCMB-ACT programme.

#### Lessons learnt and way forward:

CBTS as a public health model should be continued and replicated in other UCMB network facilities. The use of this model has yielded benefits such as reduced lost-to-follow-up, increased retention levels in care and promotion of adherence among patients. These parameters directly influence positively on the general quality of health of ACT patients. 🍏

#### About the Author

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# HIV/AIDS Care and Treatment – CHAK taking over an internationally managed programme

An interview with Dr. Stanley Kiplangat,  
Health Services Manager at Christian Health Association of Kenya  
and principal investigator of the CHAK CDC project

**EPN: What kind of HIV project is CHAK running?**

*Dr. Kiplangat:* Since October 2011, CHAK is running a programme financed by CDC (Center of Disease Control) from the USA. It is an HIV/AIDS Care and Treatment Programme including prevention through faith-based health institutions in Central, Eastern Kenya and Nairobi, titled Expanding High-Quality HIV Prevention, Care and Treatment within Kenyan Faith-Based Health Facilities. The programme was inherited from an international partner called AIDS Relief. It will run until September 2016.

**EPN: Who does the programme target?**

*Dr. Kiplangat:* The targets are the community members, the HIV/AIDS patients visiting the FBO's health facilities, clinics and hospitals, and their families. This means we are dealing with adults and children. Currently we care for 15,000 patients on treatment. In the first year, CHAK took over six hospitals. The second year nine more hospitals will be given to CHAK. Each hospital has smaller clinics, so called satellite clinics, either belonging to FBOs or the government. CHAK is the leading partner in this programme, together with other local organizations. CDC is the donor. With this programme, a lot of responsibilities will be transferred to local organizations and partners.

**EPN: How big in terms of finance is the project?**

*Dr. Kiplangat:* The budget for the first year is 2.20 million USD. The estimate for year two is 7.5

million USD. CHAK has the lead and the coordination role, manages the clinical oversight, and the monitoring and evaluation aspect. CHAK is cooperating with other partners: University of Maryland – Institute of Human Virology which offers the senior technical clinical assistance, and the Futures Group, which is the strategic information partner. MEDS (Mission for Essential Drugs and Supplies) is the partner for the supply chain. While the antiretroviral medicines are supplied by the government, MEDS is partnering for the medication covering the treatment of the opportunistic infections. It is also supporting for dispensing software. Catholic Medical Mission Board (CMMB) is mentoring on the financial aspects of the project, as they have been partnering with the project before, and site management. Other sub-grantees are the implementing institutions.

**EPN: What has to be covered by the budget?**

*Dr. Kiplangat:* First and foremost, the staff dedicated to the different tasks of the programme, e.g. clinicians, medical officers, nurses, pharmaceutical technicians, laboratory technicians, counsellors, and community health workers. Another big part of the budget covers the pharmaceutical and laboratory supplies. For the latter, laboratory equipment for the hospitals was bought. The hospitals are running the tests and charge the grant. Furthermore, the grant covers trainings and transport, e.g. vehicles with insurance, maintenance and fuel. CHAK and all part-

ners have their own segmented budget and the responsibility for that.

**EPN: CHAK covers Central, Eastern Kenya and Nairobi. How are the other regions of Kenya covered?**

*Dr. Kiplangat:* Western Kenya and Nyanza are taken over by Kenyan Episcopal Conference (KEC). The country is somehow divided among the FBOs. Within the responsible areas neither KEC nor CHAK make a difference in serving the church run health facilities. So CHAK will also serve catholic institutions and KEC serves health facilities from protestant churches. So it is a kind of ecumenical project or cooperation.

**EPN: What has been achieved in the project, even if it is still at its beginning?**

*Dr. Kiplangat:* Local partners have been empowered. We have streamlined the supply of the ARVs which are provided by a government organization and outside partners in order to improve the supply and to reduce the shortages. The hospitals and their staff have benefited from trainings, e.g. in governance as we do not only look at the HIV/AIDS responsible unit but have to empower the whole health facility.

**EPN: What challenges did you face so far?**

*Dr. Kiplangat:* The supplies for laboratory reagents and test kits were impaired by shortages in Kenya which slowed down the programme. The procurement by the government was unfortunately delayed. Additionally we have a high staff turnover in FBO health facilities. E.g. when we have trained a nurse or other health staff members especially in HIV/AIDS, soon afterwards she or he might move. So you have to retrain more people.

**EPN: What is the reason for the high staff turnover?**

*Dr. Kiplangat:* The government offers more job security, e.g. open contracts. The FBOs have limited budgets which do not allow them to offer open contracts. The government also sometimes offers scholarships to its employees. Sometimes there is also competition from other partners concerning the adherence of patients to attend the FBO health facilities. Some "competitors" are offering food or transport funding to patients as part of the treatment. The served people of course are quite poor.



CHAK – CDC Team receiving a symbolic candle from AIDS Relief, "to keep the fire burning" in HIV care, during the project launch (credit: CHAK)

**EPN: How do CHAK and KEC communicate on the programme?**

*Dr. Kiplangat:* We have forums through which we communicate with each other. E.g., we have a church health services coordination committee that meets frequently. We discuss wider things but the programme is one of them. There are joint meetings in the programme with our partners. Although we both have our own regions, it is basically the same programme.

**EPN: Even if the project is still in its first year. Are there already any lessons learned?**

*Dr. Kiplangat:* Yes! We have learned to work with the government. Although we are FBO, it pays to work very close with the government, e.g. because of the commodities given by the government. The government staff support us in supervision, for example. Also to have the stakeholder meeting with them is very important.

**EPN: Do you know of any similar programmes in other countries?**

*Dr. Kiplangat:* AIDS Relief was in many countries also with mission facilities. There was a meeting in Uganda before the start of this programme. So in Uganda, Tanzania, Nigeria etc. there might be others who started or who are in the process to be awarded similar programmes.

**EPN: Looking forward to the last phase of the programme in 2016. What will be the perspective?**

*Dr. Kiplangat:* Probably based on the performance, further decisions will be taken. After five years, the donor will do an evaluation on two major aspects: can we offer cheaper services without compromising quality? 🍏

# Church leaders speak out on the Churches' response to HIV in Kenya

Grace Wambui, Donna Kusemererwa

According to UNAIDS<sup>1</sup>, sub-Saharan Africa is the region most heavily affected by HIV with 22.9 million people living with HIV and AIDS in 2010, and a 5% adult prevalence. In a 2007 survey<sup>2</sup>, HIV prevalence in Kenya was found to be 6.3% (about 1.3 million) among people age 15–64 years. HIV prevalence among women aged 15–24 years was 5.6% compared with 1.4% among men in the same age group. Geographically, Nyanza had the highest prevalence at 14.9%, while North Eastern Province had the lowest of 0.8%. HIV prevalence was also higher in urban than rural areas in most places in Kenya.

Churches are part of virtually every community in Kenya. President Kibaki once commented that 80% of Kenyans pass through the doors of a church on Sundays<sup>3</sup>. The capacity and influence of Christian churches in Kenya makes them a natural and critical first line of response to HIV and a key to policy-making and intervention at all levels of society. After the identification of the AIDS pandemic in the 1980s, few clergy had much knowledge of HIV and AIDS or any training in HIV and AIDS care and treatment. For the most part, churches did not have policies, plans or activities designed to respond to the epidemic. Indeed, many religious leaders believed that the epidemic was a problem of the outside world and not their responsibility. However, from the mid 1990s Catholic, Protestant and independent Christian churches started engaging in response to the health-related, social and pastoral needs of people living with HIV and dying of AIDS-related illnesses. The formation of a network of religious leaders infected and affected by HIV (KENERELA+) in 2004 was an indication of the willingness of religious leaders to respond to HIV and AIDS. Other religion-based organi-

zations and associations with a focus on HIV and AIDS have been formed in Kenya including: Kenya Christian AIDS Network, Christian Health Association of Kenya and Kenya Lutheran AIDS Coordinating Committee among others. Today, many churches have implemented a wide range of interventions focusing on programmes that provide care and support to people living with HIV/AIDS (PLWHA). Faith-based organizations have responded to the specific needs of PLWHA in terms of material support such as counselling, nutritional programmes, the distribution of food parcels, setting up support groups for faith community members who are living with and affected by HIV and AIDS, as well as pastoral care. Churches have also undertaken HIV and AIDS awareness activities and engaged in anti-stigma campaigns<sup>4</sup>.

## The problem

Although a lot of initiatives exist by churches in response to the HIV and AIDS pandemic and the majority of church health facilities are fully involved in care and treatment, stigma persists within churches. It is clear that many churches are not proactively taking action.

## Methods

In April 2011, EPN conducted a survey among church leaders from various Christian churches in Kenya to assess their knowledge and attitudes on church involvement in HIV and AIDS. The Church leaders were drawn from mainstream Christian churches from different regions in Kenya.

## Survey objectives

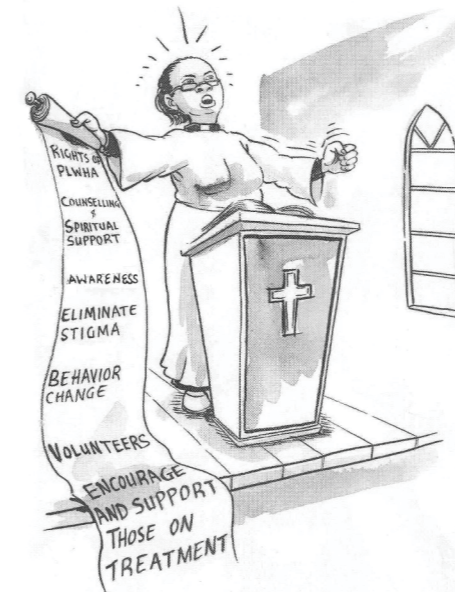
- To find out the extent to which church leaders are satisfied with the way in which their

churches offer HIV testing, prevention and counselling to the community and support services to those infected and affected by HIV.

- To investigate church leaders' perceptions on the role of churches in curbing the spread of HIV and AIDS, and ensuring access to HIV treatment.

A self-administered questionnaire was distributed to 24 church leaders attending an HIV Treatment Literacy training workshop in Nairobi in April 2011. They were from Catholic, Seventh Day, Methodist, Presbyterian, Independent and

Pentecostal churches in Nairobi, Western, Eastern, Nyanza, Rift Valley and central provinces of Kenya as they existed at the time. Respondents included 13 women and 11 men who held such positions as deacon, pastor, youth leader, women leader, church elder, bishop, church health representative and church HIV programme coordinator.



## Results

### Curbing the spread of HIV

**Creating awareness:** 18% of the respondents were satisfied with the way their churches undertake HIV and AIDS awareness activities. Two church leaders expressed dissatisfaction while the remainders were not sure that the church was doing so. 13% of the church leaders felt that the church has a responsibility to provide information on HIV and AIDS to their communities. One in every four of the church leaders felt the church had a role to preach sermons that encourage behaviour change in order to reduce the spread of HIV.

*“The congregation needs education on how to take precaution by abstaining from sex till marriage” - AIC, Nairobi*

*“Pass on the correct information about HIV and AIDS to the community” - Methodist Church, Eastern province*

*“Create forums to enlighten people on HIV” - PCEA, Nyeri*

**Prevention and testing:** the majority of the respondents (70%) felt that their churches were not doing enough to promote HIV prevention and testing. Out of the 24 respondents, only 8 indicated that their churches were adequately encouraging prevention and testing within their congregation. 58% of the church leaders felt the church has a role in encouraging prevention while 33% felt that the church should also encourage HIV testing.

*“Encourage couples to be responsive to each other’s needs and educate the youth on safe sex behaviours” - Church Leader, Nyanza*  
*“Discourage risky traditions” - Catholic Church, Western*

*“Actively support HIV prevention activities” - Church youth coordinator, Thika*  
*“Informing the flock on importance of practicing good morals as well as care and support of HIV patients through bible teaching” - Catholic Church, Kimilili*

*“Encourage people to go for VCT and lead by example” - PCEA, Butere*

## Reducing stigma

Stigma towards people living with HIV is still a problem in the church. Only 8% of the respondents felt that their churches do not stigmatize people living with HIV. 6% admitted their church stigmatizes people living with HIV while a majority (86%) were not sure if this happens in their churches.

The church leaders put forward the following ideas that the church can use in reducing stigma against people living with HIV:

*“Talk openly on HIV and AIDS and share publicly on how people infected with and affected by HIV are stigmatized” - ACK Bondo*  
*“Discourage community members from using stigmatizing references to people living with HIV” - PCEA Kiambu*

*“Set good examples by welcoming people living with HIV to the church as well as supporting them” - AIPCA Masinga*  
*“Follow the example of Jesus Christ in loving, giving hope and reaching out to people with HIV and making people understand that HIV is not a sin” - ACK Mombasa*

“Use good examples from the holy scriptures to demonstrate to people how Jesus cared for the sick and suffering with love and compassion” - PCEA Nyeri

“Sensitize community members on the effects of stigma and discrimination of people living with HIV and encourage people living with HIV to avoid self stigma” - ACK Bondo  
 “Encourage involvement of people living with HIV in church and community activities” - Catholic Church, Mumias

### Supporting people living with HIV

Of the church leaders who were interviewed, only 13% felt that their churches were offering adequate care and support to people living with HIV. 19 out of the 24 church leaders (80%) were dissatisfied with their churches' response to support people living with HIV. In addition, while almost all church leaders (88%) were not aware of any HIV and AIDS activities being undertaken by their churches, 8% were satisfied with the work that their churches were carrying out.

**Addressing gender inequalities and gender-based violence:** Most of the church leaders (68.9%) were not aware if their church was addressing gender inequalities and gender-based violence. Of the seven who were aware that the church was addressing the issue, two felt that their church could do more, while two were satisfied with their church's efforts.

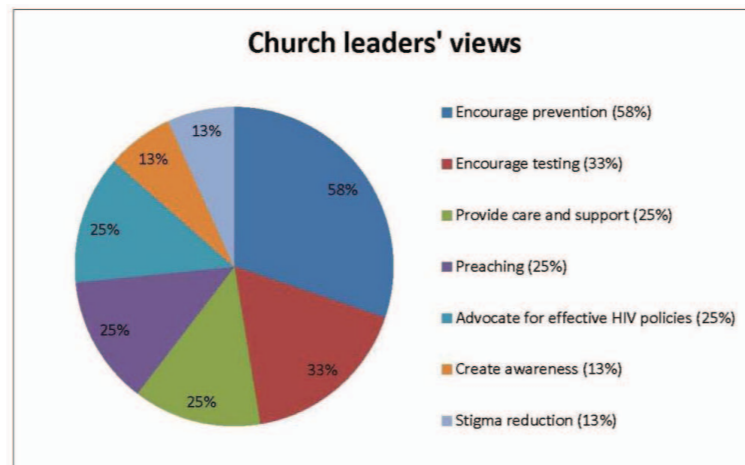
According to the church leaders, churches can do the following to provide support for people living with HIV:

- Get training on HIV and AIDS to be in a better position to support those living with HIV
- Advocate for and take part in formulation of effective HIV-policies at the national level and in churches
- Partner with health institutions to ensure that ARVs are accessible to those who need them
- Initiate support groups for counselling and emotional support for people living with HIV and AIDS and their families
- Involve people living with HIV and AIDS in response to the epidemic
- Help them set up income generating activities to enable them meet medication costs
- Look out for financial support, food and poverty alleviation projects to help families survive and make it easier for people living with HIV to access treatment

- Provide home-based care and medical treatment for people who are ill
- Take measures to eradicate stigma and rejection of people living with HIV

The actions that churches should take to address the epidemic according to the church leaders surveyed are summarized in figure 1.

**Figure 1: Church leaders views on actions the church should take in the HIV & AIDS response**



### Access to antiretroviral therapy

Almost all (96%) church leaders acknowledged that the church has a responsibility of ensuring that people who need ARV medicines access them. However, one church leader felt that this role should be left entirely to the medical fraternity. In regard to the level of access, only 4 out of 24 (17%) of the church leaders expressed satisfaction with the level of access to ARV medicines for those who need them within their church congregation and community. In comparison, 66% of the church leaders were satisfied with the level of access to general medicines within their churches and community while 18% felt there was need for improvement. The church leaders considered a number of factors as hindering access to ARVs (see table). The barriers presented were social, including fear and denial, as well as structural, including corruption and poverty.

Structural factors	Church Leaders say
Corrupt systems	“Corruption which interferes with equal distribution of ARVs to all regions.” - Catholic Church, Kisii
Poverty and lack of finances	“ARV medicines are expensive and most poor people cannot sustain the cost.” - PCEA, Nairobi
Long distance and poor roads	“Lack of transport cost to health facilities.” - Reverend, Kakamega “Distance to the hospitals where these ARVs are available.” - PCEA, Nyeri

Social factors	Church Leaders say
Cultural and religious beliefs	“Some cultures and churches do not allow their people to seek treatment from hospital. They believe in herbs and the healing power of God.” - Church leader, Vihiga
Fear of side effects of ARVs	“Stigma and fear of drug side effects.” - Catholic Church, Kakamega
Denial among people living with HIV	“People from my community have access to ARVs. Those who do not get them are mostly those who have not accepted that they have HIV.” - SDA, Nairobi
Fear of stigmatization and victimization	“Fear of being alienated or discriminated especially by the family.” - PCEA Kiambu “Fear of being victimized.” - Church Leader, Vihiga
Laxity in accessing VCT services	“When one has HIV and needs to take ARVs, they are not able to get them.” - PCEA, Tetu
Lack of information	“Lack of proper knowledge on use and effectiveness of ARV medicines.” - PCEA, Nairobi

### Discussion

The church has an important part to play in the HIV response. According to the church leaders, the church is a strong partner in the life of the community and therefore strategically placed to mobilize action on health-seeking behaviour. Furthermore in faithfulness to the teachings of Jesus, the church has to be compassionate to the needy and suffering, to offer financial support and encourage patients to seek treatment. Communities trust the church to maintain confidentiality and therefore it is well placed to offer HIV counselling and testing activities. When the church embraces those infected, they experience faith, love, hope, forgiveness and spiritual support which encourages them to live positively.

The church needs to continuously stimulate the conscience of its congregation and the community to get actively involved in responding to the HIV crisis. HIV is in the church and so the church should be in the forefront of curbing the spread of the disease. Furthermore, the church is mandated with the responsibility of caring for the sick and suffering as Jesus did. It is a responsibility for the church to care for and provide support for people living with HIV including ensuring access to life-prolonging medicines.

In a special commentary to CNN in July 2011, Pastor Rick Warren said that the Church is a powerful weapon against HIV and AIDS, stating accordingly that the Church has a role to<sup>5</sup>:

- C** - Care for and support the sick
- H** - Handle HIV counselling and testing
- U** - Unleash Volunteers to participate in HIV activities
- R** - Reduce stigma against people living with HIV
- C** - Create awareness & champion health behaviour
- H** - Help in antiretroviral drugs for HIV patients

Church leaders can be especially instrumental in eradicating the stigma and discrimination faced by people living with HIV and AIDS<sup>6</sup>. Religious leaders are key to mitigating the epidemic because they are trusted and respected members of society and are influential in shaping social values and public opinion<sup>7</sup>. Moreover, they can help find resources for spiritual and social care and promote action through their presence in local communities. Many religious leaders around the world have set a good example and gone a long way to de-stigmatize HIV by getting tested and publicizing their own results or by standing up for people living with HIV and AIDS.

### Conclusion

The majority (87%) of church leaders included in this survey are not aware of any HIV and AIDS activities being undertaken in their churches and of those who were aware, only a few were satisfied with the way the churches were responding to various HIV and AIDS related needs in the church. The church leaders pointed out prevention (58%) and testing (33%) as priority areas of involvement by the church in curbing the spread of HIV and AIDS. Stigma reduction would appear to be a key area requiring intervention as only 8% of the respondents could confidently say that their church did not stigmatize people living with HIV. To address stigma, the church leaders felt that there was a need for training on their part as well as spreading anti-stigma messages to the community through preaching and education forums. 🙌

### About the Authors

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HIV + AIDS TL Guide for sale

HIV + AIDS TL courses on demand

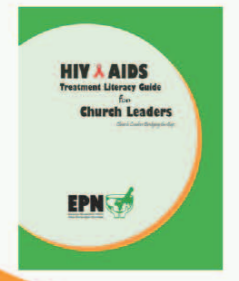
# HIV AIDS

## Treatment Literacy for Church Leaders

Church Leaders Bridging the Gap

### Empowering church leaders

Religious leaders have a key role to play to educate and support their communities in regards to HIV treatment issues. The EPN Treatment Literacy Guide and courses aim to introduce church leaders to some of the skills they can use and the ways that they can influence outcomes.



*“We have been using home based fellowship to reach for the people living with HIV. We encourage them through bible verses and encourage them to seek treatment and adhere to ARVs. We also encourage their families to give them support and see them as normal people and avoid referring to them with stigmatizing terms.”*

A participant of an HIV Treatment Literacy workshop in 2011, reporting on the changes made after the workshop.

EPN's **HIV and AIDS Treatment Literacy Guide** is available for sale at a subsidized price of 10 USD, in English and French. The 132 page book provides powerful insights on how church leaders can take up advocacy issues in matters of antiretroviral treatment - which are a life prolonging intervention for people living with HIV - and to deal with stigma and discrimination in the church.

The guide with a foreword by Archbishop Desmond Tutu is loaded with key care and treatment messages on **the role church leaders can play** in advocacy and community mobilization and contains also exercises that help the church leader better understand the content and engage the congregation.

Retired Archbishop Dr. Benjamin Nzimbi of the Anglican Church of Kenya, who officiated at the function held to officially launch the book in 2010, reiterated the fact that the issue of HIV and AIDS continued to be a taboo subject especially in the church quotas and that most church leaders were still ignorant on the matters of HIV and AIDS care and treatment. He commended the book as **a must read for every church leader who wants to address the issue of stigma and discrimination in the church** and learn how to care for those infected and affected by the disease. He also said that church leaders need to understand the issues of faith healing, stating that many church leaders have lead many people to stopping their ARV treatment.



### Course Objectives

There are so many challenges presented by the increasing number of patients who need HIV diagnostics services and antiretroviral therapy. A growing number also need to access second and third line regimens due to failure of treatment or resistance. Concerted **community based sustainable efforts** are needed to minimize and avoid these challenges. EPN is convinced that **religious leaders** have a key role to play to educate and support their communities in regards to HIV treatment issues. As such, EPN is offering an opportunity to church leaders to be able to advocate for access to these services through a **tailor made Treatment Literacy program**. This course aims at providing mechanisms for support, love and development of an HIV competent society with the religious leaders being actively involved to encourage and support HIV patients to start treatment and stay on treatment.

### Empowering church leaders

As a church leader, it is possible to influence outcomes. The EPN Treatment Literacy courses aim to introduce church leaders to some of the skills they can use and the ways that they can influence outcomes through:

- encouraging churches to have and implement good policies
- working with local church health facilities
- acceptance and support of those on treatment, including children
- improving the understanding of treatment issues
- increasing testing and treatment-seeking behaviour
- taking the message to communities

To successfully achieve these things, church leaders are empowered by helping them gain an understanding of:

- the key messages around treatment for HIV and AIDS
- what AIDS treatment means for the church and how this might change policies and practices

### Practical Details

**Target Audience:** church leaders from all churches and denominations.  
**Course design:** two options are available based on the group to be trained:

- **Intensive:** a 3-day training covering coursework of lecture and discussions and field visits - ideally a minimum of 30 participants.
- **Modular:** tailored to match the needs of the participants and can be split into a maximum of 6 sessions over a period of 2-3 months. The training can be organized at a location convenient to the participants.

### Course facilitation

EPN is a non-profit making organization and all courses are run on a cost recovery basis. These courses can be organized on demand for any group in any country. Contact us for prices.

### Facts on HIV (2008)

- It is estimated that 33.4 million people are living with HIV in the world and about 2.1 million are children under 15 years
- Only 42% of the 9.5 million who need ARV drugs are on life saving treatment
- Over 2 thirds (22.4 million) of people who are living with HIV are in sub-Saharan Africa

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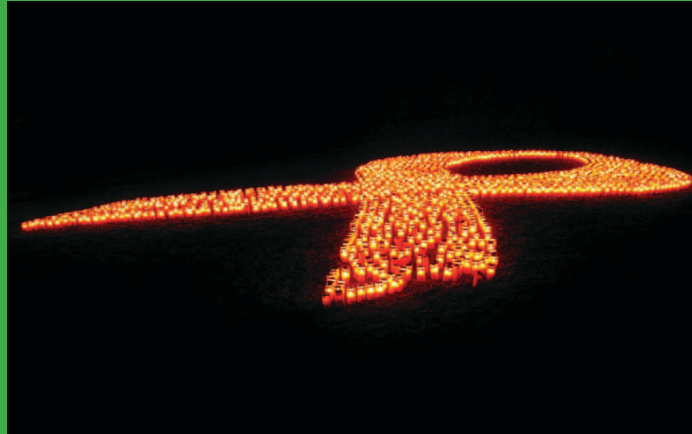
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