USER FEES, TRANSPORT COSTS, AND THE ETHICS OF EXEMPTION: HOW FREE IS FREE ART?

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The Southern African HIV Clinicians Society initiated an online discussion forum on 'HIV Ethics and Policy' in 2007. The case study below concerns the 'hidden' costs associated with access to antiretroviral therapy (ART), and discusses a number of proposed solutions to the problems faced by indigent patients with HIV/AIDS (to read the entire debate, see http://groups.google.com/group/policy-ethics/topics?start=10&sa=N).

CASE STUDY

Tertiary hospital

At a large tertiary level hospital in South Africa, patients were in the past expected to contribute to the costs of their care by paying means-tested fees, per visit to an outpatient clinic, or per day in case of a hospitalisation. Fees started at R160 per outpatient visit for the lowest income tier. Patients were exempted from the payment if they could prove that they did not have a regular income.

In practice, patients in the lowest income tier were accepted into the clinic for their first 3 visits, but had to bring proof of no income at their 4th visit at the latest. During the first year of the ART clinic's operation, this proof of income (or the absence of it) could have been a handwritten affidavit stamped at their local police station. During the second year, however, this policy was changed and patients had to supply a print-out from the employment registry at the Department of Labour. Hospital staff observed an increase of patients defaulting from treatment after their third visit. Patients were complaining that the new procedure meant that they had to travel to the city centre and queue for a day at the Department, or sometimes for several consecutive days, in order to obtain the necessary documentation. In October 2006 hospital fees were abolished for patients accessing the ART clinic, but patients were still expected to settle their outstanding fees for the period before this general exemption took hold.

An analysis of patients' transport costs at this clinic shows a mean cost of almost R26 per visit, with 61% of patients using minibus taxis as their means of transport. The analysis found that this amounts to a significant proportion of patients' income, especially as a monthly expense over a long period of time.

Secondary hospital

At another ART clinic in a semi-rural secondary health care hospital, the same analysis showed that while mean transport costs are somewhat lower, patients who do not have the cash for a taxi (about 10% of the clinic population) walk several hours on foot to get to the clinic. The clinic staff are concerned that these patients are going to default from treatment if they get sick or demotivated.

Primary health care hospital

At a third ART clinic, in a rural primary health care hospital, patients from the catchment areas of nearby hospitals that have not yet been accredited for ART are collected by bus once a week and driven to the ART clinic in a scheme financed by the provincial Department of Health. The clinic operates in an area that has no working system of minibus taxi routes. Patients comment on the significant stigmatisation they perceive as being associated with having to wait for the 'AIDS buses' in a central part of their township.

Questions for discussion

1. Is it ethically sound to exempt the patients at the ART clinic from the tertiary hospital's fee policy?
   (a) Should the exemption apply to all ART patients, or only to those without income or employment?
   (b) In the latter case, how should patients be expected to prove that they qualify?

2. Should the exemption policy be applied to other patients in chronic care?
   (a) What about inpatients?
3. What are possible solutions to the problem of transport costs?
   (a) Would voucher schemes or the bus scheme mentioned above be viable alternatives to patient self-funding of transport?
   (b) What should the criteria be for patients to qualify for vouchers?

CASE STUDY RESPONSES

A - SUBMITTED BY JOHN GOSLING

Responses to questions 1 and 2

Patients attending ART clinics should be exempt from all hospital fees – irrespective of their income. Because of the extent of the pandemic and the backlog in providing adequate treatment to the approximate 850 000 people who qualify for ART, all outpatient and inpatient treatment for HIV/AIDS should be provided free of cost. This will encourage better compliance and also pave the way for patients to access treatment more readily, whether they have financial constraints or not.

This tertiary hospital is to be lauded for completely abolishing hospital fees for those patients attending ART clinics. However, it would seem unreasonable to expect patients to settle outstanding fees that were owed before the implementation of this policy. This is especially churlish in view of the fact that the Department of Health regularly fails to spend its allocated budget. Surely some of the unspent finances could be used to settle this outstanding debt, which is probably not very large anyway?

The HIV/AIDS pandemic is of such major proportions, and is claiming the lives of so many whose lives could be extended if they were able to access ART in a timely fashion (it is currently estimated that between 800 and 1 000 deaths due to AIDS-related causes occur every day in South Africa), that there ought to be no question of having to prove whether or not any given patient 'qualifies' for free treatment.

In Brazil, ART has been free since 1996. The programme (including aggressive and frank prevention programmes) has improved the health, and extended the survival, of tens of thousands of Brazilians. It has saved the country an estimated $2.2 billion in hospital costs between 1996 and 2004. Access to free AIDS treatment has made Brazilians more willing to be tested for HIV and has made it easier to address the types of behaviour associated with transmission.[1] If the government of Brazil has been able to provide funding for this treatment programme, which has been so highly effective, it ought to be possible for the South African government to do the same.

The answer to the question whether this policy of free treatment ought to be applied to all chronic medical conditions, including inpatient treatment, should be a resounding yes. Unfortunately, this goal is unrealistic in the immediate foreseeable future because of a very poorly administrated Department of Health as well as crumbling medical infrastructure. However, this goal ought to be one of the main issues to be revisited by the government and should be implemented in the very near future.

Response to question 3

The suggestion of travel vouchers is an excellent one. These ought to be supplied on request to all persons attending ART clinics. Given that most patients attending public clinics are indigent, there is little possibility of abuse of such a system. Travel vouchers would ensure that patients keep their appointments more regularly and therefore become more compliant with their ART regimens. Furthermore, it is the express intent of the state, as enshrined in the Bill of Rights, that 'everyone has the right to have access to health care services'. (section 27(1)(a)). One could argue that this right would include free transport for those who cannot afford the taxi fare and who may live at considerable distances from the clinics.

B – SUBMITTED BY KARIN VAN DEN BERG

It is important to consider that every person in South Africa who is formally employed pays taxes that are used to fund the public health care system in this country. The implication is that those who have the means have already contributed to the public health care system and therefore should not have to pay again. Those who are unemployed clearly do not have the means to contribute, and they should indeed be exempt from payment. Such a system removes the need for a 'means test' or any expensive debt collection system – a system that is not working efficiently. The above policy should be applicable to all persons seeking help at a public health facility, irrespective of the condition for which the help is sought.

With regards to the 'AIDS bus', it would seem unethical to provide certain chronically ill people with a 'better' or more comprehensive service than people who have 'only' diabetes or asthma. It implies that one patient is more important than another. If the same service were provided to all patients requiring monthly chronic medication, there would be no stigma associated with using the service.

CONCLUSION – GESINE MEYER-RATH

1. USER FEES AT HOSPITAL OR CLINIC LEVEL

Background

In 1989 the World Bank, as part of its structural reform approach, issued a document entitled *Financing Health Services on Developing Countries: An Agenda for Reform*.[2] It promoted a number of interventions aimed at improving

health sector financing in low-income countries, including the concept of cost recovery at the level of the health care provider in form of user fees. Subsequently a number of countries introduced user fees in both the health and education systems with varying results, but almost invariably leading to lower-than-necessary access of health care by the poorest sectors of society, and to delayed diagnosis and treatment for a number of diseases, thus ultimately resulting in higher cost. A case in point is provided by Kenya, where user fees for public sector outpatient services were introduced in 1989 and withdrawn after only 9 months in 1990.

A study reviewing access to services for sexually transmitted infections found significant reductions in utilisation during the period of user fees, with a 60% reduction for men and 35% for women, with one exception. For gonorrhoea, women's utilisation increased significantly and progressively during the user fee period. This, the authors hypothesised, could have been due to growing rates of infection secondary to falling rates of treatment.[3]

The impact of user fees on adherence and mortality in patients on ART

For ART roll-out programmes, the literature is unequivocal in describing a detrimental effect of user fees or other cost contributions by patients on adherence and remaining in care, and the relative superiority of free provision over provision in which patients have to bear some or all costs. Table I summarises the findings of the relevant studies published to date.

Interestingly, the first two large reviews of the results of ART programmes in resource-limited settings in terms of mortality and immunological and virological outcomes over the first 12 months of treatment both compared free-of-charge and fee-for-service programmes. They found respectively:

- that 'provision of treatment free of charge in low-income settings was associated with lower mortality',[5] and
- that 'the provision of medications free of charge to the patient was associated with a 29 - 31% higher probability of having an undetectable viral load at months 6 and 12'.[7]

A further study looked at the 'social cost' of a scheme of user fees with exemption in treatment centres in Ouagadougou, Burkina Faso.[9] The researchers describe these costs to include, among others, 'patients' perception[s] of arbitrariness about application of exemptions, to difficulties to adjust [the] payment scheme to changing economic conditions, and to necessary negotiations within the relationship between patients and health workers who decide the rate of payment', and, at the level of the health care worker, the 'means and time necessary for socioeconomic enquiries for exemptions and to the symbolic cost of choosing between patients'.[9]

User fees for hospital services in South Africa

In South Africa, user fees are set at the discretion of the Minister of Health, and in some instances the relevant provincial member of the Executive Council (MEC) responsible for health,[10] and are mostly applied at tertiary (university hospital) level. The argument is that these institutions provide specialised care and have much higher overhead costs than institutions at secondary and primary levels of care. As mentioned in the case study, the tertiary hospital in question has since abolished user fees for patients at the ART clinic. This correctly led to many Discussion Forum contributors demanding the same exemption to apply to all patients who have to access the hospital regularly for chronic care. Generally, the question remains whether the amount that can be recouped by charging patients is higher than, and therefore justifies, the administrative costs of collecting these charges.

A second argument for introducing user fees, that they help to minimise the 'moral hazard' of unnecessary demand (i.e. demand for health care that is deemed superfluous or is demanded at a higher level of care than necessary) does not hold in the case of ART, and much other chronic care. This is because the cost of delaying health care is much higher than the cost of accessing care as and when the patient deems it necessary. Comments of contributors to the Discussion Forum were motivated by concerns about the long-term sequelae of financially motivated treatment interruption or cessation, especially the development of drug-resistant virus. Indeed, the preliminary results of a file review at the tertiary hospital show that especially during the first months of its operation in 2004, many of the newly joining patients had previously accessed some form of ART in the private sector, often sub-optimal dual therapy, and had had to interrupt 'buying the drugs' when they ran out of money. Whether this translates into higher rates of resistance development for these patients compared with the clinic population that was treatment-naïve on entry into to the clinic is still subject to analysis.

2. BUT USER FEES AREN'T THE PROBLEM – WHAT ABOUT TRANSPORT COST?

Questions 2 and 3 approached the problem of the additional burden that accessing an ART clinic on a monthly basis poses to often already overburdened people. The problem of access costs for chronic health care to the poor has been well researched, and a large number of remedies have been designed and tried out in different settings over time. Two of these remedies were included for discussion, travel vouchers and designated bus transfers, with the latter potentially re-introducing the problem of stigma.

The obstacle of transport cost has been quantified for ART patients in a few studies. One study involving 789 patients in public sector and NGO clinics in South Africa showed that patients paid a median R20, R10 and R27 in accessing a public urban hospital, a peri-urban and a rural non-governmental clinic, respectively,[11] with the top decile paying R60, R23, and R71, respectively. This compares well with the mean cost of R26 and R19 for patients accessing the urban tertiary care clinic and the semi-urban secondary care clinic that were mentioned in the case study. Compared to patients' income these costs are high, and it is not clear why they should be borne by the patient.

TABLE I. CHARACTERISTICS AND FINDINGS OF STUDIES ON THE IMPACT OF PATIENT CHARGES ON ART OUTCOMES

Country	Years	Setting (number of patients in study)	Outcomes	Comments
Uganda[4]	1998 - 2002	St Francis Hospital, Kampala (*N* = 321)	21% of patients interrupted treatment for > 1 year because of financial constraints	Price drops in 2000 led to many patients returning to clinic; regimens often sub-standard and determined by patients' ability to pay
18 countries in Africa, Asia and South America[5]	N/A (before 2006)	Review of mortality data from treatment cohorts in ART-LINC collaboration, 12 of which provide ART free of charge (*N* = 4810)	Provision of treatment free of charge in low-income settings associated with lower mortality (adjusted HR 0.23; 95% CI 0.08 - 0.61)	
India[6]	N/A (before 2005)	Y R Gaitonde Center for AIDS Research and Care in Chennai (*N* = 304)	Cost was most common reason for non-adherence (32%)	'Patients seem to be taking "drug holidays" to save money'
11 countries in Africa, Asia and South America[7]	1997 - 2003	Meta-analysis of effectiveness data from clinical trials and observational studies of ART programmes (*N* = 2464)	Provision of medications free of charge associated with a 29 - 31% higher probability of having an undetectable viral load at months 6 and 12	
Uganda[8]	1997 - 2004	3 treatment centres in Kampala (*N* = 304)	Monthly income < 50 US$ was associated with non-adherence (OR = 2.77, 95% CI 1.64 - 4.67)	Non-adherence defined as > 95% of doses missed in last 3 days

3. THE WAY FORWARD

There is a great need for policy makers to consult more with health care practitioners 'on the ground' whose work provides them with unique insights into the obstacles their patients are struggling with. A number of important initiatives are currently under way to remedy the situation in South Africa, ranging from increased lobbying for the economic rights of people living with HIV/AIDS, to reviewing and improving the current CD4 count-based disability grant criteria, to potentially introducing a chronic illness grant. It seems that after years of political struggle to provide antiretrovirals in the public sector, and with increasing numbers of patients on treatment who expand the collective knowledge and experience of treatment challenges, a second wave of detailed operational thinking and activism has been initiated. Creative research is needed to identify feasible and scaleable interventions that support patients who have expressed their readiness to take lifelong treatment in putting their conviction into action. Three years into the public sector roll-out of ART, the discussion about how to avoid hidden costs and how to increase support strategies for patients on ART has just begun.

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