



Cost to patients of obtaining treatment for HIV/AIDS in South Africa

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Background. South Africa is providing antiretroviral (ARV) drugs for HIV/AIDS free of charge in order to increase access for poorer patients and promote adherence. However, non-drug costs of obtaining treatment may limit access. We estimated the costs that South African patients incur in obtaining antiretroviral therapy (ART).

Methods. A random sample of adult pre-ART and ART patients attending a public urban hospital (site 1), a peri-urban (informal settlement) non-governmental organisation (NGO) clinic (site 2), and a rural NGO clinic (site 3) were interviewed during a routine clinic visit. Mean and median costs were calculated for each site.

Results. Ninety-one per cent of subjects paid for transport to attend the clinic. The median cost was modest (R10 - R28), but patients in the top decile at sites 1 and 3 paid R50 or more. Mean transport costs were substantially higher at site 1 (R75) than at site 2 (R18) or Site 3 (R47). Site 1 waived its R45 visit

fee for most subjects, but more than 80% of subjects at sites 2 and 3 paid fees of R30 and R70, respectively. Few subjects at any site paid for substitute labour (7%) or suffered income loss (12%) during the visit. In the previous week, 60% of all subjects purchased non-prescription medicines or special foods, at a median cost of R81, R45 and R50 for sites 1, 2 and 3, respectively. The upper quartile of patients paid more than R150 for these purchases. Twelve per cent of patients reported paying for other medical care in the previous week, while 48% said that they had utilised caretakers' time.

Conclusions. Patients must visit a treatment clinic at least 6 times in the year in which they start ART. The average cost per visit is R120, plus travel and waiting time. Patients and caregivers also spend considerable time and money between visits. Patient costs should be considered in efforts to sustain adherence and expand access.

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In late 2003, the South African National Department of Health announced its Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa.¹ The plan included provision of antiretroviral therapy (ART) free of charge at public health care facilities to medically eligible patients, with the goal of making effective AIDS care and treatment accessible to the large majority of the population not able to afford private medical care. By September 2006, some 235 000 adult South Africans were receiving ART from public health care facilities, along with roughly 80 000 treated in the non-governmental organisation (NGO) and private sectors.²

Although patients at public clinics and many NGO clinics do not have to pay for antiretroviral (ARV) drugs, it is widely understood that treatment is not 'free'. Patients bear the costs

of transport to and from the clinic and the opportunity costs of the time required for frequent clinic visits. Although ARVs themselves are free of charge, many clinics charge a visit fee and/or expect patients to pay for supplemental drugs needed as part of their treatment. In addition, patients are often persuaded by caregivers, pharmacies, traditional healers and commercial advertisers to purchase high-quality foods and a wide range of legitimate and illegitimate products and services claiming to improve their health while on ART.

Throughout the world, both the fee and non-fee costs of obtaining medical care have been found to limit access to acute care and adherence to chronic care.^{3,4} In African countries, charging fees for ARVs has repeatedly been associated with high rates of loss to follow-up and mortality.^{5,7} In Ethiopia, for example, travel time, travel distance, and transport and accommodation costs were found to be major barriers to accessing eye care services⁸ and completing tuberculosis treatment⁹ and reduced the use of clinic and hospital services among poor people in Cote d'Ivoire.¹⁰ Research in Malawi identified transport costs as a barrier to initial uptake of ART, as well as to adherence.¹¹ However to the best of our knowledge only one previous study of the non-fee costs to patients of enrolment in ART programmes has been conducted in South Africa, and it included only public sector sites in a single province.¹²

In view of the evidence that cost is an important barrier to accessing medical care and to ART uptake and adherence, it is useful to know how much South African patients are

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spending on their care. In this article we present self-reported expenditure data from a cohort of adult patients enrolled in public and NGO treatment programmes in Gauteng and Mpumalanga.

Methods

The data presented here are drawn from a longitudinal study of the social and economic outcomes of HIV/AIDS treatment conducted at three treatment sites. The sites are described in Table I. Site 1, the Themba Lethu Clinic, is the HIV clinic of Helen Joseph Hospital, a large, urban public hospital in Gauteng Province under the Gauteng Department of Health. Site 2, the Witkoppen Health and Welfare Centre, is also in Gauteng and is a non-governmental and Gauteng DoH primary care clinic mainly serving an area of informal settlements outside Johannesburg. Site 3, the ACTS Clinic, is a non-governmental HIV/AIDS clinic that serves a largely rural population in Mpumalanga province. Site 1 is funded primarily by the provincial government, site 2 by a combination of donors and the provincial government, and site 3 by donors. All three sites provide ARV drugs to patients free of charge, though a clinic visit fee was charged during the study period to those able to pay.

Between July 2005 and June 2006, a random sample of adult patients receiving ART or pre-ART care at the study sites were enrolled in the study. Patients who were eligible for the study included all those receiving pre-ART care and those who had initiated ART less than 6 months before recruitment. The baseline questionnaire, which was administered during subjects' routine clinic visits, included detailed questions on the costs subjects incurred to visit the clinic on that day and money spent on health-related purchases in the week preceding the

visit. Mean and median costs and interquartile ranges were then calculated for each site.

Results

Study sites and participants are described in Table I. A total of 1 072 subjects were enrolled in the cohort and provided baseline data. As Table I indicates, 56% of the sample was drawn from site 1, 29% from site 2, and 15% from site 3. Across all the sites, most subjects (79%) were female, with a weighted average age of 34 years. Fewer than half of the subjects reported being employed, either formally or informally, at the time of the baseline interview.

Table II reports on transport mode and travel time and the mean and median costs incurred by study subjects for (i) transport; (ii) clinic fees; (iii) payment of substitute labour; (iv) income loss on the day of the clinic visit; (v) purchase of special foods and medicines and medical care provided outside the study clinic in the week preceding the visit; and (vi) caretaker time required in the past week. As is the case with many cost data, the distribution of costs in our study was highly skewed, with most subjects paying relatively modest amounts but a few subjects paying very large amounts. For such data, it is recommended that as much detail as possible be provided on the distribution.¹³ For each site and cost item, therefore, we included the overall sample mean and the mean, median, interquartile range, and top decile costs for subjects who incurred a cost for that item (Table II). Figs 1a - c further illustrate the distribution of transport costs, total costs per visit, and costs for special foods and medications for the entire sample.

Almost all subjects used minibus taxis or buses for the trip to the clinic. Median round trip travel time ranged from 1 hour

Table 1. Description of study sites and subjects

Value	Site 1	Site 2	Site 3
Study sites			
Site name	Themba Lethu Clinic, Helen Joseph Hospital (Gauteng DOH)	Witkoppen Health and Welfare Centre	ACTS Clinic
Province	Gauteng	Gauteng	Mpumalanga
Sector	Public	NGO	NGO
Service area	Urban	Informal settlement	Rural
Facility level	Referral hospital	Primary care clinic	HIV/AIDS clinic
Approximate number of patients on ART (Sept 2006)	4 500	500	700
Sample characteristics			
Number	606	310	156
% of sample	57	29	15
Average age (years)	34	35	36
% female	78	82	78
% employed in formal job	24	28	30
% employed informally	16	33	13

DOH = Department of Health; NGO = non-governmental organisation.



Table II. Costs incurred by study subjects (value in 2005 rands unless otherwise noted)

	Site 1 (urban hospital)	Site 2 (informal settlement clinic)	Site 3 (rural clinic)	All
No. of respondents	606 [*]	310 [*]	156 [†]	1 072
Costs incurred for today's visit				
Transport mode (%)				
Minibus taxi or bus	81	87	81	83
Private car	14	8	15	12
Walked	3	5	1	3
Other	3	0	3	2
Travel time (minutes, round trip)				
Overall mean (SD)	119 (88)	79 (83)	158 (88)	113 (90)
Median (IQR)	120 (60 - 160)	60 (40 - 90)	180 (78 - 188)	90 (60 - 155)
Top decile (90th percentile)	240	120	300	240
Transport cost (round trip)				
Overall mean (SD)	75 (317)	18 (70)	47 (83)	55 (245)
% paying > R0	90	91	95	91
For those paying > R0				
Mean (SD)	84 (333)	20 (74)	50 (84)	60 (256)
Median (IQR)	20 (10 - 29)	10 (10 - 15)	28 (14 - 39)	18 (10 - 28)
Top decile	50	24	90	50
Clinic fee				
Overall mean (SD)	11 (19)	23 (22)	66 (21)	22 (27)
% paying > R0	26	81	94	52
For those paying > R0				
Mean (SD)	42 (6)	28 (21)	71 (10)	43 (23)
Median (IQR)	45 (35 - 45)	30 (30 - 30)	70 (70 - 70)	35 (30 - 70)
Top decile	45	30	70	70
Payment for substitute labour[§]				
Overall mean (SD)	4 (18)	2 (22)	10 (87)	4 (38)
% paying > R0	6	4	13	7
For those paying > R0				
Mean (SD)	60 (46)	76 (101)	77 (237)	67 (136)
Median (IQR)	50 (40 - 60)	38 (21 - 83)	20 (10 - 23)	40 (20 - 60)
Top decile	120	225	75	100
Loss of income				
Overall mean (SD)	13 (70)	24 (203)	1 (8)	14 (121)
% paying > R0	12	16	4	12
For those paying > R0				
Mean (SD)	149 (187)	177 (536)	69 (44)	159 (373)
Median (IQR)	100 (53 - 150)	90 (60 - 100)	69 (54 - 85)	90 (50 - 135)
Top decile	200	150	100	200
Total cost of visit				
Overall mean (SD)	104 (327)	67 (218)	124 (122)	96 (277)
% paying > R0	94	97	97	95
For those paying > R0				
Mean (SD)	111 (337)	69 (221)	128 (122)	101 (283)
Median (IQR)	30 (17 - 65)	40 (30 - 50)	98 (84 - 122)	40 (22 - 88)
Top decile	150	125	174	142
Costs incurred in previous week				
Purchase of special foods or medicines for own use				
Overall mean (SD)	100 (299)	174 (754)	54 (89)	115 (464)
% paying > R0	61	60	57	60
For those paying > R0				
Mean (SD)	164 (368)	293 (961)	94 (101)	191 (587)
Median (IQR)	81 (30 - 160)	45 (20 - 129)	50 (30 - 100)	60 (27 - 150)
Top decile	300	300	250	300



Table II. Costs incurred by study subjects (value in 2005 rands unless otherwise noted) (continued)

	Site 1 (urban hospital)	Site 2 (informal settlement clinic)	Site 3 (rural clinic)	All
Payment for other medical care¹				
Overall mean (SD)	14 (75)	12 (51)	39 (74)	17 (70)
% paying > R0	11	9	28	13
For those paying >R0				
Mean (SD)	125 (196)	135 (118)	141 (72)	132 (151)
Median (IQR)	69 (35 - 119)	110 (45 - 180)	150 (100 - 200)	100 (45 - 160)
Top decile	250	278	200	240
Caretaker's time in previous week (hours)¹¹				
Overall mean (SD)	2.6 (4.8)	2.3 (8.4)	2.9 (3.0)	2.6 (5.9)
% using any caretaker time	49	37	63	48
For those using any caretaker time				
Mean (SD)	5.3 (5.7)	6.2 (12.9)	4.7 (2.4)	5.4 (7.6)
Median (IQR)	5.0 (2 - 5)	2.5 (2 - 5)	5.0 (3 - 5)	5.0 (2 - 5)
Top decile	10.0	10.0	8.0	10.0

¹For loss of income and payment for other medical care, *N* = 603; for purchase of special foods or medicines for own use, *N* = 604.

²For clinic fee and payment for other medical care, *N* = 309; for substitute labour, *N* = 308; for loss of income, *N* = 306; for purchase of special foods or medicines for own use, *N* = 305.

³For clinic fee, *N* = 145.

⁴Question asked: 'Did you have to pay anyone to take over your tasks while you are at the clinic, including payment for child care?'

⁵Question asked: 'Did you spend any other money on any other medical care (formal or traditional) for yourself last week?'

¹¹Question asked: 'About how many hours did this person (person who takes care of you or does your tasks when you are sick) spend helping you last week?'

SD = standard deviation; IQR = interquartile range.

at site 2 to 3 hours at site 3; the top decile of subjects travelled for more than 4 hours. For the 91% of subjects who paid for transport, there was a similar distribution of median transport costs – lowest for site 2 and highest for site 3. This is not surprising, given the location of the three sites and associated patient catchment areas. Site 2 draws most of its patients from nearby informal settlements, while site 3, situated in a rural area, attracts patients from a much larger region. Site 1, in a major urban centre, serves both urban and township residential areas at varying distances.

Perhaps less expected is the finding that for the majority of subjects, transport costs were fairly modest, remaining under R40 per round trip through the 75th percentile at all three sites. Only among the 10% of subjects who paid the largest amounts for transport did costs exceed R50, leading to the highly skewed distribution shown in Fig. 1a. A separate analysis (not shown) found very little relationship between travel time and transport cost; almost none of those who paid more than R100 for transport reported a round trip travel time greater than 3 hours. Clinic staff noted that families of patients who incurred high transport costs had usually rented a private car for the trip, owing either to lack of public transportation or the patient's condition.

Patients' costs for clinic fees depended almost entirely on the policies of the individual clinics. The public hospital, site 1, had a standard fee of R45 per visit but waived this fee for nearly three-quarters of the study sample, based on patient ability to pay. Fees at this site have since been eliminated completely. Most subjects obtaining care at the two NGO sites

did pay the clinic fee, which was set at R30 at site 2 and R70 at site 3. Both sites subsidised or waived this fee for the poorest of their patients. The role of the fee in deterring clinic attendance cannot be explored in this study, as data were collected only from patients who did attend, at least on the date of the baseline interview. The rural clinic (site 3), where the visit fee of R70 could be expected to pose a barrier to many patients, is located roughly 20 km from a public ARV rollout site at which no fee is charged. Possible explanations for patients' preference for the NGO clinic may be its location, shorter waiting times, facility appearance, and/or reputation for quality.

Few subjects reported paying for substitute labour while they visited the clinic (4 - 13%) or losing anything from their salaries or wages because of the time spent at the clinic (4 - 16%). Most subjects were not employed at the time of the interview; for those who were, employment regulations in South Africa require that all employees have access to paid sick leave, reducing the income loss that patients might otherwise incur. Income loss was most common at site 2, where many patients work informally and are paid only for work performed.

When all of the costs associated with the clinic visit (transport, fee, substitute labour, and income loss) are combined, only 5% of subjects in the full sample reported that they did not incur any costs. The average total cost per visit was R96 across the entire sample; the distribution, as shown in Fig. 1b, was highly skewed, with a median of R40 among those paying more than R0.

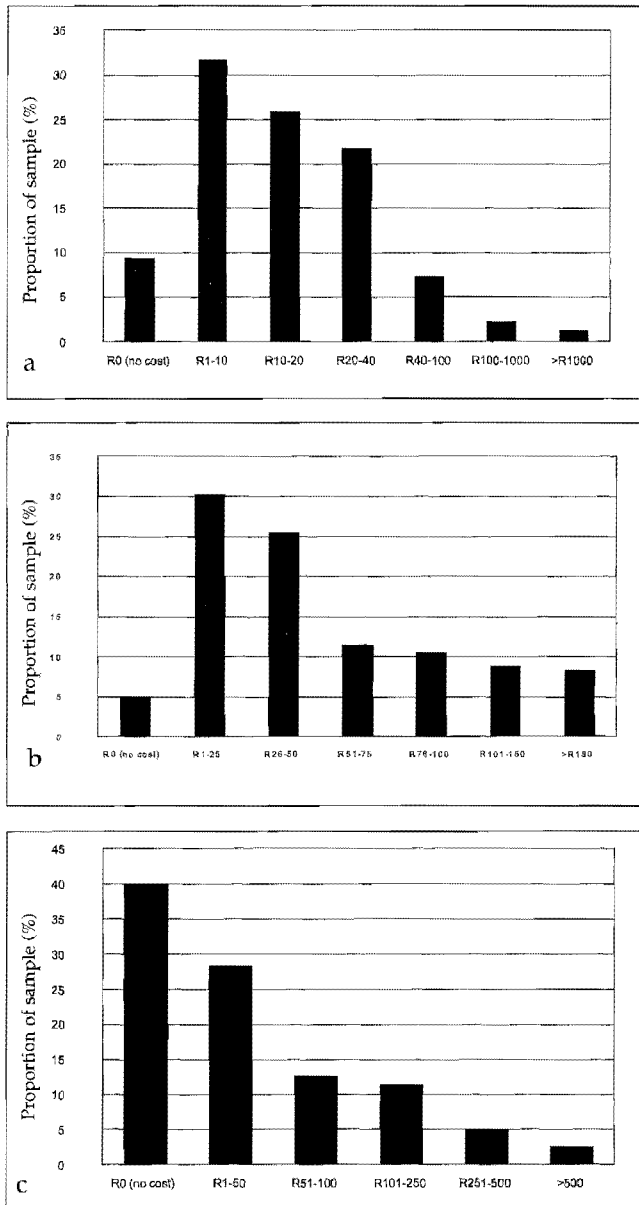


Fig. 1. Distribution of most frequently incurred costs for the entire sample (a – transport costs (round trip); b – total cost per clinic visit; c – special foods and medications).

Perhaps the most surprising finding in this study is the large amounts of money subjects reported spending on special foods and medications in the week preceding the interview. Approximately 60% of subjects reported making such purchases in the preceding week, and the median amounts spent by those who did, viz. R45 - R81, exceeded costs for transport and clinic fees. As illustrated in Fig. 1c, enough subjects spent very large amounts (more than R100) to generate an overall average for the entire sample of R114/subject. The content of these purchases is not clear, but interviewers were instructed to ask only about items that subjects purchased specifically to improve their own health, not general purchases

or purchases made for others. Interviewers reported that fruit and vegetables, vitamins, herbal remedies, non-prescription 'immune boosters', and various non-prescription substances claiming to have anti-AIDS properties were the most common items mentioned.

Also unexpectedly, only 13% of subjects reported spending any money on medical care obtained outside the study clinic in the previous week, although those who did spent large amounts, with a median ranging from R69 to R150. Although the question explicitly included payments made to traditional healers, interviewers guessed that many subjects were unwilling to disclose such payments in the belief that use of traditional healing would meet with disapproval. The interviewers speculated that the great majority of subjects consulted traditional healers in addition to attending the clinic.

Finally, approximately half the sample said that other people had spent time taking care of them or helping them with their tasks in the previous week. Those who utilised caretaker time in the previous week did so for a median of 5 hours.

Discussion

Although ARV medications are provided at no charge to patients at public facilities and many NGO facilities in South Africa, AIDS treatment is 'free' for only a handful of those on ART. We found that 95% of a random sample of patients in care at one public and two NGO sites in Gauteng and Mpumalanga incurred costs on the day of their clinic visit, and half faced a cost of more than R40 per visit. Transport was the only cost incurred by nearly two-thirds of subjects at site 1, the public hospital; at sites 2 and 3, most subjects paid for both transport and visit fees. Across all three sites, a majority of subjects reported spending money on special foods and medicines in the previous week, and the amounts spent were large, with a median of R60 for the 60% who made such purchases.

Distribution was highly skewed for all types of costs incurred by study subjects. At the lower end of the distribution, subjects at site 1 for whom the clinic fee was waived and whose only other cost was transport spent a median of just R20 per visit. At the upper end, subjects at site 3 who paid for both transport and clinic fees spent a median of R98 per visit. In general, each site included some subjects who paid surprisingly large amounts for transport and for purchases of special foods and medicines, suggesting that for a small fraction of patients, there is both ability and willingness to pay for medical care when necessary. On the other hand, the costs incurred by even the 25% of subjects who spent the least make it likely that cost is deterring many eligible patients from enrolling or remaining in treatment programmes.

The transport costs and rates of income loss presented here can be compared with those from two other studies relevant to South Africa, one from the Western Cape¹² and the other from



Table III. Comparison of results with other patient cost estimates

Cost	Western Cape*	Botswana†	This study
Study sites	5 public hospitals and clinics	4 public district hospitals	1 public hospital, 2 NGO clinics
% of sample paying for transport	64%	NA	91%
Transport cost (full sample)	R3 (mean)	R13 (median)	R55 (mean)
Lost income because of clinic visit (% of sample)	6%	29%	12%
Source	(Pienaar <i>et al.</i> ¹²)	(Kgatlwane <i>et al.</i> ¹⁴)	This study

* Calculated by authors from data provided.

† Values shown reflect an exchange rate of Pula 1.3/Rand 1.0, the average rate during the period of data collection. NA = data not available.

neighbouring Botswana,¹⁴ as shown in Table III. Compared with the Western Cape study, which included many subjects who walked to the clinic, subjects in our study were more likely to pay for transport, and the amounts our subjects reported paying far exceeded those recorded for the Western Cape and Botswana samples. A minority of subjects in all studies suffered a loss of income because of the clinic visit, presumably reflecting the low employment rates in the study populations, as well as the role of paid sick leave in smoothing income flows.

South African patients who become eligible for ART under national treatment guidelines can expect to make at least 6, and sometimes as many as 10, clinic visits in their first year on treatment, including pre-ART preparation visits and post-initiation monitoring and medication pick-up visits. For those in the upper half of our cost distribution, for whom the total cost per visit exceed R40, the amounts of money required to initiate and adhere to therapy in the first year are substantial. Whether they are prohibitive, such that some patients are discontinuing or interrupting treatment due to cost while others never start at all, is unknown. However, as the national treatment programme expands further into peri-urban and rural communities it should be anticipated that costs to patients will be a barrier to universal access.

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All authors contributed to designing the study, analysing and interpreting the data, and editing the manuscript. S Rosen drafted the manuscript.

I Sanne is the Program Director of Right to Care, a NGO that supports delivery of ART at the study sites. The authors have no other competing interests.

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