Is Universal Access a Myth or Reality at Local Level?

Sr Alison Munro

Director, Southern African Catholic Bishops' Conference (SACBC) AIDS Office, Pretoria, South Africa

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I. Introduction

- South Africa is the country with both the highest number of people infected with HIV, and the largest antiretroviral therapy (ART) programme in the world. Huge strides have been made towards universal access to treatment over the past eight to ten years, globally and in South Africa.

- Because of enormous challenges, some of them insurmountable at least in the short term, universal access is in fact a myth. The world continues to face new infections, challenges around vaccine and drug development, prevailing costs, and the ever-present recognition that AIDS is more than a problem to be treated only medically and scientifically.

- Where treatment that is available is accessed because the underlying and accompanying economic, political, clinical, social and cultural environment is in some measure favorable, one can talk of the possibility of universal access in that local setting. Conversely when there is even just one factor mitigating against access, one must see universal access as a myth.

- If it is true that numbers of HIV infection are rising and if it is true that for every new patient put on treatment there are still new infections , universal access cannot be a reality. How does one ever reach the backlog of patients not yet on treatment for whatever reason (they don't know their status, there are no facilities nearby, they are afraid of stigma…), and how does any country retain the momentum needed to keep such huge numbers of people on treatment for the rest of their lives?

- How does any country fund such a huge ongoing programme that isn't yet showing any signs of going away or being reduced in scale?

II. The challenges to universal access to treatment

- *The provision and procurement of drugs and laboratory tests, and the related costs*, at current funding levels, *is at some point unsustainable*. The ongoing costs for the sheer numbers of people needing treatment over the years they will need to be on treatment are exorbitant. Universal access without a cost-effective vaccine or treatment remains a myth. While there are currently an estimated 1,2 million people on treatment in South Africa there are more than that number of people not yet on treatment, and/or unlikely to access it.

- *Sometimes societal, cultural and religious beliefs are obstacles* in the way of patients accessing treatment or remaining on treatment. Family members may insist that patients consult traditional healers rather than clinicians trained in ART management, or that they desist from ARV treatment once it appears that their health is improving.

- *Women access treatment more than men do*. Roughly two thirds of the country's patients are women, with people in general continuing to present very late in the disease for treatment. Adherence to ARV treatment in the Church programme is good, in a good measure as a result of the adherence monitoring. Nonetheless individual people struggle not to default once their well-being improves.

- *Only small numbers of children are accessing treatment*, often because of the difficulties around the consent of guardians or their lack of information, and the challenges that continue to be experienced even by clinicians around the treatment of children.

- *Dire social conditions* faced by the poor, including unemployment, lack of adequate housing, poor delivery of basic services in under-resourced townships and rural villages and in more than 2000 informal shack settlements, a crumbling education system, and a vulnerable health care system *are part of the reality facing the country ,* and putting a strain on access to basic health services.

- *Not all people have access to essential primary health care services* (with referral to the necessary secondary level health facilities when required). Geographic access to treatment sites, real and perceived stigma and discrimination, and poor information remain challenges in some areas.

- *South Africa has insufficient trained health personnel in the public sector* to meet the country's health care needs beyond HIV. Some nurses, including those in the SACBC AIDS Office programme, have been trained in nurse initiated management of antiretroviral therapy (NIMART) and are completing the practical modules needed for the completion of their qualifications.

- *The country does not yet have a national patient data management system in place*. New systems are in the development phase, but are not yet in a position to manage data coming from the different provinces in a single national system. Patient data, and patients, can be lost between provinces.

- *Tuberculosis (TB) is not always accurately diagnosed*, and consequently not always treated. TB/HIV co-infection is an enormous challenge in South Africa.

III. It's not only about drugs and laboratory services, but drugs and laboratory services do cost money: the SACBC AIDS Office experience

- The most costly component of the programme is the ARV drugs and the laboratory tests. Half of the SACBC AIDS Office ART budget goes to pay these costs. Drugs that may be purchased under the grant have to have Food and Drug Administration (FDA) and Medicines Control Council (MCC) approval, and while some are generics, there still remains a high number of drugs that are patent and more costly than those the South African DOH is using.

- The Centre for Disease Contol (CDC) South Africa is beginning negotiations around the acquisition of ARV drugs under the South African government tender. It is not clear yet how much these drugs would save the PEPFAR programme, but it is known that the South African DOH managed to negotiate with its pharmaceutical suppliers a 50% saving on its own ARV drug bill (mainly generics) on its latest tender.

- The results of a drug trial released in Washington and Johannesburg in late May give some new hope to people with HIV. The results indicate that the earlier people go on treatment the less likely they are to transmit HIV. Currently in SA most people are put on treatment if they have a CD4 count of 200 or less, and at a CD4 count of 350 if they are pregnant or have TB. Already there are concerns about the cost implications related to the 350 CD4 count – clearly there are huge budget implications around this, viz because more people both in theory and in fact will be on treatment.

IV. The PEPFAR-funded ART Treatment Programme of the SACBC AIDS Office: A case study

Beginnings

- The South African Catholic Church's treatment programme began in late 2003 with a grant from the Dutch Catholic funder Cordaid. It was rapidly scaled up as part of a nine country award to Catholic Relief Services (CRS) and implemented by the SACBC AIDS Office, from 2004 with PEPFAR Track 1 funding.

- Over the five years of the programme the SACBC AIDS Office opened 23 treatment sites, most of them at home based care (HBC) sites run under the auspices of the Catholic Church, and many of which had received their initial home based care funding through the SACBC AIDS Office from Catholic and other donor agencies.

- The programme had the approval of the National Department of Health (DOH), but it battled in some instances to get the approval of the provincial DOH of the relevant provinces. Those were the days of denialism in South Africa, with the South African government not providing an all-out concerted effort to fight the pandemic. People were dying because treatment was not available in the public sector.

Expansion

- As the government scaled up its treatment response and sites opened in different parts of the country over the next number of years, the SACBC AIDS Office was able to transfer patients into the public health system. One of the sites, a major Catholic hospital became a PEPFAR recipient in its own right when funding was transferred in "PEPFAR II " to local indigenous organizations.

- The SACBC AIDS Office was able to withdraw in all from eight sites, and in PEPFAR II has continued working with fourteen treatment sites. There are currently over 16 000 patients on treatment in the programme in the 14 sites. Over all about 30 000 patients in the 23 sites were initiated on treatment over the past eight years.

- The SACBC AIDS Office PEPFAR-funded treatment programme is entering its final twenty four months, and has begun the phase of ensuring the sustainability of patient treatment beyond the particular PEPFAR grant.

Ensuring sustainability

- Negotiations are underway in all the provinces in which our programme currently operates to ensure that the ARV drugs are received from the DOH so that patient treatment is not interrupted once PEPFAR funding is discontinued.

- CRS transitioned the PEPFAR award to the SACBC AIDS Office at the end of the first five years of the programme, and now in phase two the SACBC AIDS Office is in the process of transferring its programme into various public private partnerships. Two Catholic facilities in the current programme have recently begun receiving part of their drug supply from the DOH in their respective provinces.

- Some provinces wish to supply the drugs and laboratory services directly to the Church projects; this has to do both with their recognising the quality care and service provided at Church sites, and in the knowledge that sustainable provision of ART is the issue at stake.

Public private partnership models currently unfolding

- One project will close down by the end of the new financial year as it transfers all its patients to public sector clinics in places where there was previously no DOH-provided treatment at all when PEPFAR funding began in 2004.

- A second model looks at the provision of drugs and laboratory tests to the Catholic facility within the next few months by the DOH, with PEPFAR continuing for the moment to support the personnel and administrative costs.

- A third option involves the DOH requesting that the patients of some satellite centres of a major site be transferred to their nearest government clinics, while the main treatment site will receive South African government drugs, and will continue to initiate patients on treatment.

V. A case study within a case study

Foreign nationals and treatment

- The socio-political situation of sub-Saharan Africa plays out in various scenarios in the arena of AIDS. South Africa and Botswana are home to numerous refugees and asylum seekers from a number of countries in Africa. About eighty five percent of the patients of one of the church run treatment sites in Johannesburg are from elsewhere in Africa: the DRC, Malawi, Zambia, Zimbabwe, Cameroon. There are patients who travel from Mozambique once a month to fetch their drugs rather than deal with stigma in their own community and country.

- Some of these patients are over time being referred to treatment facilities in their countries of origin (particularly Zimbabweans), but some possibly fall through the cracks. Commendable though it is for the programme to reach out to foreign nationals, one is also only too aware of the fragility of such an initiative in the grand scheme of events when people are also likely to move on elsewhere, possibly even returning to their countries of origin, and possibly defaulting on treatment.

VI. The new National Strategic Plan for South Africa

The post Thabo Mbeki government under President Jacob Zuma and Health Minister Aaron Motsoaledi has committed to the delivery of health services including the delivery of ART. Major consultations across all sectors are currently underway concerning the updating of the National Strategic Plan for HIV, AIDS and TB for the next five years. The draft of the new strategic plan is being released this week at the South African AIDS Conference in Durban. The final new five year plan is due to be released on 1 December this year. Over the next number of years programmes will continue to be capacitated and developed. Universal access will however remain a myth.