

The financial burden of HIV care, including antiretroviral therapy, on patients in three sites in Indonesia

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This paper assesses the extent of the financial burden due to out-of-pocket payments for health care incurred by people living with HIV (PLHIV) and the effect of this burden on their financial capacity. Data were collected in a cross-sectional survey of 353 PLHIV from three cities in Indonesia (Jakarta, Jogjakarta and Merauke). Respondents in Jakarta were sampled from one hospital and one non-governmental organization working with PLHIV. In Jogjakarta and Merauke, all HIV patients on antiretroviral therapy (ART) who came to selected hospitals during the interview period were asked to participate in the survey. The survey collected data on the frequency and extent of payments for HIV-related care, with answers cross-checked against medical records. Results show that PLHIV had different burdens of payments in the different geographical areas. On average, respondents in Jogjakarta spent 68%, and PLHIV on ART in Jakarta spent 96%, of monthly expenditure for HIV-related care, indicating a substantial financial burden for many ART patients. These patients depended on several sources of finance to cover the costs of their care, with donations from their immediate family being the most common method, selling assets and payments from personal income being the second most common method in Jakarta and Jogjakarta, respectively. Most PLHIV in these two areas did not have insurance. In Merauke, there were little observed out-of-pocket payments because the government covers medical costs via the local budget and health insurance for the poor.

The results of this study confirm previous findings that providing subsidized ART drugs alone does not ensure financial accessibility to HIV care. Thus, the government of Indonesia at central and local levels should consider covering HIV care additional to providing antiretroviral drugs free of charge. Social health insurance should also be encouraged.

Keywords ART, HIV/AIDS, financial barriers, access, Indonesia

KEY MESSAGES

- There is a substantial financial burden for people living with HIV and their families in accessing and receiving HIV care, both before and after starting ART, although the burden is higher after starting ART.
- Findings suggest that 45% of all respondents suffered catastrophic expenditure, indicating that paying for HIV care is likely to cause poverty for many people living with HIV.
- Health insurance can alleviate individual financial burdens related to HIV care and treatment.
- The Indonesian government should consider providing the full package of HIV care services free of charge.

Introduction

Access to HIV care and antiretroviral therapy (ART) remains a challenge to HIV/AIDS control programmes in developing countries. Global figures from 2007 indicate that only 31% of people in need actually received ART (WHO 2008). The High Level Meeting on HIV/AIDS at the UN General Assembly in 2006 resulted in a unanimous endorsement of the goal of moving towards universal access to prevention, treatment, care and support by 2010 (United Nations General Assembly 2006; UNAIDS 2008). One of five strategies for achieving this goal is accelerating the uptake of ART (WHO 2007).

Previous studies have identified several barriers to accessing HIV care (Mills *et al.* 2006) that limits ART uptake, including social and cultural barriers, geographical barriers and financial barriers. More specifically, barriers identified include lack of knowledge regarding HIV prevention (Louis *et al.* 2007), low ability to pay for ART drugs (Msellati *et al.* 2003; Kumarasamy *et al.* 2005; Bobrova *et al.* 2007), cost of transportation (Mshana *et al.* 2006; Louis *et al.* 2007), cost of food supplementation, perceived low quality of health service (Mshana *et al.* 2006; Louis *et al.* 2007), stigma (Kumarasamy *et al.* 2005; Mshana *et al.* 2006; Larsson *et al.* 2007) and fear of abandonment by a partner (Larsson *et al.* 2007). Barriers on the health provider side are also reported, including unclear policies and regulation for providing treatment to intravenous drug users (IDUs), and low capacity of staff to provide ART treatment (Bobrova *et al.* 2007).

Indonesia is a low- to middle-income country, with a GDP per capita of US\$1897 in 2006. Overall, the country has a low HIV prevalence, listed at 0.1% for 2005 (UNAIDS 2008), but the prevalence is higher in certain geographical areas and in certain high-risk populations. In 2007, UNAIDS estimated that there were 43 000 people in Indonesia with advanced HIV infection and that, of these, only 6600 (15%) were receiving ART (UNAIDS 2008). The National AIDS Commission in Indonesia estimated that 24% of people with advanced HIV infection received ART (National AIDS Commission 2008). In the remote province of Papua, where there is a generalized epidemic, only 3% of PLHIV received ART. Furthermore, 50% of the IDU population is estimated to be HIV positive, but as few as 3% of these are on ART (National AIDS Commission 2008). These figures suggest that there are considerable barriers to accessing ART in Indonesia.

One study conducted in Indonesia indicated that geography and finance were important barriers to access (Atma Jaya University 2006). While Indonesia has a large network of government-subsidized health centres and hospitals, evidence

suggests that in general out-of-pocket payments (OOPs) are an important source of health care financing in Indonesia. For example, the national health account database lists that 57–63% of health finance in 2005 was from private sources, of which 70% was out-of-pocket, indicating that about 40% of health care in Indonesia was financed out-of-pocket (Soewondo *et al.* 2009; WHO 2009).

By the end of 2006, Indonesia's Ministry of Health had established over 100 voluntary counselling and testing (VCT) sites and provided ART at 75 selected hospitals. Antiretroviral drugs (ARVs) are provided free of charge to patients. However, PLHIV must pay for other services including VCT, medical consultations and examinations, laboratory monitoring and drugs other than ARVs. Additionally, there are opportunity costs associated with HIV care, most notably time spent away from work and travel costs. Thus, even though ARVs are free to patients, overall HIV care is not; hence, real and perceived costs might hamper access to therapy.

While financial barriers may hamper PLHIV access to HIV care, there are few data on how much people pay for HIV care in relation to their income, especially in Southeast Asia. This study aims to assess the extent of the financial burden experienced by PLHIV due to HIV care in Indonesia. Describing the financial burden of these patients and identifying where further financial subsidies are needed to ensure access and adherence can help the Government of Indonesia meet their public health commitments and goals (that 80% of people in need will be on ART by 2010). Further, this information is useful to PLHIV to inform their advocacy efforts and to increase their understanding of the extent of payments they are likely to incur for HIV care.

Methods**Study setting and design**

In 2006, a cross-sectional survey was conducted in three cities: Merauke, Jogjakarta and Jakarta. Respondents were PLHIV. PLHIV on ART were interviewed at one hospital outpatient clinic per city: Sulianti Saroso Hospital for Infectious Diseases (RSPI) (Jakarta), Sardjito General Hospital (Jogjakarta) and Merauke District Hospital (Merauke). PLHIV not on ART were interviewed only in Jakarta through an non-governmental organization (NGO) (Kios Atmajaya).

The three study sites represent areas in Indonesia with different HIV prevalence patterns. Jakarta, with a population of over 12 million, has a concentrated HIV epidemic in a number of populations. Jogjakarta is a city of 1 million people with a

concentrated epidemic in a few populations. Both cities have developed transportation infrastructure and are accessible from nearby towns via paved roads and public transportation. Merauke is a small town in Papua. Most of the surrounding villages are in mountainous and jungle areas, and people have to travel to Merauke by small planes, or, when there are no flights, spend several days travelling.

In Merauke and Jogjakarta, all registered patients on ART were asked to participate in the survey. In Jakarta, patients on ART were assigned numbers and participants were selected by drawing numbers at random. Interviews were conducted when patients attended the outpatient clinic. PLHIV not on ART were selected from individuals in contact with the NGO. Because of the high cost associated with overseas trips and current availability of HIV care in Indonesia, respondents were excluded if they had sought HIV care outside Indonesia.

Data collection

Data were collected using a standardized, validated and field-tested questionnaire. The questionnaire comprised questions on respondents' socio-demographic status, OOP payments for HIV care, sources of financing for payments, respondents' perception of the financial burden that they bore due to HIV care and other information related to determinants of ART access such as insurance status and distance travelled for HIV care. Respondents were asked to identify medical spending for five categories: drugs and remedies; consultation fees; laboratory tests and diagnostics; procedures and hospitalization; and transport and accommodation. Respondents were asked to report all expenditure since their diagnosis with HIV (including VCT); responses were cross-checked with medical records.

Household monthly expenditure was measured by asking respondents to recall their total expenditure during the last month. Respondents were then asked to report their total spending on 13 different categories of expenditure, including health.

Ethical approval

The study was approved by the Ethical Review Board of Gadjah Mada University, Jogjakarta. Respondents gave verbal informed consent to be interviewed to medical staff before being approached by study interviewers, when signed informed consent was obtained. Trained and supervised interviewers conducted the surveys. Respondents were given a chance to ask questions after the interview, and the interviewers were trained on HIV/AIDS knowledge. The interviews were taped; recordings were erased immediately after transcription. Names of the study participants were not recorded on any written or electronic material, and respondents were identified only by non-traceable identification numbers. Study staff kept all records in locked cabinets and only study staff had access to the records.

Data entry and analysis

Two operators entered the data separately, with comparison by a third party and discrepancies checked against original documents. SPSS statistical software version 12.0 (2007; SPSS

Inc., Chicago, IL, USA) and Stata 7 were used for the analysis (Release 7.0; Stata Corporation, College Station, TX, USA).

Due to the high skew of the expenditure data, results are reported using both means and geometric means. The t-test was used to assess the difference between the means or geometric means between different populations for continuous variables; chi-squared and Fisher's exact tests were used for categorical variables.

Catastrophic payments, used to assess the financial burden of health care payments, have been defined differently in different studies. Several studies have used health care payments over 10% of total household expenditure to define catastrophic payments (Pradhan and Prescott 2002; Wagstaff and van Doorslaer 2003; Russell 2004; van Doorslaer *et al.* 2007), while another recommends comparing health expenditure with non-subsistence expenditure (Xu 2005). However, we do not have data on household size (in part due to the transitory living arrangements of some of the respondents) or subsistence levels needed for the latter method. Thus, this study used the total average monthly cost for HIV care in comparison with total monthly expenditure. Following the literature, 10% of household expenditure for HIV care is used as the definition of high burden, while 25% of non-food expenditure is used for sensitivity analysis (van Doorslaer *et al.* 2007).

Household expenditure has been recommended as a proxy for income, especially for survey data (Hjortsberg 2003; Trujillo 2003). The total reported monthly expenditure is used in this analysis; the total expenditure based on summing expenditure across the 13 categories is used for sensitivity analysis.

Results

Description of the sample

Surveys were completed for 353 respondents, consisting of 60 patients in Merauke (out of 64 registered patients), 43 patients in Jogjakarta (out of 43 patients), 125 ART patients (out of 547 patients) from RSPI (henceforth 'Jakarta ART'), and 125 PLHIV not on ART in Jakarta (henceforth 'Jakarta Non-ART'). Eight people at the Jakarta ART site (2%) declined to be surveyed, and four patients in Merauke were unavailable for interview at the time of the survey. Three patients from Jogjakarta were excluded because they had received HIV care outside Indonesia.

Table 1 presents the demographic characteristics of the respondents. The mean age in Merauke and Jogjakarta was close to 31 years. In Jakarta, the mean age was 28.9 years for Jakarta ART and 27.9 for Jakarta Non-ART (not statistically different at $P < 0.10$ level). However, the age structure between the sites does differ, with 21 (35%) respondents in Merauke and 72 (29%) in Jakarta below 25 years, while in Jogjakarta only 4 (9%) were under 25 years of age. Merauke had more respondents over the age of 40 (13 or 22%) than the other areas.

Excepting Merauke, the majority of respondents were male, representing more than 70% (33 in Jogjakarta, 192 in Jakarta) of respondents and reflecting the gender distribution of PLHIV in Indonesia outside of Papua. Respondents categorizing themselves as transgender were found in Jogjakarta (two respondents or 5%) and Jakarta (14 respondents or 6%). Thirty-one (72%) of Jogjakarta respondents were from rural

Table 1 Demographics status of the respondents

	Merauke (n = 60)		Jogjakarta (n = 43)		Jakarta ART (n = 125)		Jakarta HIV (n = 125)	
	Freq	%	Freq	%	Freq	%	Freq	%
Age								
<25	21	35.0	4	9.3	34	27.2	38	30.4
25–29	7	11.7	14	32.6	47	37.6	51	40.8
30–39	19	31.7	21	48.8	39	31.2	34	27.2
>40	13	21.6	4	9.3	5	4.0	2	1.6
Mean age	30.9		31		28.93		27.89	
Sex								
Male	27	45.0	33	76.7	103	82.4	89	71.2
Female	33	55.0	8	18.6	21	16.8	23	18.4
Transgender	0	0.0	2	4.7	1	0.8	13	10.4
Marital status								
Married	25	41.7	17	39.5	32	25.6	25	20.0
Separated/divorced	1	1.7	2	4.7	5	4.0	7	5.6
Stable partner	5	8.3	0	–	1	0.8	0	–
Widow/widower	8	13.3	2	4.7	9	7.2	7	5.6
Not married	21	35.0	22	51.2	78	62.4	86	68.8
Residence								
Urban	47	78.3	12	27.9	117	93.6	114	91.2
Rural	13	21.7	31	72.1	8	6.4	11	8.8
Education								
Unschooling	8	13.3	0	–	7	5.6	4	3.2
Elementary	14	23.3	2	4.7	15	12.0	16	12.8
Junior High School	19	31.7	2	4.7	75	60.0	78	62.4
Senior High School	17	28.3	19	44.2	27	21.6	27	21.6
University	2	3.4	20	46.4	1	0.8	0	–
Occupation								
Civil Servant	5	8.3	2	4.7	2	1.6	0	–
Private employee	2	3.3	9	20.9	35	28.0	21	16.8
Farmer	3	5.0	0	–	0	–	0	–
Self employed	16	26.7	16	37.2	35	28.0	45	36.0
Unemployed	34	56.7	16	37.2	53	42.4	59	47.2
Distance to ART centre								
0–10 km	43	71.7	26	60.5	78	62.4	66	52.8
11–20 km	5	8.3	3	7.0	21	16.8	21	16.8
21–30 km	4	6.7	7	16.3	9	7.2	21	16.8
31–40 km	4	6.6	2	4.7	0	–	3	2.4
>40 km	4	6.7	5	11.5	17	13.6	14	11.2
Method of transportation								
Bus	25	41.7	5	11.6	41	32.8	58	46.4
Train	0	–	0	–	1	0.8	7	5.6
Aeroplane	0	–	0	–	0	–	0	–
Car	3	5.0	7	16.3	21	16.8	7	5.6
Motorcycle	7	11.7	30	69.8	52	41.6	43	34.4
By foot	10	16.6	0	–	–	–	–	–
Bicycle	–	–	1	2.3	6	4.8	0	–
Others	15	25.0	0	–	4	3.2	10	8.0
Insurance status								
Insured	59	98.3	14	32.6	22	17.6	18	14.4
Uninsured	1	1.7 ^a	29	67.4	103	82.4	107	85.6

^aOne of the Merauke respondents did not have insurance but was covered by local government.

areas, compared with 13 (22%) in Merauke and 19 (8%) in Jakarta. Overall, the education level of the respondents is relatively low. However, respondents in Jogjakarta appeared to be better educated than those at the other sites, with 39 (over 90%) having completed senior high school or university. Being unemployed was the largest occupational category, ranging from 16 respondents (37%) in Jogjakarta to 34 respondents (57%) in Merauke.

Five (12%) and 31 (25%) respondents in Jogjakarta and Jakarta lived over 40 km from the ART centre. In Papua, 43 respondents (71%) lived less than 10 km from the ART centre, compared with 60% and 58% of respondents in Jogjakarta and Jakarta, respectively. In Jakarta, 78 respondents (62%) on ART lived less than 10 km from the site, while only 66 (53%) of Non-ART respondents lived less than 10 km away (statistically significant, $P < 0.05$). However, both groups had similar numbers living far from ART centres, with 14% and 11% of ART and Non-ART people, respectively, living over 40 km away from an ART centre.

Overall, 37% of respondents used motorcycles for transportation. Only 10 (17%) respondents in Merauke had access to private transportation (either car or motorcycle), compared with roughly half (49%) of Jakarta respondents and the majority (86%) of Jogjakarta respondents. However, a greater percentage ($P < 0.05$) of Jakarta ART respondents than Non-ART respondents used private transport (58% compared with 40%); this may be a reflection of the higher average monthly expenditure among those on ART.

Financing HIV care

The magnitude of payments for HIV care, including ART, varies from region to region. Compared with the other locations studied, respondents in Merauke incurred very small OOP payments, with a geometric mean of Rp 35 686 (about US\$4) per month, representing 5% of total monthly expenditure. No respondent paid over 10% of their monthly expenditure on HIV care.

In Jogjakarta, the geometric mean OOP payment (excluding transportation and accommodation) since the start of treatment was Rp 9 794 348 (US\$1065), representing Rp 429 928 (US\$47) per month (mean spending per month was Rp 570 267 or US\$62). Fourteen respondents (33%) had spent, in total since the start of HIV care, over Rp 10 million (about US\$1000).

For Jakarta ART respondents, the mean monthly expenditure for HIV care was Rp 1 398 768 (US\$152), with a geometric mean of Rp 451 048 (US\$50). Two respondents in Jakarta had very high monthly expenditure on HIV care (over Rp 15 million or \$1500), which reflected high payments for inpatient care and short overall time on treatment. For Jakarta Non-ART respondents, the mean OOP was not as high as respondents on ART, with an average of Rp 1 078 752 (US\$117) or a geometric mean of Rp 46 394 (US\$5) per month ($P < 0.05$ for both mean and geometric mean).

Average monthly expenditure in Jogjakarta was Rp 1 093 537 (US\$119); average HIV care expenditure (including transportation and accommodation) over the course of treatment was 68% of monthly expenditures (see Figure 1), or about 107% of non-food expenditure. For Jakarta ART, total monthly expenditure was Rp 1 457 112 (US\$158), while for Jakarta Non-ART it was Rp 1 078 752 (US\$117) (difference significant at $P < 0.05$).

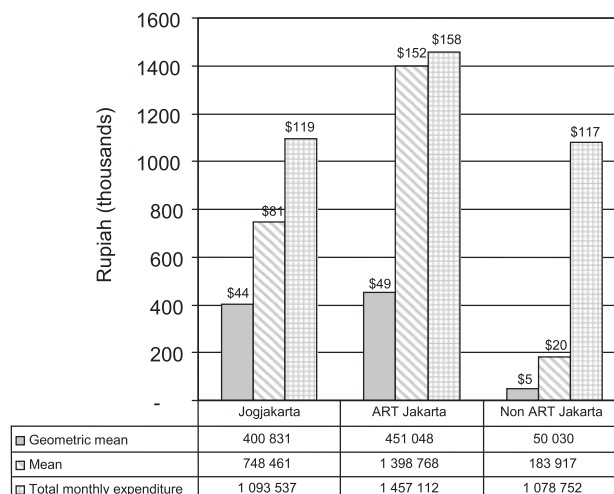


Figure 1 Average monthly payments by patients for HIV-related health care since the start of treatment compared with average monthly expenditure. *Note:* Indonesia's GDP per capita was estimated at US\$1897 (\$158 per month) in 2006

OOP expenditure for HIV care among Jakarta ART respondents was on average, 96% of monthly expenditure (about 160% of non-food expenditure), but only 17% of monthly expenditure (24% of non-food expenditure) for Non-ART respondents.

The average expenditure for health care in only the last month (as opposed to the average since the start of respondents' HIV care treatment) was Rp 187 588 (US\$20) in Jogjakarta, Rp 438 000 (US\$48) for Jakarta ART and Rp 55 200 (US\$6) for Jakarta Non-ART. This represents 17%, 30% and 5%, respectively, of all monthly expenditure.

As expected, total monthly expenditure as reported by respondents and total monthly expenditure as calculated by summing across 13 categories of expenditure were highly correlated. However, the summed expenditure showed lower overall expenditure than the reported totals, indicating that this method was not correcting for potential recall bias; these data are not used further.

Table 2 reports the respondents' primary source of financing payments made for HIV care. In Merauke, the government, as the provider of health insurance for the poor, is the sole source of financing excepting transportation (which is less than 1% of total payments). In Jogjakarta, 80% of respondents derived their main source of financing from their regular income or from relatives (mostly their parents), with about 20% having used savings or having sold household assets. In Jakarta, a higher percentage relied on their family to pay for care, and over 30% of respondents on ART had to sell assets or take out a loan, indicating a serious strain on household finances. More than 93% of the Non-ART respondents in Jakarta are able to use household income or gifts from family as their primary means of paying for care, compared with 64% of those on ART.

Table 3 shows that the largest category of OOP payments is for procedures and hospitalization services. Non-ART respondents in Jakarta, for instance, incurred up to 60% of their total payments for procedures and hospitalization. However, for Jakarta ART respondents, the percentage spent on procedures and hospitalization (39.9%) is only marginally more than the percentage spent on drugs and remedies (39.7%).

Table 2 Primary mechanism for financing HIV care

Source of financing	Merauke (%)	Jogjakarta (%)	Jakarta ART (%)	Jakarta Non-ART (%)
Household income	–	35	6	33
Household savings	–	5	2	2
Selling assets	–	14	20	2
Gift from outside household	–	–	–	–
Government/public subsidy	100	–	–	–
Grants/donation from family	–	47	58	61
Borrowing from outside household?	–	–	11	1
Private insurance	–	–	3	2
Total (%)	100	100	100	100

Table 3 Total payments by component since the start of HIV care in Indonesian Rp (US\$)

	Merauke (<i>n</i> = 60)		Jogjakarta (<i>n</i> = 43)		Jakarta ART (<i>n</i> = 125)		Jakarta Non-ART (<i>n</i> = 125)	
	Cost	%	Cost	%	Cost	%	Cost	%
Drugs and remedies	–	–	1 100 116 (\$120)	11.2	4 725 888 (\$514)	39.7	121 968 (\$13)	7.4
Consultation fees	–	–	–	–	484 936 (\$53)	4.1	169 960 (\$18)	10.4
Lab & diagnostic fees	–	–	1 541 861 (\$168)	15.7	1 054 762 (\$115)	8.9	234 076 (\$25)	14.3
Procedures & hospitalization	–	–	5 608 140 (\$610)	57.3	4 744 480 (\$516)	39.9	992 320 (\$108)	60.5
Transport & accommodation	38 500 (\$4)	100	1 544 233 (\$168)	15.8	891 800 (\$97)	7.5	122 328 (\$13)	7.5
Total	38 500 (\$4)	100	9 794 349 (\$1,065)	100	11 901 866 (\$1,294)	100	1 640 652 (\$178)	100
Average number of months in care	27.6		17		15.5		17.4	
Travel distance: average payments per month for transport								
<10 km			29 147 (\$3)		80 237 (\$9)		123 764 (\$13)	
10–40 km	N/A		156 532 (\$17)		110 324 (\$12)		25 179 (\$3)	
>40 km			265 747 (\$29)		100 296 (\$11)		12 171 (\$1)	
Travel distance: average payments per month for accommodation including accompanying family members								
<10 km			1211 (\$0.1)		80 173 (\$9)		44 547 (\$5)	
10–40 km	N/A		1191 (\$0.1)		132 152 (\$14)		6186 (\$1)	
>40 km			4557 (\$0.5)		59 124 (\$6)		N/A	
Age: average payments per month by age group								
<25 years			1 117 577 (\$121)		3 011 987 (\$327)		398 313 (\$43)	
25–30 years	N/A		966 799 (\$105)		865 358 (\$94)		190 130 (\$21)	
>30 years			460 456 (\$50)		1 166 911 (\$127)		127 576 (\$14)	

In Jogjakarta, respondents living far from the ART Centre had to pay more for transportation, but this was not found in Jakarta, where people who travel further are more likely to take public transportation (Fisher's exact test $P < 0.05$). Some respondents also paid for accommodation but this does not appear to be associated with distance travelled. Table 3 also shows that respondents aged less than 25 spent more.

Discussion

Do people accessing HIV care suffer a high financial burden?

The results above indicate that, except in Merauke, PLHIV and especially patients on ART suffer a financial burden due to payments made for health care services. Figures 2, 3 and 4

compare the average monthly payments for HIV care since treatment began and total monthly expenditure for Jogjakarta, Jakarta ART and Jakarta Non-ART respondents, respectively. Since the 10% threshold used in the literature is admittedly an arbitrary representation of catastrophic payments (especially for wealthier households) (Wagstaff and van Doorslaer 2003), three lines radiating from the origin represent the percentage of monthly expenditure that a respondent paid for HIV care. Lines are drawn at 10%, 40% and 100% (which represents where patients paid the same amount for HIV care per month as they reported to have spent in total during the last month). These graphs show that for the two sets of respondents on ART, the highest payments incurred were not among the respondents with highest total expenditure.

In Jogjakarta, any method of calculating catastrophic payments results in a substantial percentage of respondents having

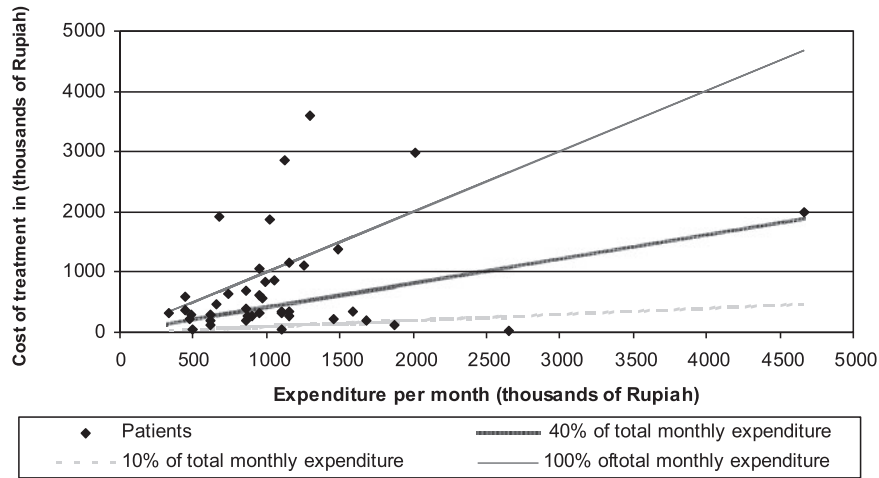


Figure 2 Comparison between payments for HIV care and total expenditure per month in jogakarta

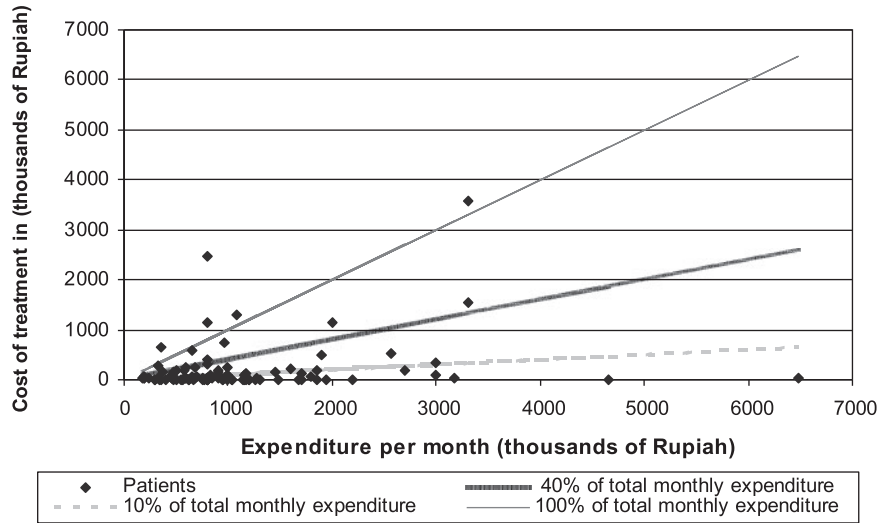


Figure 3 Comparison between payments for HIV care and total expenditure per month in Jakarta (Non-ART)

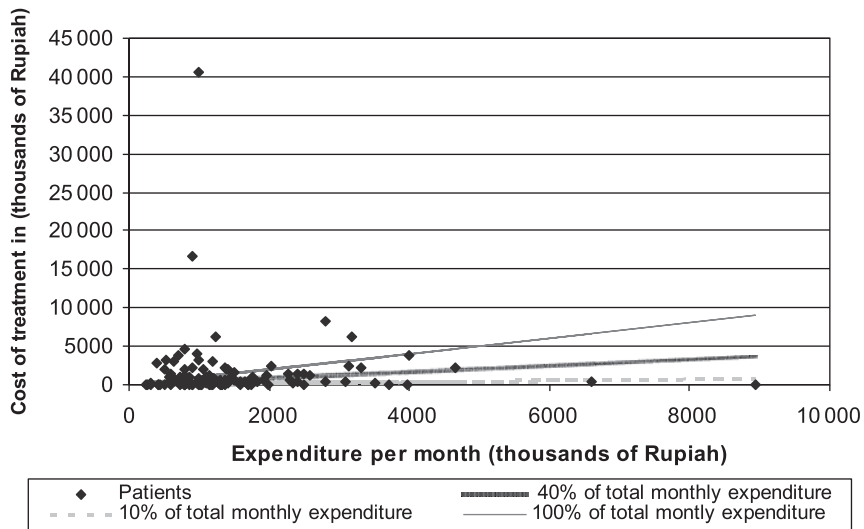


Figure 4 Comparison between payments for HIV care and total expenditure per month in Jakarta (ART)

incurred a high financial burden. Using average monthly expenditure for HIV care since the start of treatment, 37 respondents (86%) paid over 10% of their total monthly expenditure on HIV care, 21 (49%) respondents paid over 40% and 8 (19%) paid over 100% (35, or 85%, paid more than 25% of their non-food expenditure). When using health expenditure in the last month, 18 (42%) respondents devoted more than 10% of their expenditure to health care (15, or 35%, paid more than 25% of their non-food expenditure for health care).

While the percentages incurring a high financial burden are similar between respondents on ART in Jogjakarta and Jakarta, Figures 3 and 4 highlight the differences in the financial burden related to HIV care between those on ART and those not on ART. Five (4%) Non-ART respondents paid over 100% of their monthly expenditure for care, 12 (10%) paid over 40% and 36 (29%) paid over 10%, compared with 27 (22%), 58 (46%) and 93 (74%), respectively, among the ART respondents. If health expenditure in the last month is used rather than average monthly expenditure since start of treatment, 47 (38%) ART respondents devoted more than 10% of their expenditure to health care (39, or 31%, of respondents paid more than 25% of their non-food expenditure) compared with only 22 (18%) among Non-ART respondents (17, or 14%, paid more than 25% of their non-food expenditure). It is, perhaps, not surprising that people not on ART have lower payments than those on ART, as they should be at a lower stage of HIV infection, have less laboratory testing and require less inpatient care.

Expenditure for HIV care is a substantial financial burden for most of the respondents in Jogjakarta and Jakarta also when compared with overall expenditure on health care in Indonesia. The average monthly expenditure on health among households that had sought medical care, derived from Susenas¹ 2004 data, was Rp 105 101 (US\$12) in Jakarta and Rp 79 433 (US\$9) in Jogjakarta. While Susenas almost certainly underestimates health expenditure, expenditure for HIV care found in this study is almost a hundred times greater than found in Susenas.

While direct comparisons between cities is problematic due to the arbitrary selection of the three cities, the stark contrast between the findings from Jogjakarta and Jakarta and those for Merauke, where respondents spent relatively small amounts out of pocket, and none incurred catastrophic payments, bears stressing. Two factors explain this discrepancy. First, all but one of the respondents in Merauke were covered by Askeskin, a social health insurance scheme where the government pays the premium for poor people, or Askes, a health insurance policy for civil servants. Second, the local government and a local NGO further paid for items not covered under the insurance schemes. Only a few of the respondents in Jogjakarta and Jakarta had any health insurance coverage. Despite reporting, on average, low monthly expenditure, which should make them eligible for coverage under the Askeskin scheme, they did not report that they were, in fact, covered by Askeskin. This is certainly one reason for the high burden of OOP payments for HIV care in these areas.

The payments incurred by younger respondents tended to be greater than those by older respondents. This may be because young respondents include a higher proportion of IDUs than

other age groups. In addition to payments for HIV care, these IDUs might need methadone therapy, costing Rp 15 000 (US\$1.6) per day (personal correspondence with Alice Cowell, 2006), further exacerbating the strain on their financial situation (costs of methadone treatment were excluded from the costs of HIV care in this analysis).

Limitations

This study has several limitations. The cities included in the study were deliberately selected, do not represent the Indonesian situation as a whole, and the results cannot be generalized to all of Indonesia. Recall bias in measuring transport and accommodation costs, as well as the medical costs of Non-ART respondents, could not be verified due to lack of access to patients' medical records. Further, total monthly expenditure is based on respondents' recall, and is likely to be under-reported (Deaton 2004). Thus, for the ART patients, verified expenditure is compared with monthly expenditure that is likely lower than is actually the case, which may overstate the extent of catastrophic payments. However, we have also compared reported health expenditure with reported total expenditure, and the results, although somewhat attenuated, still support the conclusion that there is a high financial burden related to HIV care.

Further, to truly assess the extent to which finance acts as a barrier to accessing HIV care, the relative perceptions and household financial situation of people accessing care should be compared with people who did not access care. However, it is difficult to identify people who are eligible for HIV care and ART who have not sought treatment. This may be underlined by the fact that the majority of respondents in Merauke, which has a large rural catchment area, came from an area within 10 km of the ART clinic. Thus, this study is limited to reporting the observed financial burden among people who are accessing HIV care.

On a related note, the cross-sectional nature of the survey opens the possibility that the results are subject to selection bias. Specifically, there likely is a connection between the amount that people pay for HIV care, their relative economic status and their likelihood of continuing treatment. Thus, people who are poor, have incurred high payments for HIV care or both, are likely to have either never started ART treatment or to have dropped out of HIV care and thus will not have been included in this study. The fact that the Jakarta ART respondents had higher general expenditure, on average, than the Jakarta Non-ART respondents suggests that this might be the case. However, this study cannot definitively answer these questions, and further study, either a comparison of loss to follow-up between sites and/or a cohort study, is needed.

This study assessed financial burden only in relation to total expenditure and did not look at, for example, rates of impoverishment. Further, we did not assess the opportunity costs of accessing HIV care in terms of time or income lost, instead focusing only on directly incurred expenditure. However, opportunity costs may be substantial and have implications in terms of people's ability to access HIV care (Russell 2004; Rosen *et al.* 2007). Finally, although some of the respondents' medical expenditure was incurred before 2006, we

were unable to assess the exact time and could not adjust for inflation. Thus, total expenditure for HIV care reported here may be underestimated in real terms.

Comparison with other studies

Studies done in other countries corroborate that patient-incurred costs can act as a barrier to accessing HIV care. However, there are few data available for Southeast Asia, which would be the most relevant comparator for this study. The only study found was from Cambodia, which suggested that even when drugs are provided free of charge, the significance of the other costs (including laboratory costs, travel costs, paying doctors to ensure correct treatment, etc.) still operate as a barrier to access (Dhaliwal and Ellman 2003).

Experience from other countries supports the argument that HIV care is a serious financial burden on many households with PLHIV. In South Africa, HIV-affected households borrowed more, saved less and sold more assets than unaffected households (Booyens 2002). In Senegal, Ndoye *et al.* (2004) found that the enrolment of new patients in an ART programme tripled after the fall in the international price of ARVs at the end of 2000, indicating that payments limited access to ART. In India, Kumarasamy *et al.* (2005) found that most AIDS patients perceived the cost of ART as a barrier, with many reporting extended drug holidays, turning to family and/or friends, or taking drastic measures (i.e. selling family jewels, property) for financial assistance. An evaluation done by Katzenstein *et al.* (2003) also found that constraints on government expenditure would prevent the public and private sector from establishing equitable access to ART in most developing countries.

Our study adds to this literature by showing that, even if the drugs themselves are free to the patients, other costs can still represent a serious financial burden. This has also been found, to a limited extent, in other literature. A study from South Africa suggest that payments made for transportation can be an important source of patient costs (Rosen *et al.* 2007), and another from Malawi found that higher cost of transport alone is associated with lower patient uptake of ART (Zachariah *et al.* 2006). Neither of these studies assessed the financial burden of payments for accessing HIV care.

The findings from this study also reinforce (but do not conclusively show) findings from other contexts that a high financial burden for HIV care might contribute to lower treatment compliance with ART, since patients may discontinue (or temporarily suspend) therapy if they are unable to pay or they feel they are becoming a burden on their families. One study from Brazil showed that financial constraints were an important patient-reported barrier to adherence to ART (Brigido *et al.* 2001). Financial constraints were also reported to be the most significant barrier to antiretroviral adherence in patients living with HIV and AIDS in Botswana prior to the introduction of free treatment (Weiser *et al.* 2003). A study by Muko *et al.* (2004) found that in Cameroon a majority of patients stopped taking the drugs after 6 months due to financial constraints.

This study does not definitively determine whether the payments for HIV care born by PLHIV do inhibit them from accessing or continuing HIV care in Indonesia, but given the

documented cost and international evidence, this is most likely the case. However, further work is needed to assess the extent to which financial barriers inhibit access compared with other potential barriers (Mills *et al.* 2006). In addition, even when treatment is completely free of charge, meaning in fact there is no financial barrier, a person may be unaware of this, and thus financing remains a barrier *de facto*. In Chicago, for example, it was found that although payment exemptions exist for the poor, they still report that access to services is hindered 'due to cost' (Kenagy *et al.* 2003). While in Indonesia patients may similarly be unaware of the government insurance scheme for the poor and the subsidy for ARVs and thus choose not to access care, complete removal of cost-related barriers to HIV treatment, and public awareness thereof, is likely to increase access and adherence.

Conclusion

Although Indonesia has had a policy to provide free ARVs since 2003, this study indicates that seeking care for HIV/AIDS is still a financial burden to patients. The fact that the proportion of HIV care expenditure constituted well over 50% of reported monthly expenditure in Jogjakarta and among Jakarta ART respondents supports this conclusion. While there are also non-financial barriers to access, the evidence found in this study suggests that financial issues remain a problem for many PLHIV in Indonesia and that some PLHIV do not have financial access to comprehensive HIV care.

Given the magnitude of OOP payments found here, the government's policy to subsidize HIV care should be examined more closely. Further, this study also reveals that PLHIV who are not yet on ART do have to make payments for health care. This may result in exhaustion of financial resources early in the course of infection and inhibit regular follow-up. Thus, for example, the financial subsidy from the government could be extended from ART drugs to other components, such as drugs for treating opportunistic infections and medical examinations and laboratory tests to monitor HIV infection and treatment. Local governments' role in providing financial assistance to PLHIV should also be strongly encouraged. Health insurance programmes, especially social health insurance, should clearly cover treatments related to HIV/AIDS, although they do not necessarily need to cover ART drugs (which are already provided by the government). Further, organizations working with PLHIV and the government should encourage eligible PLHIV to enrol in social health insurance schemes.

This study also adds to the international literature on the effects of patient payments for services and treatments related to HIV care. Several studies, discussed above, have already found that these payments contribute to lowered access and treatment compliance. This study only suggests that this is also true in Indonesia. However, developing countries aiming to provide universal access to HIV care need to seriously consider the impact of charging patients for these services, in relation to the sustainability of the programme, if they are to meet their goals.

Endnotes

¹ Susenas is a national socio-economic household survey representative at the provincial level.

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Conflict of interest

The authors hereby state that during the study and report writing had no conflict of interest whatsoever.

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