

# The challenges experienced by nongovernmental organisations with regard to the roll-out of antiretroviral therapy in KwaZulu-Natal

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## Abstract

**Background:** Successful administration of antiretroviral therapy (ART) requires full adherence to the regimen by the patient. The introduction of ART needs a well-functioning health system with adequately trained health professionals, laboratory support, a constant supply of drugs and social systems to assist with patients' adherence and to prevent future treatment failure.

**Objectives:** The objective of this study was to explore and describe the challenges experienced by nongovernmental organisations with regard to the roll-out of antiretroviral therapy.

**Design:** A qualitative, exploratory and descriptive study was conducted to determine the challenges experienced by nongovernmental organisations (NGOs) with regard to the roll-out of ART in KwaZulu-Natal. Nine participants were included purposefully from the NGOs that participated in this study. Data were collected through semi-structured individual interviews. Open coding for analysis was used.

**Results:** The findings revealed four themes: challenges relating to sustainability, adherence, health infrastructure and behaviour.

**Conclusion:** The results indicate a need for multisectoral collaboration in the roll-out of ART to ensure a concerted, comprehensive and sustainable programme.

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## Introduction

Successful administration of antiretroviral therapy (ART) requires the patient to adhere fully to the regimen. Inadequate adherence can lead to treatment failure and antiretroviral (ARV) drug resistance. Large-scale ART programmes with inadequate attention and support for drug adherence can render the available ARV drugs unproductive and negate the advances made in creating effective ART programmes.<sup>1</sup> The introduction of ART needs a well-functioning health system with adequately trained health professionals, laboratory support, a constant supply of drugs and social systems to assist with patients' adherence and to prevent future treatment failure.<sup>2</sup>

The South African National Aids Council (SANAC) is a national body that was established to oversee and advise government on human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) in South

Africa. In 2007, the Council adopted the national AIDS strategy and recommended it to government. Government responded to the call by adopting new guidelines in April 2010.<sup>3</sup> This was a giant step, considering the ART guidelines of 2004.<sup>4,5</sup> Scaling up the number of people on ARV treatment requires immense financial resources and involves great challenges, including the need for lifelong commitment to ARVs, support for patients to enable them to adhere to a daily regimen, and the establishment of an adequate health infrastructure.<sup>6</sup> The World Health Organization (WHO) released new HIV guidelines in December 2009, calling for the initiation of ART in the case of an unqualified CD4 count of 350 cells/ul or below.<sup>7</sup>

KwaZulu-Natal is the province with the highest HIV prevalence in South Africa.<sup>8,9</sup> The USA provided AIDS funding through the President's Emergency Plan for AIDS Relief (PEPFAR) in 2003.<sup>10</sup> The WHO, together with the Joint United Nations Programme on HIV/AIDS (UNAIDS),

launched the 3 by 5 initiative,<sup>11</sup> a global target to provide people living with HIV and AIDS in low- and middle-income countries with life-prolonging ART by the end of 2005. The 3 by 5 target was missed, in that only 17% of those who needed ART had accessed treatment by the end of 2005. PEPFAR and a group of eight leading industrialised countries called on the world to move as closely as possible towards universal access to ART by 2010.

Nongovernmental organisations (NGOs) are independent, not-for-profit voluntary groups who drive the campaign for access to treatment, lower drug prices, improved care and more effective policy on HIV and AIDS, led by the Treatment Action Campaign (TAC) and the Aids Law Project.<sup>12</sup> The South African Catholic Bishops Conference (SACBC), the Africa Centre and Amangwe Village have been spearheading the roll-out of ART in KwaZulu-Natal. The main funder was PEPFAR.<sup>13-15</sup> Although funding has increased rapidly, a variety of obstacles remain to scaling up treatment access.<sup>11</sup> Discontinuation or interruption of therapy is even more dangerous than periodic nonadherence.<sup>16</sup>

Government must address the shortage of healthcare workers, a concern raised by SANAC, to properly implement the new guidelines and ensure that the HIV counselling and testing campaign is sustainable over time.<sup>17</sup> In 2007, in KwaZulu-Natal, 35.6% of health posts were vacant and some hospitals did not have a pharmacist.<sup>18</sup> Furthermore, it was recognised that poor budgeting and poor financial management led to weak health systems and healthcare delivery. It was estimated that 30 people died daily in the Free State province after ARV drugs ran out towards the end of the 2009 financial year.<sup>6</sup> According to a report on AIDS in eight sub-Saharan countries, major donors have decided to limit or stop spending on HIV treatment and AIDS drugs.<sup>19</sup> New policies on large-scale ART roll-out, global recession and a cut in HIV financial aid are some of the issues that face South Africa.

The purpose of this study was to explore and describe the challenges experienced by NGOs with regard to the roll-out of ART, with the aim of highlighting recommendations to enhance the success of ART roll-out.

## Method

### Study design and setting

A qualitative approach was used, with an exploratory and descriptive design.<sup>20</sup> By utilising a qualitative approach, an attempt was made to understand the challenges experienced by NGOs from the subjective perspective of the individuals involved in the roll-out of ART. The complexities and diversity of their work were captured by describing the context in which they operated.<sup>21</sup> The setting was offices of the NGOs and the clinic where roll-out of ART takes place in KwaZulu-Natal.

### Population and sampling method

The target population was the NGOs involved in ART roll-out in KwaZulu-Natal. Purposive sampling was used to select the participants. Purposive sampling was chosen because it allowed for the selection of individuals with ART roll-out experience.<sup>20</sup> Nine participants were included from the three largest NGOs involved in ART roll-out in KwaZulu-Natal. To be included in the study, participants had to be working for the NGOs and to be specifically involved in the roll-out of ART. Those who were not interested in participating in the study were excluded.

### Ethical considerations

Ethics clearance for the study was obtained from the Higher Degrees Committee of the Department of Health Studies, University of South Africa. Permission to conduct the study was obtained from the relevant NGO authorities responsible for the sites where the study was conducted. Informed consent to participate in the study was obtained from the participants. Confidentiality and privacy were ensured by using a password-restricted computer to store the information, and anonymity was guaranteed by assigning codes to interviewees instead of names.<sup>22</sup>

### Data collection

Data were collected through audio-recorded individual interviews.<sup>20</sup> Nine interviews were conducted, all of which were held with participants who met the eligibility criteria. The transcripts from the audio tapes bore no names, but only numbers and dates to maintain confidentiality. The research question was: "What are the challenges you experience with regard to the roll-out of ART?" The researcher used probing questions that sought clarification of participants' responses to guide the dialogue. The interviews lasted approximately 20 minutes. The interviews took place at the offices of the NGOs and at the clinics involved in ART roll-out. The interview dates and times were arranged ahead of time by contacting programme coordinators who set up appointments. E-mail communication was used to confirm appointments.

### Data analysis

The audio-recorded interviews were transcribed verbatim. Content analysis was carried out to explore common themes in detail. These were then organised into units of meaning.<sup>21</sup> The two researchers coded the transcripts independently. This was followed by recoding, after which discussions were undertaken by the researchers until consensus was reached on the themes and categories. Examples from the literature were used to support the findings. To enhance the trustworthiness of the study, the researchers made use of Guba's model, which provides four criteria to ascertain rigour in qualitative studies: credibility, dependability, conformability and transferability.<sup>20,22,23</sup>

## Results

The nine participants who met the inclusion criteria included six women and three men. There were three doctors, three programme coordinators and three professional nurses. Their ages ranged from 30-60 years. Four themes emerged from the data analysis, which reflected the challenges experienced in the roll-out of ART. The themes are discussed below.

### Challenges relating to sustainability

The participants acknowledged problems with regard to sustainability of the programmes in respect of financial constraints and middle management's lack of capacity to handle the funds.

### Financial constraints

The participants indicated that NGOs are experiencing financial constraints, in line with the current global financial crisis in the fight against HIV and AIDS. The financial constraints relate to budget cuts from the main funders. One participant mentioned that: "PEFAR, the main donor, has cut funding on HIV/AIDS programmes, in some cases by 25%".

The participants stated that one of the projects in KwaZulu-Natal had run out of ARVs and that the establishment was forced to downsize and refer patients to the government because of financial constraints. In addition, all field visits were suspended because of a lack of funds with which to run field work. Some employees had to be retrenched. Discussions with the Department of Health were held to request that the Department take over the salaries of some of the staff because of financial constraints. The findings of this study concur with those in a report by SACBC, which indicated that the US government has reduced its support for AIDS relief in Africa.<sup>12</sup> This has negatively impacted on the AIDS treatment programme, which was part of the SACBC programme, and which by the end of May 2011, was no longer sponsored by the US government.

### Middle management's lack of capacity to handle funds

The findings indicated that people in senior positions lacked the management and financial skills needed to deal with grants effectively. It was revealed that appointments of candidates for financial management were made on grounds of affiliation, rather than merit. Some participants indicated that: "Decentralisation is welcome, but it has created other problems. Very few people have the management and financial skills to cope with such huge amounts of money. People did not know what to do once the budget got approved and the finance became available. The capacity of middle to senior managers is pathetic", and "Some managers lack the capacity to handle the grants effectively, leading to underspending, while on the other hand, service delivery is pathetic".

The lack of managerial capacity at all levels of the health system was increasingly cited as a binding constraint to scaling up services and achieving the Millennium Development Goals.<sup>24</sup>

### Challenges relating to adherence

Related factors to the socio-economic situation of the patients were identified as those aspects that affected adherence to ART.

### Skipping of medication doses when food is unavailable

Lack of food was indicated as contributing to a situation in which patients did not adhere to their treatment. Some participants said the following: "They do not take medicine when they do not have food. They say the tablets make one very sick when taken on an empty stomach", and "Food becomes a problem. If they do not have food, they also do not take the drugs".

Food security and nutrition are crucial to adherence, and particularly in the early stages of ART. According to the literature, some people may not start treatment when they are unsure about their source of food.<sup>25</sup> Food insecurity is a common barrier to ART adherence.<sup>26</sup>

### An inability to collect medication due to no transport fees

Another socio-economic factor that was mentioned by participants was an inability to collect medication due to having no transport fees, which ultimately led to challenges relating to adherence. The participants indicated that: "Patient transport to the main hospital is provided once a week, thereby delaying initiation of treatment", and "Patients discontinue treatment when there is lack of money for transport to collect medication supplies".

Despite the fact that HIV treatment is free, transport costs are a major obstacle for people on ART.<sup>27</sup>

### South African Social Security Agency guidelines

The participants indicated that the guidelines by the South African Social Security Agency (SASSA) were one of the factors that led to nonadherence. SASSA guidelines stipulate the criteria to be used for an HIV-positive patient to receive a grant, one of which is a CD4 cell count of 200 and below. SASSA likens HIV infection to chronic diseases, such as diabetes mellitus or hypertension.<sup>28</sup> However, in the case of HIV, a temporary grant is offered because the client can recover fully and perform all the activities of daily living should he or she comply with treatment.<sup>28</sup>

Participants mentioned the following: "Patients skip their medication in order to keep the CD4 count low, thereby making them eligible for a grant", and "Patients threaten us with unspecified consequences if we do not recommend them (as being eligible) to receive a grant. Alternatively, they

simply stop taking medication until their CD4 cell count has dropped below 200”.

### Belief system

The use of traditional medicine and religious prophets were mentioned as systems on which people frequently fall back to regain wellness and equilibrium. The participants verbalised that: “Sixty per cent to 70% of the patients mix traditional herbal medicine and ART. Enemas that are given to children impair the absorption of ART”, and “Traditional medicine is preferred by some to ART. The moment they start to feel a bit better, they ask for permission to go home. They say they want to help the doctors by consulting traditional healers in addition”.

Traditional, complementary and alternative medicine (TCAM) is commonly used by HIV-treatment-naïve outpatients of public health facilities in South Africa.<sup>29</sup> Healthcare providers should routinely screen patients on TCAM when initiating ART, and also during follow-up and monitoring, as these patients may not fully disclose other therapies.<sup>29</sup>

The findings indicated that some people hide behind religion and claim to have healing powers against tuberculosis and HIV, thus promoting nonadherence to ART. The participants had this to say: “Self-ordained religious prophets tell patients that they have been prayed for and are now healed and need not take medication”, and “A patient disappeared to visit one of the prophets ... and later came back with a very low CD4 cell count and died a few days later”.

TAC reported a church to the Advertising Standards Authority about its claims that faith healing could cure tuberculosis, HIV and AIDS. TAC also revealed how some patients are misinformed by churches about their illness, leading to the transmission of diseases, such as extremely drug-resistant tuberculosis, to other family members.<sup>17</sup>

The religion of one of the NGOs was seen to interfere with treatment roll-out. It was noted that family planning was affected, especially with regard to the Catholic religion. The church does not advise the use of modern-day family planning methods, as this is in contrast to its doctrine. The participants mentioned that: “Many women present with septic abortions. Unfortunately, we have little means to prevent this since we do not provide family planning services as a Catholic institution”, and “No contraception is allowed at this site. It is against the Catholic doctrine”.

The research findings concur with the literature on the church doctrine, which indicates that Catholics do not have the right to give instructions on birth control methods.<sup>29</sup>

### Loss to follow-up

Patients who have been initiated on treatment often do not return for subsequent visits. Three main groups of

loss to follow-up were identified as teenagers and their babies; migrant workers from Maputo, Mozambique; and women who attended the prevention of mother-to-child transmission (PMTCT) programmes post-delivery, as they went to urban centres to seek better antenatal care and only returned to the rural areas post-delivery. The participants said: “Post-delivery, girls go back to school. They seldom come back for review and follow-up”, and “PMTCT women come to urban areas to access better health facilities. Post-delivery, they return to the rural areas and so we lose touch (with) both mother and baby”, and “A third of our patients are migrant workers from Mozambique. Once initiated on treatment, very few come back for review, and follow-up is impossible”.

### Challenges relating to the health infrastructure

Health infrastructure included processes that achieve positive outcomes and successful roll-out of ART. Lack of laboratory services locally, poor roads and poor communication networks were mentioned in this regard. A functional laboratory with qualified personnel is necessary for speedy processing of clinical investigations and prompt delivery of the results. Participants cited this factor as a challenge as specimens have to be sent away, thereby delaying intervention. The participants had this to say: “Results take up to seven days to return. Specimens have to be sent away to the main hospital or Durban, leading to a long turnaround time, with many results getting lost during the manual transmission”, and “The viral load machine in the laboratory of the nearest specific hospital is not working”.

The main barriers of access to treatment in South Africa include a lack of access to laboratory services for CD4 and viral load testing. These tests are a critical part of ART as patients need to be regularly monitored to see whether or not the treatment is working properly.<sup>30</sup> As two of the three NGOs in this study were located in the Umkhanyakude District, KwaZulu-Natal, the research results concur with a survey conducted by the Health Systems Trust, which indicated that Umkhanyakude is among the most deprived districts in KwaZulu-Natal province.<sup>31</sup>

### Lack of a reliable tool with which to diagnose tuberculosis

It was indicated that the lack of reliable tools delays the diagnosis, initiation and continuation of tuberculosis treatment, or even leads to misdiagnosis of patients. Some participants said the following: “A multidrug-resistant tuberculosis diagnosis can take up to six weeks”, and “Acid-fast bacilli microscopy takes two weeks, and even then, it is often negative and misleading”.

Diagnostic apparatus is needed for the prompt diagnosis and initiation of treatment for patients. However, the apparatus was unavailable, or even unreliable. Interestingly,

according to a newspaper report, a solution had been found in the interim, because government has received the world's largest order of tuberculosis diagnostic machines called GeneXpert Machines.<sup>32</sup>

### Challenges relating to behaviour

The findings of this study indicated non-disclosure and substance abuse with regard to the behaviour of patients. Some participants revealed the following: "Patients refuse to be referred to the local clinic. Someone said I would rather die than to go to any of these clinics because the nurses know me", and "They say they are sharing the tablets with the husband, who himself is unwilling to come in person, because of fear of his status being known".

The fact that most of the patients refused to be referred to a local clinic concurs with the research findings, which state that while self-stigma has dropped, a pervasive HIV-associated "blame stigma" remains very prominent in the community.<sup>33,34</sup>

Substance abuse manifested as a challenge in the form of alcohol and drug (mainly *whoonga*) abuse. Drug abuse (*whoonga*) was cited as being rife in and around Pinetown, while concentrated around Durban and surroundings, where patients are robbed of their ARVs. Some participants mentioned that: "We have some patients who come to pick up their supplies totally drunk. One wonders how they can adhere to such a strict treatment", and "Many patients come back to claim more drugs after allegedly been robbed. In some settings, spouses share one month's supply and sell the other supply to drug dealers. They then come back with an affidavit from the police and demand another drug supply".

The media has reported on the problem of drug abuse and a documentary film pertaining to this was shown on television by the South African Broadcasting Channel.<sup>35</sup> A report by East Coast Radio indicates that more children are using *whoonga*, but not to get high anymore; rather to avoid the pain that is experienced when the drug levels in their bodies start to lessen.<sup>36</sup>

## Discussion and recommendations

The study indicated that NGOs are faced with a complex set of challenges when rolling-out ARV drugs, ranging from challenges relating to sustainability in the form of funding, to challenges of adherence, health infrastructure and behaviour. The results suggest the need for multisectoral collaboration in the roll-out of ART.

The NGO programme coordinators are experiencing financial constraints with regard to sustainability, as the main funder for HIV and AIDS projects in Africa, PEPFAR, had cut spending on the programmes. Another reason for doing this was mismanagement of funds. Government

should devise contingency measures in case NGOs withdraw their programmes. The public health system must also be prepared to absorb the influx of people living with HIV and AIDS who are currently being cared for by NGOs. Middle management's lack of capacity could be addressed by ensuring proper human resource practices, where people are appointed on merit, rather than for other reasons.

The challenge of adherence has emerged as multifaceted. A sustainable approach is needed to deal with the challenge of food security which is hampering adherence. The NGOs and Department of Health must make nutrition an integral component of ART roll-out. Starting an ART programme in a resource-poor area without the provision of supplementary nutrition could be detrimental to adherence. It was indicated that a review of the SASSA guidelines is necessary for successful ART roll-out. They need to be revised and adapted to promote compliance, rather than the opposite, as is currently the case. Programmes should be designed jointly with other departments to ensure synergy and to help minimise shortcomings.<sup>37</sup>

Many clinics and centres still do not have laboratory services, which makes it difficult to monitor patients. The turnaround time for results is an average of 5-7 days, delaying necessary intervention. The literature suggests that when starting large-scale ART, guidelines should be followed, one of which is to decide on essential laboratory, clinical, counselling and pharmaceutical services and their levels of functioning.<sup>1</sup> Comprehensively equipped mobile units could be used in areas in which people experience difficulty with transport so that the services can be taken to the people and the problems with transport fees can be eliminated in order to enhance adherence.

Fear of discriminatory stigma after disclosure of status was found to relate to behaviour, as has been reported in another study.<sup>17</sup> Campaigns aimed at the eradication of the fear of rejection could raise awareness and stimulate debate, which might lead to solutions. The findings indicated that alcohol and drug abuse (*whoonga*) needs attention from social departments.<sup>35,36</sup> It is recommended that health education should focus on the importance of adherence to ART and the dangers of consulting self-ordained prophets who promote poor health-seeking behaviour among patients. The integration of traditional healers into the health system should be explored. Collaboration with traditional healers could help to foster adherence, as well as lead to standardisation and testing of the herbs used, in order to eliminate encountered problems, such as overdosing and toxicity.

## Conclusion

The challenges of lifelong ART adherence are multifaceted and the socio-economic environment of the patients cannot be ignored as they contribute to adherence to treatment.

Before any organisation implements a programme, the norm should be to carry out a comprehensive needs assessment that details the epidemiological profile, undertakes an appraisal of service needs, and compiles a resource inventory and profile of provider capacity and capability. There is a need for strategy development to overcome the challenges and enhance the success of ART roll-out. This will help to sustain the programmes run by the NGOs with regard to ART provision. The Department of Health needs to work with other departments, such as Social Development; Agriculture, Forestry and Fisheries and Public Works to ensure concerted, comprehensive and sustainable roll-out of any programme. Joint programmes ensure synergy and help to minimise shortcomings and abuse, as evidenced by the case of the SASSA guidelines.

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