

# Direct costs of health care for HIV/AIDS patients in Belgium

R. C. DECOCK,<sup>1</sup> A-M. E. DEPOORTER,<sup>1</sup> D. DE GRAEVE<sup>2</sup>  
& R. COLEBUNDERS<sup>3</sup>

<sup>1</sup>Department of Public Health, Free University, Brussels, <sup>2</sup>University of Antwerp (UFSIA) &

<sup>3</sup>Prince Leopold Institute of Tropical Medicine, Antwerp, Belgium

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**Abstract** *The cost of HIV/AIDS care was measured in Belgium in 1996. This paper is concerned with direct costs (formal and informal care). This is a prospective study, stratified by CDC-disease stage. A societal point of view was chosen. Eighty-two sequential patients agreed to join the study during outpatient visits. Data on service use and costs were obtained through a care-cost diary kept over three months. Half of the patients (41) returned a completed diary, which reduced the sample size considerably. Additional billing data were obtained from different sources and by calculating the time spent for certain services. In stage A (asymptomatic HIV), the mean ( $\pm$  SD) annual total direct costs are US\$2,373 (2,079), rising to US\$8,401 (7,520) in stage B (symptomatic HIV) and ending up at US\$27,373 (22,087) in stage C (full blown AIDS). A difference in balance of costs at different stages of disease was observed. The principal cost of outpatient pharmacotherapy in HIV patients is overtaken by the cost of hospitalization in AIDS patients. The cost of informal care is considerable (40% of the total cost) from stage B onwards. Health care use and costs increase with severity of illness.*

## Introduction

HIV has remained a major public health problem in Europe, including Belgium. In western Europe, it is estimated that about 500,000 persons are currently living with HIV. This number might increase in the medium term as a result of new antiretroviral treatment delaying the onset of AIDS and the progression from AIDS to death. This supposes a stable incidence rate, as is the case in Belgium. In 1996, 21,607 AIDS cases were recorded in western Europe (Hamers *et al.*, 1998). By the end of 1996, 7,325 HIV patients and 619 living AIDS patients were registered in Belgium since the onset of registration in 1987 (Sasse *et al.*, 1997). The socio-economic consequences of the disease have become gradually visible. Treatment and care are generating considerable expenses. In earlier treatment estimates (during the 1980s), yearly hospital (and outpatient) expenses for AIDS patients varied between US\$46,235 to US\$67,416 in the USA. European data ranged from US\$33,228 to US\$50,130 (Drummond & Davies, 1988). More recently, costs between US\$20,005 (Rietmeijer *et al.*, 1993) and US\$31,237 (Andrulis *et al.*, 1992) in the USA and US\$25,818 in the

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Address for correspondence: Dr R. C. Decock, Department of Public Health, Free University Brussels, Laarbeeklaan 103, 1090 Brussels, Belgium. Tel: 32 2 477 4725; Fax: 32 2 477 4219; E-mail: amdepoor@gesg.vub.ac.be

Netherlands (Borleffs *et al.*, 1990) were measured for the same services (all prices are converted to 1996 US\$). These studies show several limitations, e.g. partial measurement of direct medical costs including only costs of hospitalization and medical consultations, predominantly based on medical records and hospital data-bases, mainly AIDS patients, mostly retrospective or cross-sectional studies, the use of a study population in only one centre, etc.

The main goal of this study was to overcome the shortcomings of other studies and to explore an innovative methodology to measure the total costs of HIV as well as AIDS in a prospective way and from a societal point of view. In this broad perspective, all costs, whoever pays, are taken into account. They include direct costs for formal care (provided by professionals, consisting of a medical and psychosocial part, e.g. consultations, hospitalizations, diagnostic investigations, outpatient medication, counselling, social assistance, etc.), as well as costs of informal care (care provided by volunteers belonging to an organization and by relatives-primary caregivers).

## **Materials and methods**

### *Methodology*

In order to achieve the objective a *prospective approach* was opted for. The *main* information source was the *individual affected by HIV/AIDS*. He/she is the best informed about the kind and the amount of care provided. A care-cost diary method was chosen as the most appropriate information source, complemented by a short questionnaire and review of medical records and additional billing data. A period of three months was considered to be necessary in order to extrapolate to a one-year period and feasible for the patients.

### *Population*

The objective and the method make the choice of a representative population sample impossible because of the major contribution of the patient to provide data. Patients were recruited consecutively by the consulting physicians during outpatient consultations in the AIDS referral centres with the largest HIV/AIDS population in Antwerp (Institute of Tropical Medicine) and Brussels (St Pierre) and in some of the practices of specialized GPs. One or two physicians per centre were involved in the recruitment. The disease stage was classified by the physician according to the then latest (1993) revised classification criteria from the Centers for Disease Control and Prevention (CDC) (Castro *et al.*, 1992). The inclusion criteria were: having been diagnosed as HIV-infected more than six months ago and being able to keep the diary for three months.

### *Procedure*

Interested individuals were immediately sent to a research assistant, present during consultation hours, for further motivation and interview with the aim of gaining their confidence and obtaining sociodemographic data. A 'cost-care-diary' was handed over and the way to fill it in was explained in detail, verbally and in writing. Later on, regular phone calls or personal contacts with the responders were performed to support them in order to carry on till the end of the required three-month period.

### *Assessment of costs*

Every caring provision was to be registered by the patient. The researcher and the research assistant sorted out those actions for sickness not related to HIV/AIDS. Total expenditures were used to value actions. When expenditures were lacking, conversions were done on the basis of prices and tariffs, the bills provided by the hospital financial offices, by the sickness insurance funds, by pharmacists, etc. Time spent for services such as psychosocial support by professionals was converted using a mean salary (gross salary plus the employers' contribution to social security).

Time costs of non-professionals were evaluated on the basis of shadow-prices as no market prices exist for them. We opted to equate the value of time to a market wage for home working services (David, 1995; Drummond *et al.*, 1997). For *volunteers* (belonging to an agency), a mean salary (gross salary plus a employers' contribution to social security) of an individual with a high school level (minimum requirement for certain activities) has been used. For *primary caregivers* (relatives/friends), a gross salary and the employers' contribution to social security of a home-assistant (domiciliary care worker) has been used at 50% only. Half of the salary was chosen because the value of the time used by a non-professional might be lower (less efficient) than the time value of a professional.

No further explanatory analyses were undertaken to explore the effect of different estimates of the time cost of non-professionals, as it was felt that the minimum cost was used and other estimates only could have increased the cost of informal care.

Most of the data were collected during the year 1996 or shortly before, in a period in which the costly tri-therapy still was on an experimental basis, and the investigation of the viral load and the use of a measurement for viral resistance was not yet routinely applied. In order to compare our results with those in the international literature, where costs are mainly expressed in US\$, Belgian prices (francs) were converted into 1996 US\$ using purchasing power parity<sup>1</sup> by the (US) GDP price index.

Costs are expressed as means ( $\pm$ SD) because this is almost exclusively used in the international literature. The medians (and interquartal range-IQR) are also shown because this is the most appropriate expression with skewed cost and usage data.

### *Statistical analysis*

All statistical calculations were performed using SPSS 9.0. First, cost and usage frequencies were performed. To study which variables are the best predictors of direct costs, a stepwise multiple regression analysis was performed upon a logarithmic transformation of direct costs. The independent variables consisted of a set of demographic (age, sex, sexual inclination, province), medical (stage, CD4 cell count), social (living circumstances, education) and financial (income, additional insurance) factors.

## **Results**

### *Response*

Overall, 82 individuals were willing to participate. At the end of a three-month period, 41 returned a fully completed diary with reliable data (50% response by the respondents). The reasons for non-completion of the diary after initial consent were: loss to follow-up (12), death (11), major social problems (9), sudden deterioration of health status (4), fear about lost privacy (4) and leaving the country (1).

**Table 1.** Mean (SD) and median (P25, P75) resource use and cost (in 1996 US\$) per person per three-month period according to disease stage

Stage	Usage		Cost	
	Mean (SD)	Median (P25, P75)	Mean (SD)	Median (P25, P75)
<b>Stage A</b>				
<i>Formal care</i>				
Hospitalization	0	0	0	0
Consultations	2.5 (2.2)	2 (1, 4)	49 (45)	32 (23, 76)
Investigations	1.8 (0.9)	2 (1, 2)	97 (77)	75 (45, 98)
Medication	2 (3.2)	1 (0, 3.8)	355 (524)	31 (0, 859)
Psychosocial care**	3.4 (11.2)	0 (0, 0)	34 (21)	0
Diet products	0.1 (0.3)	0	1 (5)	0
Transport			24 (38)	3 (2, 38)
Other	0	0	0	0
<i>Informal care</i>				
Volunteers**	0.5 (1.2)	0	5 (11,4)	0 (0,0)
Relatives-friends**	10.6 (29.7)	0	56 (156)	0 (0,34)
<b>Stage B</b>				
<i>Formal care</i>				
Hospitalization	0.09 (0,3)	0 (0, 0)	245 (812)	0
Consultations	6.6 (9.4)	3 (3, 7)	102 (139)	56 (33, 115)
Investigations	2.5 (1.9)	2 (1, 3)	114 (115)	90 (0, 206)
Medication	7.3 (4.5)	6 (5, 10)	632 (556)	822 (73, 1043)
Psychosocial care**	6.4 (19.2)	0 (0, 2)	29 (97)	0 (0,0)
Diet products	0.6 (1.0)	0 (0, 1)	9 (17)	0 (0, 13)
Transport			18 (25)	7 (1, 23)
Other			33 (73)	0 (0, 0)
<i>Informal care</i>				
Volunteers**	29.6 (72.2)	4 (0, 9)	272 (664)	32 (0,78)
Relatives-friends**	125 (152)	64 (0, 273)	656 (798)	336 (0,1431)
<b>Stage C</b>				
<i>Formal care</i>				
Hospitalization*	1,2 (4,95)	0 (0,0)	2627 (4461)	0 (0, 4490)
Consultations	8 (7.2)	6 (3, 13)	141 (95)	113 (75, 205)
Investigations	4.8 (2.8)	4 (3, 7)	236 (187)	211 (65, 346)
Medication	9.9	11	1045 (527)	1085 (726, 1461)
Psycho-social care**	8.9 (20.2)	0 (0, 6)	119 (311)	0 (0, 102)
Diet products	6.5 (21.0)	1 (0, 2)	59 (116)	8 (0, 65)
Transport			51 (85)	32 (3, 61)
Other			38 (136)	0 (0, 9)
<i>Informal care</i>				
Volunteers**	30,2 (91.1)	0 (0, 3)	278 (838)	0 (0,30)
Relatives-friends**	428.8 (560.6)	110 (8, 1083)	2248 (2939)	579 (40, 5679)

\* Including day hospitalization; \*\* Expressed in hours, the other items are expressed in numbers (bills or real prices) SD standard deviation; P25, P75: 25th and 75th quartile.

#### *Population and disease characteristics*

Thirty-three were men (88% homosexuals), 14 were highly educated, the mean age was 38 years (SD years), nearly all were infected through the sexual route (three patients had a history of drug abuse) and 12 were living alone. Twenty-three lived in the province of

**Table 2.** Mean (SD) and (median) yearly total direct costs according to stage in 1996 (in 1996 US \$) and share of informal care

Cost component	Stage		
	A (n = 12)	B (n = 11)	C (n = 18)
Formal care	2,133 (2,168) (1,027)	4,687 (4,595) (3,560)	17,268 (18,710) (8,374)
Informal care	240 (666) (0)	3,714 (4,852) (1,342)	10,105 (11,577) (5,176)
Mean total direct costs	2,373 (2,079) (1,833)	8,401 (7,520) (3,882)	27,373 (22,087) (23,933)
Informal/total direct costs (%)	10	44	37

Antwerp, the majority of the others in Brussels. They were all from European origin except two patients from Subsaharan descent. Twenty-nine patients had an additional sickness insurance. Twelve patients were asymptomatic HIV (stage A), 11 symptomatic HIV (stage B) and 18 full-blown AIDS (stage C).

Our population fits the comparison for some characteristics (age, gender, infection route) with the 1996 figures of the Belgian HIV/AIDS register completely, but it has more individuals in an advanced stage ( $p = 0.008$ ). None of the 41 patients changed their stage during the study period.

#### Usage and costs

Table 1 shows that the mean and median resource use and costs are increasing with advancing disease stage. The inter-individual variation in both health service use and costs is great (SD, IQR) in all stages. A positively skewed distribution of usage and costs, where few people share the highest use and expenses, is shown by the median values (except for medication).

The non-medical usage (diet, transport) and costs are negligible, they will further not be discussed.

*Total direct costs.* Table 2 shows that the mean yearly total direct costs are US\$2,373 in stage A, rise to US\$8,401 in stage B and end up at US\$27,373 in stage C. The median values confirm the already mentioned skewed distribution.

#### Cost components

*Direct cost: share of formal and informal care by stage (Table 2).* In stage A the cost of informal care is 10%. In the stages B and C the informal costs are about 40% of the total direct costs.

*Direct formal costs: share of components (Figure 1).* The direct formal costs are mainly composed of pharmacological outpatient treatment, investigations, consultations and hospitalizations. Outpatient drug costs comprise 63% of formal costs in stage A, 53% in stage B

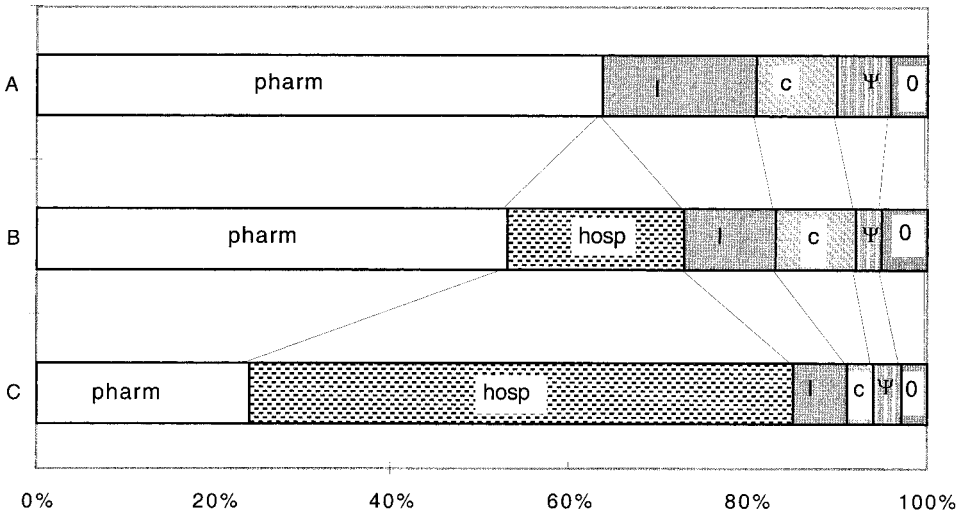


FIG. 1. Relative distribution (%) of formal costs of HIV/AIDS by stage in Belgium, 1996. *c* = consultations, *hosp* = hospitalization, *i* = investigations, *O* = other, *pharm* = pharmaca,  $\Psi$  = psychosocial care.

and 24% in stage C, whereas hospitalization costs account for 20% in stage B and 60% in stage C.

There was a small number of hospitalized patients: only one patient in stage B and six in stage C. The mean hospital duration in our study was seven and 28 days for HIV and AIDS patients, respectively.

*Total direct costs: relative importance of the five most important items (Figure 2).* In stage A the expenses on pharmaca are the most important (57%), followed by investigations (16%), while the support by relatives takes third place (9%). In stage B care by relatives takes the first place (30%), followed by pharmaca (29%) and care by volunteers (15%). In stage C care by relatives (32%) comes immediately after the cost of hospitalization (38%).

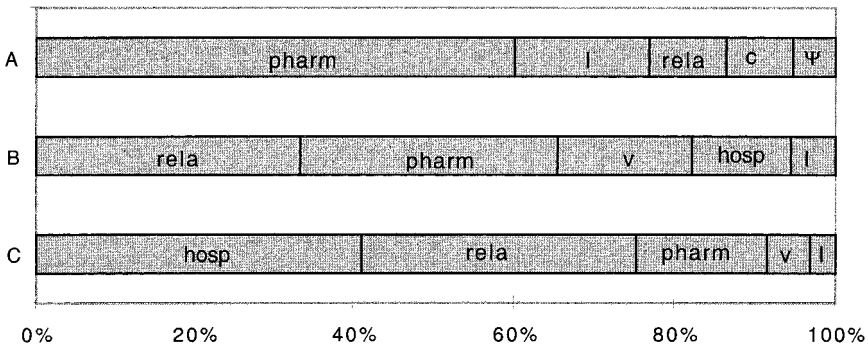


FIG. 2. Relative distribution (%) of the five most important items in total direct costs of HIV/AIDS by stage in Belgium, 1996. *c* = consultations, *hosp* = hospitalization, *i* = investigations, *pharm* = pharmaca, *rela* = relatives, *v* = volunteers,  $\Psi$  = psychosocial care.

**Table 3.** Mean annual cost of formal care for AIDS patients in studies where the patient was the central informant (in 1996 US\$).

	Benett <i>et al.</i> 1987 ( <i>n</i> = 36)	Hellinger*• 1992 ( <i>n</i> = 784)	Hurley <i>et al.</i> *•◆ 1992–1993 ( <i>n</i> = 128)		Decock <i>et al.</i> • 1996 ( <i>n</i> = 18)
			Alive ( <i>n</i> = 40)	Died ( <i>n</i> = 16)	
Cost	67,613	36,404	60,783	175,276	17,269

\* Expressed in average monthly costs, transferred to annual costs through multiplying by 12; • a diary method included; ◆ expressed in Australian dollars, the purchasing power parity for conversion of US medical costs to Australian dollars is about 1 (Hurley *et al.*, 1995; 1996).

### Statistical analysis

The Kruskal-Wallis non-parametric test was used to compare the mean direct costs between the three stage-groups. Overall, a significant difference was found ( $p < 0.001$ ).

A stepwise multiple regression analysis confirmed a significant relation between stage (HIV and AIDS) ( $p < 0.001$ ,  $\beta = 0.0569$ ) and mean direct cost. Stage explained 33% of the variance. Another 6% was explained by having an additional insurance ( $p = 0.029$ ,  $\beta = 0.279$ ). In this small sample, no effect of age and sex on direct costs could be demonstrated.

## Discussion

### Methodology

Our study contains the first comprehensive and detailed description of health care costs for HIV-infected people in Belgium. The main relevance of our study lies in the balance of costs and usage at different stages of the disease. It is different from most other studies in several aspects. Its prospective nature ensures a high validity of the survey method and shows a more accurate reflection of current resource use and costs (Postma *et al.*, 1993). A bottom-up approach, taking the individual patient with HIV/AIDS as the central informant, allows the direct and precise measurement of all relevant care components (including informal care) during a given time period (Tolley & Gyldmark, 1995).

There are definite limitations. The recruitment of the sample of patients, the small sample size and the low response rate make it difficult to extrapolate our findings to the whole HIV population in Belgium. It was impossible to calculate the life-time cost from the restricted follow-up period.

The use of a diary method is fairly innovative but requires a huge involvement by the study population as well as by the researchers. The advantages of the diary method are the inclusion of more extended provisions outside hospital and outpatient clinics and the visibility of informal care. The disadvantages of the diary method are the difficulty to use it at the start and at the end of the disease (ethically questionable towards individuals who are overwhelmed by their diagnosis or towards terminal patients). These two phases are the most costly. Initial costs were about twice as high compared to chronic costs (Scitovsky *et al.*, 1986). Most studies, looking at life-time costs, show a three- to five-fold increase of costs during the terminal phase, especially during the last six to three months (Hellinger *et al.*, 1994; Postma *et al.*, 1992; 1998; Scitovsky *et al.*, 1986; Solomon & Hogan, 1992; Solomon

*et al.*, 1989). An underestimation of our costs is almost certain, mainly because of the absence of terminal hospital costs.

The diary method is not sufficient on its own: a lot of bills in financial bodies need to be traced. Self-reported data on costs might not be accurate. Our data were validated through comparison with medical provider reports, which showed them to be correct, and by scrutinizing all billing data collected by patients.

The use of the CDC classification is probably the most scientific approach for disease staging and is mostly used. It has also limitations. The course of illness is unpredictable (acute deteriorations even in a period of three months) and the definition might change over time.

Assuming that each patient shows a stable caring pattern during the three months of observation, we assumed this period sufficient to extrapolate to a whole year.

#### *Calculation methods used*

Current market prices of different resource input are the best reflection of real cost (Postma *et al.*, 1993). However, they are not available in the medical care market in Belgium. It has been recognized that, owing to the imperfections in health care markets, market prices may not reflect opportunity costs (Drummond *et al.*, 1997). Official prices were used for the costs of medication and psychosocial support. For hospital and outpatient expenses charges were taken, although they inadequately reflect the specificity of HIV/AIDS care. Hourly payment rates would have been a better measure, but are not possible in the Belgian system.

#### *Results*

*Absolute direct costs and analysis of formal cost components.* HIV/AIDS is generally considered a costly disease. In our study, the mean annual cost (including informal care) was about US\$12,716 for a HIV patient (weighted average of the two stages) and US\$8,029 for formal care alone which is less than the mean annual formal treatment cost of US\$10,135 for a schizophrenia patient in Belgium, using a similar method (De Hert *et al.*, 1997). Both diseases can be compared as they mainly affect young people, have a chronic and unpredictable course and require a high hospitalization usage.

The mean cost of formal care for an AIDS patient was US\$17,268. Only few studies used the individual patient as the central informant (Bennett *et al.*, 1991; Hellinger, 1993; Hurley *et al.*, 1995) (Table 3). They show much higher costs (between US\$36,404 and US\$175,276). All cost calculations were based on patient interview, most used an additional diary system and all were verified by medical records. Differences in health care systems and usage (lower inpatient utilization and lower drug use in Hellinger's study), cost analysis (different cost components), patient mix (in- or exclusion of early and/or terminal patients), setting and time periods may explain the divergent results. The accuracy in data collection varies considerably. For our study there exists the already mentioned underestimation due to the fixed time period with left and right censoring. Another study, based on medical records, using a fixed time period, estimated an average cost of US\$17,567, which is very similar to our findings (Solomon & Hogan, 1992). Hospitalization costs might be further underestimated partly due to the recruitment method (during outpatient visits) and partly because of the small number of hospitalized patients.

In our study, ambulant drugs comprised 63% of total direct formal costs in stage A but only 24% in stage C, whereas hospitalization costs corresponded to respectively 0% and 60% in stage A and C. A similar finding was recorded by Hurly *et al.* (1995), where drugs



comprised 57% in phase 1 (CD4 count > 500) and 32% in AIDS patients, whereas hospitalization costs comprised 10% and 60%, respectively. Pharmaca have become an important cost component among formal care expenses, respective in the first place in HIV patients and in the second place in AIDS patients, second to inpatient costs. A similar finding was demonstrated in a recent study (between June 1995 and September 1996) (Perdue *et al.*, 1998).

One can argue that our study might be of limited value in relation to current health care costs as treatment changes quickly. These changes in care pattern and epidemiology are shown in a recent French study of 7,749 patients in ten centres followed from September 1995 to October 1996. A drop in hospitalization days by 35%, new AIDS cases by 35%, deaths by 46% and an increase in the proportion of patients receiving antiretrovirals, including highly active therapy, was found. Overall, only a slight increase of overall monthly treatment cost of US\$12 was demonstrated (Mouton *et al.*, 1997). In our study, the price of protease inhibitors and lamivudine and stavudine were not calculated because these drugs were given for free at the time of the study. If a shadow-price is used (based on 1997 prices) mean annual medication costs increased with US\$2,277 in stage C, which does not essentially influence the medication share on direct formal costs. Recent care patterns do not seem to increase costs considerably.

#### *Relative costs*

*Formal care: informal care.* For the stages B and C, informal costs are high, about 40% of the total direct costs. These costs increased with disease stage, and were twice as much for AIDS patients compared to HIV patients. In the UK, a similar trend of increasing costs of home care (informal carers, volunteers and home helps) were found, but the cost for AIDS patients was almost four times the cost for HIV-patients (Hull-York Research Team, 1993). Differences in cost components, patient mix, time and place (organization) should be taken into account. In our study, respectively one-third, one-half and almost all of patients in the successive stages made use of informal home care. Is this a cost or a benefit for society? Informal care withdraws conscription of labour from alternative productions. Some people spend all their free time or part of their working time caring for the patient. Informal psychosocial care will most probably remain important, even when the disease becomes more chronic and less severe.

#### **Conclusion**

Our study showed a reasonable cost of treatment and care for HIV/AIDS patients. The costs related to informal care are relatively high. Our cost estimates were far less compared to other (mainly American) papers. Comparisons are difficult not only due to differences in time, place and persons, but especially due to a difference in methodology. It is important to report the methods of cost studies in considerable detail and ensure validity of international and temporal comparisons. Otherwise, cost-of-illness studies might be fiction rather than fact (Rice, 1994). Disease stage needs to be included and standardized. In our study we have demonstrated that it is possible to get good detailed data from the individual themselves, but it is a huge and time-consuming task. A low number of patients will succeed if the follow-up period extends to several weeks. Other sources still need to be consulted. The diary method gives a more realistic picture of the different cost components, but only for a restricted number of patients and a fixed time period in the natural course of the disease. The most comprehensive approach to cost studies in HIV/AIDS patients is the combination of prospec-

tively collected different data sources such as a hospital and outpatient database, medical records and interviews at regular time intervals with the help of a log book. In this way, life-time costs can be accurately calculated.

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### Note

[1] The PPP exchange rate for 1996 amounted to 37.19 BEF = 1US\$.

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