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## Decision Maker Priorities for Providing Antiretroviral Therapy in HIV-Infected South Africans: A Qualitative Assessment

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### Abstract

In resource-limited settings, successful HIV treatment scale-up has been tempered by reports of funding shortfalls. We aimed to determine the priorities, including ethical considerations, of decision makers for HIV antiretroviral programs. We conducted qualitative interviews with 12 decision makers, identified using purposive sampling. Respondents engaged in one-on-one, semi-structured interviews. We developed an Interview Guide to direct questions about key priorities and motivations for HIV antiretroviral program decision making. We evaluated textual data from the interviews to identify themes. Among 12 respondents, 10 (83%) lived and worked in South Africa. Respondents came from Western Cape, Gauteng, and KwaZulu-Natal provinces and worked primarily in urban settings. The respondents supported prioritizing individual patients based on treatment adherence, pregnancy status to prevent maternal-to-child HIV transmission and/or orphans, and severity of illness. However, priorities based on severity of illness varied, with first-come/first-serve, prioritization of the most severely ill, and prioritization of the least severely ill discussed. Respondents opposed prioritizing based on patient socioeconomic characteristics. Other priorities included the number receiving treatment; how treated patients are distributed in the population (e.g., urban/rural); and treatment policy (e.g., number of antiretroviral regimens). Motivations included humanitarian concerns; personal responsibility for individual patients; and clinical outcomes (e.g., patient-level morbidity/mortality, saving lives) and/or social outcomes (e.g., restoring patients as functional family members). Decision makers have a wide range of priorities for antiretroviral provision in South Africa, and the motivations underlying these priorities suggest at times conflicting ethical considerations for providing HIV treatment when resources are limited.

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## Keywords

HIV; HIV/AIDS; antiretroviral therapy; antiretroviral priorities; ethics; South Africa; qualitative interviews

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## Background

International initiatives have dramatically increased access to HIV/AIDS treatment in developing countries (WHO, 2008). However, universal access may remain out of reach. Recent data suggest that in South Africa, a middle-income country where nearly 1 in 5 are HIV-infected, approximately half of those medically eligible for treatment according to 2004 South African guidelines receive it (AIDSinfo; SADOH, 2004). This figure likely decreases under current national recommendations, which call for earlier antiretroviral therapy (ART) initiation for pregnant women and TB co-infected patients compared to the 2004 guidelines (SADOH, 2010). Under international guidelines, which recommend earlier treatment initiation for all HIV-infected South Africans, coverage estimates decrease to 37% (AIDSinfo; WHO, 2010).

While some attribute the treatment gap to inadequate access to care (Bassett et al., 2008; Matovu & Makumbi, 2007), coverage also has been limited by drug stock-outs, funding constraints, and staff and space shortages, resulting in reported treatment suspensions and waiting lists in some parts of the country (Bateman, 2009; Cullinan, 2009; Thom, 2009; Treatment Action Campaign, 2009). For example, from November 2008 – February 2009, Free State budget shortfalls resulted in over 15,000 treatment-eligible individuals on waiting lists and drug shortages among those already on treatment (AIDS Law Project, 2009). In July 2009, Edendale Hospital (KwaZulu-Natal province) suspended antiretroviral initiation in over 2,000 treatment-eligible patients due to staff and space shortages (AIDS Law Project, 2010). Threats to donor financing, due to the global economic crisis and changing political commitments, suggest these obstacles could persist (PEPFAR, 2010; UNAIDS, 2009; Zwillich, 2009).

In settings where barriers to treatment exist, decisions about how to allocate treatment-related resources become inevitable. Challenges exist regarding how treatment should be delivered (e.g., hospital- and/or clinic-based care); who, if anyone, should receive preference (e.g., pregnant women vs. a 1<sup>st</sup>-come, 1<sup>st</sup>-served approach); and when it should be administered (e.g., receiving antiretrovirals early vs. late in disease progression). Other considerations include unavoidable trade-offs between improving health outcomes for individuals versus for the HIV-infected population. In this context, we aimed to assess qualitatively the range of priorities, including ethical considerations, for providing ART to HIV-infected South African adults.

## Methods

### Study population

We used purposive sampling (Kuzel, 1999; Weiss, 1994) to identify 12 decision makers, defined as stakeholders or policymakers involved in South Africa's HIV treatment scale-up. The study population was limited to individuals working in the health sector with a primary position in a hospital or clinic, government, non-governmental organization, donor agency or foundation, or multi- or bilateral organization. Saturation, indicating sample size sufficiency, was achieved since information gained from final interviews reiterated information gained in previous ones (Sandelowski, 1995).

## Study design

We emailed 27 individuals to participate in the study; 12 individuals accepted. Semi-structured, in-depth interviews were conducted face-to-face or via telephone. Interviews occurred in the US (Boston, January–March 2009) and South Africa (Cape Town, Durban, and Johannesburg, February–March 2009). Participants gave verbal informed consent prior to the interview and received no compensation. Human subjects approval was obtained from Harvard University (Cambridge, USA), University of Cape Town (Cape Town, South Africa), and the Western Cape provincial government (Cape Town, South Africa).

We developed an interview guide to shape the interview process, facilitate obtaining relevant information, and ensure key respondent priorities and other contextual factors important for antiretroviral provision in South Africa were explored. Questions and probes focused on priorities for treatment provision, how respondents might set these priorities, points of conflicts between or among priorities, and motivations underlying participant responses. Pre-test interviews were conducted to ensure general concepts were included, to verify questions and probes were understandable, and to assess question flow and focus (Weiss, 1994). All interviews were conducted by the same facilitator and digitally recorded and transcribed for analysis.

## Analysis

Textual data were assessed iteratively in three main stages based on a modified grounded theory approach and thematic content analysis (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Miles & Huberman, 1994; Pope, Ziebland, & Mays, 2000). In Stage 1, data were read and reread for general impressions. The data were then coded inductively (i.e., during or after data collection) by identified concepts/themes with data sub-classification occurring as necessary. Codes were both preset (i.e., defined before working with the textual data but during or after interviews took place) to reflect our research question and emergent (i.e., defined after working with the data). In Stage 2, we categorized coded data and populated categories with the data in the form of respondent quotations. In Stage 3, we performed axial coding by organizing the categories to evaluate similarities and differences both within and across respondents. Patterns within and across categories were then identified and interpreted. NVivo8 software (QSR International Pty Ltd) was used to both code and analyze the data.

## Results

### Respondent characteristics

Among 12 respondents, all self-identified as health sector decision makers. Respondents came from Western Cape, KwaZulu-Natal, and Gauteng provinces and three-quarters represented patients from rural settings. Table 1 shows additional respondent characteristics.

### Considerations for antiretroviral provision

**Treatment priorities**—Respondents discussed treatment priorities, defined as areas in which to improve antiretroviral provision, in terms of both patient and population concerns (Table 2). Priorities reflecting patient concerns referred to different patient behaviors serving as criteria for an individual to receive treatment or different patient subgroups to whom treatment could be provided preferentially. Patient concerns discussed included individual patient responsibility (e.g., targeting treatment toward patients demonstrating readiness for or adherence to treatment), maintaining South Africa's social fabric (e.g., targeting treatment toward pregnant women in order to prevent orphans), and vulnerable populations (e.g., targeting treatment toward patients based on severity of illness).

An individual's severity of illness served as a main priority for providing ART in varying ways. For example, a provincial government health worker from Western Cape supported treating individuals first-come/first-serve:

"I would be very much inclined to continue the first come, first serve system. If someone takes the trouble to present themselves, I would be very loathe to turn them away and say, 'No, we can't—we don't want you. We want the person five behind you in the queue.'"

In contrast, a physician-scientist from KwaZulu-Natal favored treating critically ill individuals before non-critically ill individuals:

"It's the one who is sickest and in front of you that will get the care. And it's bush medicine but that's how it has been even in the most sophisticated hospital."

Finally, a public sector physician from Gauteng province preferred prioritizing treatment of asymptomatic before symptomatic individuals:

"To treat a healthy person, allowing them to live longer means that they don't get sick. ...[T]hey come in later and later, and they come in very sick. And then you chew up hospitalization resources and healthcare worker resources."

However, some favoring treatment provision to asymptomatic individuals before symptomatic individuals did so in the context of increased access to care to improve patient health outcomes more generally.

Priorities reflecting population concerns referred to broader systems-level approaches toward and aggregate health outcomes related to treatment provision. Respondents discussed antiretroviral coverage (e.g., the number receiving ART or the fraction receiving ART among those eligible to receive it (SADOH, 2004)); treatment delivery (e.g., point of care, location of care, provider type); integration of ART delivery across diseases (e.g., tuberculosis); and antiretroviral treatment and management policy. They generally supported efforts to increase the number of individuals receiving ART and to change treatment management for stable patients from a vertical approach (via doctors in hospitals, with therapy delivered separately from treatment for other diseases) to an integrated approach (via nurses in a primary health care clinic, with therapy integrated into management of other diseases). They also favored improved treatment accessibility, typically by providing treatment and care in facilities closer to patients.

However, they disagreed regarding the intensity of treatment (e.g., number of antiretroviral regimens, types of drugs making up the regimens, labs for routine follow-up) that should be standard of care in South Africa. For example, some supported a less restrictive policy:

"We said two treatment regimens to begin. Maybe we haven't always communicated it well to government. It was never a concept of we would stick with two regimens. That is just not okay," (female physician-scientist, Western Cape)

In contrast, others favored more restrictive treatment policies:

"In the Free State [province], where we ran out of money, if you'd told me six months ago, we would have substituted drug X for drug Y and we would have ditched blood test A and blood test B." (male public sector physician, Gauteng)

Respondents overwhelmingly opposed making decisions about ART provision based on patient socioeconomic or -demographic characteristics. When asked if opinions would change given that wealthier individuals are likely both to receive treatment at all and access it earlier (Wouters, Meulemans, Van Rensburg, Heunis, & Mortelmans, 2007), respondents

did not revise their responses. They believed that practical and logistical concerns made prioritizing patient groups on these criteria infeasible:

“[I]t’s too difficult to do. If you ask me as a theoretical exercise, you might want to say, ‘We’ll prioritize people with children.’ I don’t understand how you do that. Because she drags a child in. ... You can’t prove that’s the [patient’s] child.”

Other criteria, such as clinical status, were considered more objective. Additional areas in which respondents believed treatment prioritization decisions should not be based included treatment-induced behavior change (i.e., disinhibition) and individual- or population-level drug resistance concerns.

**Barriers to and financing for treatment provision**—To put findings regarding treatment priorities into context, we assessed barriers to treatment provision. Respondents discussed: inadequate provision of care in primary care clinics; insufficient numbers of health care professionals; limits on clinic space; scarcity of drugs; inadequate program management; health system structure; and limited funding. Respondents often articulated the inter-relationships among these constraints. For example, one respondent cited space limitations within the context of an already strapped public health system:

“[T]he clinic infrastructure is already groaning outside HIV. A lot of clinics were built well before 20 years ago or more and the population wasn’t what it is now. Burden of disease wasn’t what it is now. So, they’re filled with everyday complaints like pregnancy, children, immunizations, groans, coughs, chronic hypertension, diabetes, etcetera. And then into that you’ve gotta kind of muscle in the next place for HIV.” (male provincial government worker)

Respondents held strong convictions that government sources should support HIV treatment provision in part or in full. A female medical doctor noted:

“I think ARVs should be government funded. I mean I think it is all very well having a kick start from a donor funding agency. But I think they need to be phased out very quickly and find a way to bring government in line to do this is my sense.”

In contrast, a non-governmental organization worker noted the need for donor or other external support:

“If those [donor] funds were pulled out, it would just come to a grinding halt. The whole HIV program would collapse. In fact the health system of South Africa would collapse.”

However, those who believed the South African government should fully financially support ART provision offered few concrete mechanisms for generating additional government funds.

While most respondents cited funding, whether government- or donor-supported, as an underlying obstacle to treatment provision, the majority indicated funding resources were not limited since alternative funding sources could always be found. A provincial government health worker noted:

“Money can be conjured out of nowhere... That’s not the rate-limiting factor.” Most of these respondents believed that treatment-related constraints generally were temporary and surmountable given resource re-allocation, changes in management and spending practices, and/or political will. However, respondents who did raise concerns about funding stability (predominantly in the context of the global economic crisis) believed that funding constraints would exist permanently. This concern was discussed in terms of patients needing lifelong treatment and that treatment need in South Africa would increase over time.

## Underlying motivations and ethical considerations

Motivations underlying respondent priorities for providing treatment broadly fell into two areas—humanitarian concerns and feelings of responsibility. For some, easing patient suffering or improving quality of life motivated underlying priorities for treatment provision. Additional humanitarian concerns included social welfare:

“Part of our legacy is of an extremely brutal society, and it’s from a political history of apartheid with communities that have been shattered and a lot of crime. And there’s a sense within communities that they’ve never had a government that really cares for them and nurtures a sense of caring for one another in the society. And that is the core to a healthy society, I think. HIV is an opportunity show that.” (public sector physician, Western Cape)

For others, feelings of responsibility toward individual patients and providing them the best possible care motivated their treatment-related priorities. One individual remarked:

“You know, for me it’s just “First do no harm.” I think that’s the only thing that really drives me.” (bilateral agency representative)

Given resource constraints, many aimed to provide ART fairly and supported using clinical status to triage patients:

“Fairness is just equal opportunity... And fair for me means everybody who qualifies will be put on and I will not be expected to sway from this outside sound clinical judgment” (non-governmental organization worker, Gauteng).

Respondents were also concerned with improving individual clinical outcomes (e.g., patient morbidity and mortality), individual social outcomes (e.g., patient restored as a functional member of the family), and population clinical outcomes (e.g., saving the most lives).

In evaluating these motivations, we found that respondent beliefs reflected different ethical considerations. Considerations ranged from maximizing health outcomes (e.g., by prioritizing treatment for healthier HIV-infected individuals) to providing equality of opportunity for health care (e.g., adhering to object criteria for treatment initiation) to prioritizing vulnerable populations (e.g., symptomatic or critically ill individuals). However, supplying treatment preferentially to other populations historically considered vulnerable, such as the poor or less educated, was not supported.

We also found that some respondents exhibited internally conflicting beliefs when discussing how they might determine priorities for antiretroviral provision. For example, some discussed treating symptomatic ahead of asymptomatic HIV-infected individuals, and vice versa. One private hospital worker noted:

“Part of my job is to try and cut through those rationing things and say to the healthcare worker, ‘No, sorry. This patient’s an emergency. You have to see him irrespective of the conditions.’”

Later in the interview, when queried about prioritizing patients based on clinical status, the same respondent stated:

“I would use the [antiretroviral] drugs to treat the healthiest population, because that’s going to create the most benefit.”

Similarly, a provincial government worker said:

“Clinical need is obvious. The sicker person should get first. But then that’s also a gray area because at some point you might decide the unsalvageable person shouldn’t get, you know.”

Finally, respondents raised issues regarding individual patient responsibility (e.g., treatment adherence) and equity, including antiretroviral coverage and other distributive issues that would improve treatment access.

## Discussion

Our study suggests that HIV treatment decision makers have wide-ranging priorities, including individual patients well-being and broader population outcomes. However, the motivations underlying these priorities indicate at times conflicting ethical considerations for providing HIV treatment when resources are limited.

These findings come when the HIV/AIDS community may face a crossroads. While international guidelines now recommend earlier treatment initiation and consideration of 3<sup>rd</sup>-line regimens (WHO, 2009, 2010), evolving political priorities and the consequences of a global economic downturn jeopardize future HIV-related financial commitments (PEPFAR, 2010; Zwillich, 2009). In South Africa, national guidelines recommend later treatment initiation; however, earlier ART initiation was recently recommended for pregnant women and HIV/TB-co-infected patients and the possibility of 3<sup>rd</sup>-line regimens also has been introduced (SADDOH, 2010). Although South Africa's publically funded HIV/AIDS conditional grant is projected to increase over time, external donor funding levels remain in question (PEPFAR, 2010; SADDOH, 2010; The Global Fund, 2010).

Our study had some limitations. First, we confined the sample to 12 health sector decision makers since funding, time, and accessibility constraints limited our ability to extend our sampling. This may have excluded information had our sample included respondents from other sectors and/or representative South African patients. However, we found that information gained in the final interviews was repetitive of that gained in previous ones, indicating saturation among health sector respondents had been achieved (Sandelowski, 1995). Additionally, most respondents believed that, through their work, they represented additional sectors, including education, business, and law. Second, individuals involved in pre-test interviews did not come from the same sample population as the respondents. However, pre-test interviews informed revisions to the interview guide that allowed collecting richer and more meaningful data. Third, in our sampling, we may have over-represented the better-resourced Western Cape province relative to other less-resourced provinces. However, since we aimed to determine the range of priorities for antiretroviral provision, versus their relative frequency, we do not believe our results would have changed. Finally, we were not able to collect conclusive information regarding respondent's support of different ethical considerations. Given interview time constraints, we limited main questions to those that would assist in determining the range of priorities relevant for HIV treatment provision in South Africa and posed probes on ethical considerations only as time permitted. We believe the ethical insights provided enough information from which to identify a potential range of ethical considerations supported by respondents and ethical conflicts respondents they might experience. However, additional time would have allowed deeper delving into these issues.

Our findings raise a number of implications and areas for future work. For example, differing motivations and underlying ethical considerations may lead to disagreements about priority setting. Research is warranted regarding whether these disagreements exist; if they differ based on stakeholder role, training, or other dimension; and how disagreements might be resolved. Moreover, while disagreements may arise in a research context, further work is required to determine if they occur in practice.

In a climate of uncertain HIV-related funding but a growing number of HIV-infected individuals presenting for and remaining in care, decision makers face difficult policy choices. Understanding HIV treatment priorities and the ethical considerations underlying them can assist in providing treatment efficiently, effectively, and within a belief system reflecting that of local stakeholders.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

## Respondent Characteristics

Characteristic	Respondents (n=12)
Male sex, number (%)	7 (58%)
Highest education level, number (%)	
Bachelors	1 (8%)
Masters	3 (25%)
Professional or doctorate	8 (67%)
Primary workplace setting, number (%)	
Government	3 (25%)
Non-governmental organization	2 (17%)
Institute of learning	3 (25%)
Hospital	3 (25%)
Donor organization	1 (8%)
Time in primary setting (years), median (IQR)	9.5 (6–16.5)
Other workplace settings, number (%) *	
Government	3 (25%)
Non-governmental organization	4 (33%)
Institute of learning	2 (17%)
Hospital	3 (25%)
Donor organization	1 (8%)
Faith-based organization	2 (17%)
Community-based organization	3 (25%)
Primary sector represented	
Health	12 (100%)
Other sectors represented, number (%) *	
Education	3 (25%)
Business	2 (17%)
Law/human rights	1 (8%)
Level of decision making, number (%) *	
Governmental level	9 (75%)
Organizational level	8 (67%)
Individual/patient level	5 (42%)
Province(s) represented *	
Gauteng	2 (17%)
KwaZulu-Natal	3 (25%)
Western Cape	6 (50%)
Other	1 (8%)
Unknown	1 (8%)
Urbanity of patients represented **†	
Urban	7 (88%)

Characteristic	Respondents (n=12)
Peri-urban	5 (63%)
Rural	6 (75%)
Number of HIV-infected individuals represented (range) <sup>‡</sup>	13,000 (clinic-based setting)
	–
	225,000 (provincial government setting)

\* Percentages do not sum to 100% because responses were not mutually exclusive.

<sup>†</sup> Respondents were not posed direct questions regarding the urban representation of patients for whom they were responsible. However, 8 of 12 respondents provided this information during the interview.

<sup>‡</sup> Respondents were not posed direct questions regarding the number of patients for which they were responsible at either the individual or organizational level. However, 5 of 12 respondents provided this information during the interview.

**Table 2**

Description of Selected Priorities for Making Treatment Decisions in South Africa \*

Level of Concern	Priority	Sample Quotations
Patient	Adherence	<i>If somebody is really perceived to be an adherence risk, doctors say, 'Well hold on. Maybe, you know, this person may not necessarily just get this drug.' They may need to either work it at—or if I had to choose I might choose somebody who appears to be more reliable.</i>
	Children/orphans	<i>...[T]he orphan problem is just a huge, huge problem and getting worse all the time. If you can keep mothers alive to keep their children alive, you solve a lot of downstream problems.</i>
Population	Coverage	<i>Success is measured by numbers of people on antiretrovirals who are going back to their lives. And that's the bottom line.</i>
	Access	<i>Because we say that we want more people to get onto treatment. But health facilities are 400 or 500 kilometers away from where people live. ...And that accessibility is the most important. Just bring the treatment closer to the people, whether that means is you put it in a van or all primary healthcare clinics are accredited as ARV clinics.</i>
	Integration	<i>The intersection of the TB and HIV epidemic where you basically have two different silos providing care is a big operational issue that needs to be addressed in order for people to get one-stop shopping in terms of their health care needs."</i>

\* Sample quotations regarding additional priorities for antiretroviral provision are presented in the main text.