

Indirect Costs in Ambulatory Patients with HIV/AIDS in Spain

A Pilot Study

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Abstract

Objective: To estimate indirect costs in Spanish ambulatory patients with HIV/AIDS and to identify changes in employment status and their current QOL.
Method: Information was obtained through 32 interviews/enquiries carried out with ambulatory patients receiving medical attention at Gregorio Marañón and Puerta de Hierro hospitals in Madrid, Spain. The study variables included information on sociodemographics, economics, and clinical and QOL (EuroQol instrument; EQ-5D) parameters of these patients.
Results: Our main result showed the existence of high indirect costs (lost income and lost wages; 2002 values) at the individual level. We identified a strong effect in terms of income losses (the annual loss of income ranged between €5271 and €6150 per patient) and lost wages (the annual loss of wages ranged between €7537 and €8793 per patient). We also observed a strong impact on household income (the annual loss of household income ranged between €6693 and €7813). There was a great variability in these costs among the patients depending on their QOL, gender and education. We detected a statistically significant and positive correlation between QOL and having a job.
Conclusions: We observed a high level of QOL among the patients, which reflects the potential benefits of pharmacological treatment. We found that the better the QOL, the higher the probability of being employed. However, indirect costs were high among patients despite their good QOL.

Since the discovery of HIV at the beginning of the 1980s and its manifestation as a syndrome of human immunodeficiency, it was perceived that HIV/AIDS was bound to be one of the most important health problems in the twentieth century.^[1] Unfortunately, these suspicions were founded.^[2] HIV/

AIDS has an appalling effect on population health. It also represents further socioeconomic problems for individuals, families, communities and governments throughout many countries.^[3-6]

In Spain, since 1981 more than 58 000 cases of AIDS have been recorded, with a death rate of

55%.^[7] A recent survey estimated the number of patients with HIV infection to be 120 000 in this country.^[8] The high total number of cases and the outstanding cost of treatment render HIV infection as one of the priority targets of health policy. In developed countries, medical advances in recent years have not resulted in a definitive cure, although they have allowed an improvement in the QOL of the patients, as well as a delay of the terminal phase of this illness. The majority of patients with HIV infection are working-age people (75% being between the ages of 25 and 39 years),^[9] who, until recently, were forced to quit the labour market because of their illness. Pharmacological advances are now allowing patients to remain in the work force for longer.

Most of the economic studies in this area have determined direct costs only.^[10-17] However, an ideal study should identify and assess total costs. Given the inherent difficulties when valuing costs associated with pain and incapacity (intangible costs), valuation of these costs in monetary terms does not seem appropriate. Economic assessments incorporating costs associated with productivity losses (indirect costs) are more common in health economics literature.^[18,19] The scarce analysis carried out in this area reflects the importance of these costs.

A recent study conducted in Switzerland^[20] measured the cost-effectiveness ratio of highly active antiretroviral therapy in patients with HIV/AIDS. The outcomes showed that, just considering direct costs, this kind of treatment does not represent an excessive cost compared with cost-effectiveness studies performed for treatments for other illnesses. The cost-effectiveness ratio was 33 000 Swiss francs (SwF; 1 SwF = \$US0.67) [base case], SwF14 000 (optimistic), and SwF45 000 (pessimistic) per year of life gained. When changes in productivity were included, cost savings occurred in the base-case and optimistic scenarios. The cost-effectiveness ratio was SwF11 000 per year of life gained

in the pessimistic scenario.^[20] Other recent work

estimated that the cost-effectiveness ratio ranges from \$US13 000–23 000 per QALY gained.^[21]

Studies assessing indirect costs are quite scarce in the international field. We are not aware of any such studies on patients with HIV/AIDS in Spain. The goal of this pilot study was to test the suitability of a survey for estimating HIV/AIDS indirect costs in a larger population. The objectives were to (i) identify job changes among patients from the time they were diagnosed with HIV infection; (ii) quantify changes in employment on their individual and household incomes; and (iii) identify the current state of their QOL.

Methods

The Survey

The survey was divided into five blocks of well-differentiated questions: (i) personal data on age, gender, educational levels, etc.; (ii) data on time spent travelling to, waiting for and receiving health-care; (iii) clinical data (CD4+ cell counts, viral load, pharmacological treatment received, etc.); (iv) QOL data (EuroQol instrument; EQ-5D); and (v) data on labour activity and individual and household incomes. The survey was administered by survey-research qualified staff. The variables are presented in table I.

After several meetings with clinical staff in Gregorio Marañón and Puerta de Hierro hospitals in Madrid, Spain, it was decided to focus the survey on those people receiving ambulatory care and to conduct the interviews at the place where the patients received their medication, at the time they collected it. This had the advantage of capturing the largest group of patients with HIV attending the specialist, with a tendency toward growth in the near future. The mechanisms for selecting patients were as follows:

- In the Puerta de Hierro hospital, the doctor informed the patients about the aim of this study. Only 30% of the patients refused to participate in the study.

- In the Gregorio Marañón hospital, a double selection procedure was used: (i) the doctor informed the patients about the aim of the study; and (ii) the patients were informed about the study by the

medical staff of the pharmacy. From the first procedure, 70–80% of the patients refused to participate in the study. From the second procedure, 40–50% of the patients refused to participate.

The patients were selected for a period of 3 weeks. Those individuals who participated completed all the questions. Our experience with the interviews pointed out that the men were more reluctant to answer questions than the women. Furthermore, the fact of having roughly the same number of individuals of both genders implies a bias, since more men are infected with HIV infection than women. Owing to the high percentage of patients that refused to participate, we cannot reject the possibility of a selection bias.

Economic Model

We differentiated between wage losses and income losses. The function of income loss was defined as: income loss = gross income when HIV infection was diagnosed – gross income when the individual was interviewed. Therefore, we dealt with differences between, on one hand, the sum of incomes from labour, benefits and other sources of income available to the patient when he/she was diagnosed with HIV infection, and, on the other hand, the sum of incomes when he/she was interviewed.

Several patients were granted benefits, which act as buffers for lost income. From the societal point of view, one valid indicator of the indirect costs associated with an illness is the loss of productivity caused by that health problem. The human capital theory was used for the identification and measurement of indirect costs. Based on this approach, and under some assumptions, losses of productivity can be related to losses of wages.^[22-25] Therefore, patients were asked about their gross wage. From a theoretical point of view, the loss of wages can be divided into two components: $P_w = P_{prod} + D$ with

P_w being lost wages, P_{prod} lost productivity for illness and D lost wages for discrimination in the labour market against these patients. Unfortunately, it is difficult to identify and measure the latter factor. Therefore, in this study, we simplified the definition as follows: lost wages = gross wages when HIV infection was diagnosed – gross wages when the individual was interviewed.

So, we have (equation 1):

$$P_i = I_0 - I_1$$

and (equation 2):

$$P_w = W_0 - W_1$$

with P_i being the loss of income, W_0 and I_0 wages and incomes, respectively, when the individual was given an HIV diagnosis and W_1 and I_1 wages and incomes when the individual was interviewed and where:

- if the individual was working both in the past and in the present $P_w = P_i = W_0 - W_1$
- if the individual was working in the past but not in the present ($W_1 = 0$), then $P_w = W_0$
- if the individual was working neither in the past nor in the present ($W_0 = 0$), then $P_w = -W_1$.

The total cost comes from the sum of the direct costs, productivity losses and intangible costs. In this context, benefits are seen as transfers from the public sector or from non-governmental organisations to patients with HIV.^[26,27] So, benefits are important from the individual point of view, but not from the societal point of view.

We analysed the main relationships between the variables. For this purpose, we used Spearman and the Pearson statistics. We used the former statistic, when dealing with discrete variables, and the latter with continuous variables (table II).

Results

Table I presents the characteristics of the population under survey. The EuroQol instrument was used to determine the patients' QOL; scores were,

on average, 0.75 out of 1. The analysis of correlation (table II) found a positive and statistically significant relationship between QOL and CD4+ cell counts and a negative one (not statistically significant) between QOL and viral load levels.

Ninety-four percent of the sample received a treatment regimen consisting of three or more drugs, while the rest received two-drug treatment. Every patient took an average of 11 tablets (SD ± 4.3), with several patients needing about 20 tablets per day. About half of the individuals admitted to having problems complying with the medication regimen. These problems were related to an excessive number of pills, difficulties with complying with timetables and/or adverse effects.

Another relevant aspect of this illness, in terms of QOL, arises from limitations in the patient's daily activities and from the public (or home) care he/she receives. As expected, there is a negative relationship

between QOL and limitations in daily activities, i.e. the better the QOL, the fewer the limitations (table II). The issue of homecare costs was not directly assessed in this study, nor was it an important subject which should be considered with a larger population sample.

Forty-seven percent of the sample were wage earners, 9% were self-employed, 28% received benefits and 9% were students. Thus, more than 50% of the population were working and 30% received a benefit. The relationship between QOL and having a job at the interview was positive and significant, whereas receiving a benefit had the opposite effect on QOL (table III).

Of those who were currently unemployed, 79% were employed when they were diagnosed with HIV infection, while 21% were not. What is most remarkable is how quickly those previously em-

Table III. Relationship between QOL and current employment situation

EuroQol instrument	Current employment situation (no. of patients (%))	total
Not working	working	
0–50	5 (100)	5 (100)
51–75	8 (72.7)	3 (27.3)
76–100	1 (6.3)	15 (93.8)
Total	14 (43.8)	18 (56.3)

ployed lost their jobs: 82% lost their job the same year they received the diagnosis, 9% lost their job 2 years later and another 9% kept their job for 4 years. There did not seem to have been a significant change regarding this situation. That is, patients lost their jobs almost immediately both in 1989 and in 1995 or even in 1999.

When current income was compared with income earned when patients were diagnosed with HIV infection, there was a definite decrease in forms of individual income, individual wage and household income (table IV). We actualised all monetary values to January 2002. The average monthly income when patients were diagnosed with HIV infection was €1225, while the average monthly income when the interview was conducted amounted to €786. Therefore, average monthly individual in-

come losses were €439. The null hypothesis of equality between past and present incomes was tested and rejected; the difference between means was statistically significant.

Losses were higher for males than for females, both in terms of incomes and wages (see table IV and figure 1). This is not a surprising result since, in the Spanish labour market, the rate of employment and wages for males far exceed those of the female population. As for average household incomes, we found significant differences between past household incomes and present ones (table IV). However, the number of comparable cases was small ($n = 19$). Comparisons among past and present households incomes were quite difficult for two reasons: (i) people in the sample were between 29 and 49 years of age – in this age group there are frequently changes in family composition, due to marriage, couples separating, parental home leaving, etc.; and (ii) HIV diagnosis can date back to a period of longer than 10 years during which time a patient's situation at home may have undergone important changes such as those resulting from childbirth, divorces, etc.

The highest losses took place among individuals with low levels of education, while those losses

were not so acute in individuals with secondary or tertiary education (see figure 2). Further research is required to investigate whether a higher level of education allows individuals to keep their jobs or find new jobs, or whether an individual with a higher level of education is able to better defend his/her rights.

Discussion

The high QOL of participants observed in this study was remarkable. The patients' EuroQol score was around 0.75, a stark contrast with the situation some years ago.^[26,27] The participants in this study were aware of their illness for 7 years on average, which confirms that the advent of highly active antiretroviral therapy has led to a substantial decline in morbidity and mortality and an improvement in QOL experienced by patients with HIV.^[26] However, our results are not suitable for generalisation to the whole population. Obviously, the sample is small. However, the typical profile of patients with HIV infection would be close to that of our sample for the following reasons:

- Patients with HIV under ambulatory care represent the highest proportion of the infected population.
- Patients receiving ambulatory care theoretically enjoy a better QOL than those requiring in-hospital care; therefore, our estimations represent a minimum threshold of the economic impact of AIDS.
- HIV infection is increasingly becoming a chronic illness. The data from the sample in this study is, thereby, useful for prediction of future costs.

Another relevant result is that, in spite of good health indicators (such as high QOL scores [EuroQol instrument], high CD4+ cell counts, low viral load levels), income losses are high compared with the Spanish average wage. We must point out that our measurements are based upon opportunity costs in terms of lost remunerated time, not upon

opportunity costs in terms of leisure time.^[24,25,28,29] In our pilot study, annual individual income losses ranged between €5271–6150 and wage losses between €7537–8793. Finally, household income losses (€6697–7813) resulted not only from patients' income losses, but also by the impact of their illness on the incomes of other household members; household income losses were higher than individual income losses. Although this finding suggests that HIV/AIDS affects both the patient's incomes and other family members' incomes, we tested the null hypothesis of equality between means of household and individual income losses, and this difference was not statistically significant.

Equally, it is interesting to note how this loss of income has different effects upon different groups of people, with stark contrast being recorded in terms of education level and gender. For example, individuals with higher levels of education experienced lower income losses compared with people with lower levels of education, while men experienced larger income losses than women both in absolute and relative terms.

QOL was the key explanatory variable in our study (table II). Significant relationships were found

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imply an increase in total direct costs, since other healthcare cost components have been reduced (e.g. hospitalisation costs)^[13,19] On the other hand, in spite of indirect costs continuing to be quite significant, the benefits of reincorporating patients into the labour market are very important both from the individual and the societal points of view. Nevertheless, we should not make the mistake of confusing the costs avoided (whether direct or indirect) through using an intervention with its overall benefits. The most important outcome achieved by the new pharmacological treatments for patients with HIV/AIDS has been to increase both their life expectancy and QOL.

Conclusion

We support that knowledge of indirect costs which patients with HIV/AIDS bear would entail an important advancement in the assessment of the global impact of this illness, in addition to providing relevant information for more suitable planning of social and health services.

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