

COST ASSESSMENT IN PATIENTS WITH HIV/AIDS

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Abstract- The economic burden of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is far greater than its direct medical costs. This study estimated annual indirect costs of the HIV/AIDS epidemic in Islamic Republic of Iran in 2006-2007 from societal perspective. A patient cost diary in sets of six booklets covering a total of 6 months (from October 2006 and followed until March 2007) was developed in order to estimate total indirect resource use. Service costs for HIV-infected individuals were indexed to 2006-2007 prices. Annual indirect costs, consisting of the costs of informal services, lost economic productivity, and other non-medical expenses such as transportation expenditures due to HIV/AIDS illness and treatment were included. Lost production was valued using Human Capital Approach. This study included sixty known and detected HIV positive persons and patients younger than retirement age who had record in HIV Consultant Center of Imam Khomeini Hospital. Annual patient-based indirect costs of HIV/AIDS were US \$ 616.00 (95% confidence interval [CI]: 401.49-830.43), and indirect costs of HIV/AIDS for each person were nearly sixty percent of direct costs in the same year. Also, annual population-based indirect costs of HIV/AIDS in detected cases were US \$ 8,440,000 (95% CI: 5,501,000-11,379,000) and in total estimated cases were US \$ 40,653,000 (95% CI: 26,498,000-54,809,000). As indirect costs have significant portion in total costs of disease, both direct and indirect costs, when obtainable, should be used to assess the economic consequences of HIV infection and treatment interventions.

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INTRODUCTION

By targeting predominantly young and middle-aged adults who are the mainstay of the economy and the principal support of their families, the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic destroys the very fabric of societies and by exacerbating poverty, it makes populations more vulnerable to the spread of HIV/AIDS. The impact of AIDS may be felt as an

immediate shock, as when a family loses a breadwinner, or an organization a key worker. The seriousness of the impact depends not only on the numbers infected and directly affected by HIV, but also on the resources available to cope with the situation, whether at family, community or national level.

Economic evaluation is important with regard to health interventions in world, especially for diseases that have substantial effect on society. The economic burden of HIV/AIDS however, is far greater than its direct medical costs such as hospitalization, physician visits, and prescription medications. Patients, as well as family members and friends, who provide care, incur costs that may not be covered by the government or insurers, include lost wages,

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informal care and support services, housing subsidies, and disability benefits (1).

There is a paucity of studies on the indirect costs of HIV infection in both industrialized and developing countries, with most studies of cost addressing only direct medical costs or including only aggregate estimates of the indirect cost of HIV infection (2). Despite the fact that such studies are few, they demonstrate that significant portion of indirect cost in total costs of disease and sometimes even change the result of costing evaluation (3).

In recent years, the number of people diagnosed with HIV infection has increased substantially and epidemic appears to be accelerating at an alarming trend in Islamic Republic of Iran. According to the last report of Center for Disease Control (CDC) office of Health Ministry of Iran, there were 13702 detected HIV/AIDS people in 2006 (4). However, real total number of infected people is estimated higher. Total estimated people who live with HIV/AIDS in 2006 in Iran according to UNAIDS (United Nations Programmes on HIV/AIDS) reports are 66000 [36000 – 160 000] cases (5).

Currently there is lack of proper information on the use, cost and outcome of HIV service provision in Iran. In recent years, some studies calculate direct cost of HIV/AIDS but there is no study about indirect cost of HIV/AIDS or any other disease. We conduct this study to show not only indirect cost of HIV/AIDS but also registration gaps in Iran. We hope that in this regard, more studies will be done in Iran in the future.

MATERIALS AND METHODS

This study estimated the average annual patient- and population-based indirect costs of HIV infection from societal perspective. There are different perspectives, which we can use to show indirect cost but it is widely recommended that cost studies should be conducted from the societal perspective. From this broad perspective, all costs and savings are considered (6). We calculated the indirect cost for one year so we did not evaluate cost of early death due to HIV/AIDS (7).

We selected 60 cases with simple random method that were alive and in productivity ages. This cross-sectional study included known and detected HIV positive persons younger than retirement age (65 years for men and 62 years for women) who had records in HIV Consultant Center of Imam Khomeini Hospital (one of most important public centers in Iran for HIV positive persons to give free care and medication). Patients were recruited in October 2006 and followed until March 2007. Ethics committee of our institution approved the study protocol before the initiation of study enrollment. We obtained informed consent from all participants. Because HIV/AIDS is a taboo in our society, the patients' records (their names and telephone numbers) were kept confidential.

In this study, we used a cost diary to obtain data from patients. In order to obtain the information as completely as possible, the layout of the diary was designed to be suitable for patients' self-completion. Each patient was given the diary in a booklet form, containing the instructions and a completed form example. We also asked the patients to record only HIV related resources used. The contents of cost diary were obtained from a published study (3). We translate the diary items to Farsi and validate its contents by interview the patients and professional staffs during the pilot phase of study.

Each diary covered a period of up to 4 weeks, in which each column represents 1 week. The patients received the diaries in sets of six booklets covering a total of 6 months. To encourage a high response, prepaid envelopes were provided in order to send the first three booklets back after the 3 months. For any unreturned diaries, the patients were asked with a kind request to return them as soon as possible. At the first interview, the patient received a verbal detailed instruction to fill in the diary at each moment he/she used one of the services included in the diary. The instruction is repeated in writing in each set of booklets and verbally at each face to face interview to encourage prospective reporting of the information. The completed diaries were discussed with the patient during these interviews, to minimize partial responses and missing values. The patient was also asked to bring receipts for

RESULTS

any purchased and bills of expenses that were related to HIV/AIDS to check the information recorded in the diary. After handing back the diaries, the patients were encouraged to complete the next set of diaries.

For pretest before widespread distribution, a group of HIV positive persons were interviewed to verify the clarity and completeness of the diary. Components of the cost diary were costs incurred by the patients and the families, such as hours of paid and unpaid household help, nonmedical expenditures related to HIV/AIDS, and production lost due to illness-related absence, consisting of the numbers of work off days (paid and unpaid) and days lost from housekeeping and other daily activities.

Costs of unpaid help by family or friends were valued using the national minimum wage of 7620 Rials (US \$ 0.82) per hour, according to Ministry of Labor and Social Affairs of Iran (8) as a shadow price in 2006-2007. For this calculation assumptions were based on replacement cost approach (9). Lost production were valued using human capital approach (7) and as we couldn't get national average gross hourly wage and our population usually was working in low wage jobs, we used national minimum hourly wage as a proxy for it. Main dependent variable was indirect cost and in our study the indirect cost consists of three elements: informal care costs (10-11), productivity loss (12-13), and other nonmedical expenditures related to HIV/AIDS for patient such as coping strategies and transportation (3).

Results were analyzed using STATA (version 8). Chi square and *t* tests were used to test differences between groups. We considered *P* value less than 0.05 as significant and confidence interval (CI) was 95%.

The mean age of cases was 33.7 (SD: 8/2) years. The average duration of HIV detection in them was 4.8 years (SD: 5, rang: 1 to 28 years). Numbers of people living in a house with cases were in average 3.5 persons. Nearly 65% of cases had low education (less than 8 years), and insurance's membership proportion was 42% and about 11% had come from other cities to take services. Anti retrovirus drug (ARV) usage rate was 61.5% and employment rate was 53.8%. Injecting drug use (IDU) represents the most prevalent mode of transmission (57.7%). Other information related to samples is shown in Table 1.

At all, cases were absent averagely 46.3 (CI: 18.3-74.3) days per person-year from work due to HIV/AIDS, and in employed patients, this number was 86 (CI: 46.9-125.1) days per person-year.

61.5% of cases were helped by their family and of those, the hours that their family expend were 392.25 (95% CI: 233.90-550.60) per person-year and in all cases this number was 243.85 (CI: 115.28-372.41) per person-year.

The amounts of indirect costs are showed in two ways; first, we calculated patient-based annual cost items and indirect cost, which are demonstrated in Table 2, and then a population-based approach was used to show the total cost that society had to pay for HIV/AIDS epidemic in one year in Iran. If we consider only the detected and registered cases (13702 persons), result is similar to Table 3 and if we consider total estimated people who live with HIV/AIDS in 2006-2007 in Iran according to UNAIDS reports (66000 cases), result is similar to Table 4.

Table 1. Comparison of main demographic factors between our study and officially reports of CDC about HIV/AIDS registered people in December 2006 in Iran

| Demographic factor | Our study | CDC Report |
|-----------------------------|--------------------------|---------------|
| Age (Inter quartile range) | 26-41 (years) | 25-44 (years) |
| Sex (%) men | 88.5 % (CI: 70%-97%) | 94.5% |
| Rout of Infection | | |
| IDU | 57.7 % (CI: 36.9%-76.6%) | 64.6% |
| Transfusion | 11.5 % (CI: 2.4%-30%) | 1.8% |
| Sexual | 11.5 % (CI: 2.4%-30%) | 7.4% |
| Unknown | 19.2 % (CI: 6.5%-39.3) | 25.8% |

Abbreviations: IDU, injecting drug use.

Table 2. Annual patient-based indirect costs of HIV/AIDS in Iran (2006-2007 prices)

| | US \$ | Rials Iran |
|--|-------------------------------|--|
| Average patient-based annual informal costs and 95% uncertainty limits | 201.16 (95.10- 307.22) | 1859326.502 (879017.7111 - 2839636.309) |
| Average patient-based annual non-medical expenditures related to HIV/AIDS and 95% uncertainty limits | 109.19 (69.60 - 148.78) | 1009231.154 (643310.1195 - 1375151.357) |
| Average patient-based Productivity loss costs and 95% uncertainty limits | 305.6117 (120.73 - 490.49) | 2824768.943 (1115909.239 - 4533629.572) |
| Average patient-based annual indirect cost and 95% uncertainty limits | 616.00 (401.49 830.43) | 5693326.599 (3710937.871 - 7675715.327) |

Abbreviations: HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.

There was no statistical relation between ARV drug usage and employment rate ($P = 0.75$). In subgroups of ARV drug using patients, there was no significant difference for one year per person total indirect costs ($P = 0.74$) and also in all of the cost items, including informal, productivity costs and nonmedical expenditures with P values of 0.68, 0.46 and 0.44, respectively

Finally there was no different employment rate ($P = 0.95$) and one year per person total indirect costs ($P = 0.62$) between cases that were infected by injecting drugs and other groups.

DISCUSSION

In the context of a cost study, there are various sources to obtain data, such as patient records, data bases from insurance companies, hospital or provider data bases, interviews with patients or providers, questionnaires and diaries (14). In order to yield comprehensive cost data, because there were no routine and institutional records of these expenditures in Iran, we at least partly depend on respondents' recall for collecting this costing data

through self-reporting channels such as questionnaires and diaries.

Compared to questionnaires, diaries have been reported to offer several advantages in terms of feasibility and validity. While questionnaires usually rely on momentary recall, diaries provide information prospectively over a period of time. In a study by Goossens and his colleagues, it was showed how the cost diary might be used successfully in cost studies. They evaluated some aspects of validity, feasibility, period of data collection, and self-reported specialist care contacts were generally in agreement with data from an insurance company (3). In our study, as shown in table 1, the main demographic factors of samples were similar to last report about demographic factors of known HIV/AIDS positive persons in Iran in December 2006, so the recruited patients in current study can be representative of the entire detected and documented HIV positive and AIDS patients in Iran. Hence we didn't know anything about unknown cases in Iran, we assumed that their socioeconomic and disease related factors may be similar to known cases. This assumption may not be necessarily true, and need to be considered why some HIV/AIDS

Table 3. Annual population-based indirect costs of HIV/AIDS in Iran, in detected cases (2006-2007 prices)

| | US \$ (million) | Rials Iran (million) |
|--|-------------------------------|------------------------------------|
| Annual population-based informal costs of HIV/AIDS | 2.756 [1.303 - 4.209] | 25476.5 [12044.3 - 38908.69] |
| Annual population-based non-medical expenditures related to HIV/AIDS | 1.496103 [.9536 - 2.038] | 13828.48 [8814.63 - 18842.33] |
| Annual population-based Productivity loss costs of HIV/AIDS | 4.187 [1.654 - 6.721] | 38704.99 [15290.19 - 62119.79] |
| Annual population-based indirect costs of HIV/AIDS | 8.440 [5.501 - 11.379] | 78009.97 [50847.28 - 105172.7] |

Abbreviations: HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.

Table 4. Average and 95% uncertainty limits of population-based annual indirect costs of HIV/AIDS in Iran in total estimated cases, (2006-2007 prices)

| | US \$ (million) | Iran Rials (million) |
|---|------------------------------|---------------------------------|
| Annual population-based informal costs of HIV/AIDS | 13.277 [6.277 20.276] | 122715.6 [58015.17 187416] |
| Annual population-based nonmedical expenditures related to HIV/AIDS | 7.206 [4.593 9.819] | 66609.23 [42458.47 90760] |
| Annual population-based Productivity loss costs of HIV/AIDS | 20.17037 [7.968 32.372] | 186434.8 [73650.02 299219.5] |
| Annual population-based indirect costs of HIV/AIDS | 40.653 [26.498 54.809] | 375759.6 [244921.9 506597.2] |

Abbreviations: HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.

persons don't submit themselves to such referral and free centers. If they are so rich and don't need free services they probably pay more resources for their illness and consequently their indirect costs is more and if they don't know about their infection they certainly infect more people and in this way also increase all costs. However, in this study we consider all uncertain factors to protect overestimation. As most of HIV/AIDS cases in Iran are IV drug users they may had no productivity before HIV infection. they may be rejected by their family and have no more productivity loss because of HIV. They may have low income occupations and their family usually are from low socioeconomic classes. Costs of unpaid helped by family or friends and lost production were valued minimum national hourly wage 7620 Rials (US\$ 0.82) per hour (8) as a shadow price in Iran in 2006-2007. These prices are not necessary true for other disease that may be more frequent in other socioeconomic classes and as Iran is moving from having a concentrated HIV/AIDS epidemic among injecting drug users to a more generalized situation, we must consider this differences in future. Nevertheless, this minimum level of costs is still parallel to direct costs of HIV/AIDS that calculated by CDC center of Health Ministry of Iran; according to their report direct costs of HIV/AIDS were US \$ 1025.306 in 2005 for each HIV/AIDS person (4).

In our study indirect cost of HIV/AIDS from societal perspective for each person was US \$ 616.00 (CI: 401.49-830.43), so indirect cost of HIV/AIDS for each person is nearly sixty percent of direct costs in 2006-2007 in Iran. This is in agreement with 1997 England study that showed

indirect costs were between 45% and 102% of direct treatment costs during one year (2).

In our study average population-based annual indirect cost of HIV/AIDS in detected cases was US \$ 8,440,000 (CI: 5,501,000–11,379,000) and in total estimated cases was 40,653,000 (CI: 26,498,000–54,809,000), and according to UNAIDS report national funds spent by governments for direct treatment costs was US \$ 14,000,000 during 2006 (5).

There were different values for indirect cost of HIV/AIDS in medical literatures *e.g.* it was calculated in England in 1997-1998 from the societal perspectives ranged from US \$ 6515 per person-year for asymptomatic individuals to US \$ 13,140 for patients with symptomatic non-AIDS, and US \$ 34,825 for patients with AIDS. In this study, cost items were costs of community and informal services, loss in economic and disability-related unemployment benefits (2). A study in Spain showed high indirect costs of HIV/AIDS (lost income and lost wages) at the individual level and strong effect in terms of income loss (the annual loss of income ranged from Euro 5271 to Euro 6150 per patient) . Lost wages (the annual loss of wages ranged from Euro 7537 to Euro 8793 per patient). a strong impact on household income (the annual loss of household income ranged from Euro 6693 to Euro 7813) (15). An economic evaluation study in Canada showed that the present value of the total loss of future production for all men aged 25-64 years who died in Canada during 1987-1991 was estimated to be 39.74 billion in 1990 US\$. Deaths due to HIV/AIDS accounted for 5.3% of this total loss or 2.11 billion in 1990 US\$ (16).

In developing countries, cost items differ from developed countries. The reason is that some of the benefits such as housing benefits and disability-related unemployment benefits and communities services do not exist in developing countries and concept of production is different. In addition, many of informal and family cares are free. As a result, some times complex and attractive methodologies were innovated *e.g.* a study was conducted by Fox *et al.* to estimate the impact of HIV/AIDS on individual labor productivity during disease progression in Kenya. Their cost items were 1. Work output per day spent plucking (amount of tea leaf plucked was 16.0% less in their second year before termination and 17.7% less in the year before termination), 2. Number of paid days and unpaid leave were (between 26.4 and 39.2 annual leave days more than comparison pluckers), 3. Number of light duty days (between 19.2 and 21.8 more days doing less strenuous tasks in the 2 years before termination) (17). In India, a study showed that the median medical and non-medical expenditures for treatment and services are US \$ 122 in a reference period of six months (18).

One of the main limitations in our study was the lack of systematic and well-documented costing data and extremely incomplete data recording in HIV Consult Centers. In Imam Khomeini hospital' HIV/AIDS consultation center, more recording files were made for referral patients. The patients may be referred to this center in more advance stages. As is evident in our study, percentage of HIV-infected persons receiving antiretroviral therapy was 61.5% (95%CI: 40.5 – 79.8) but in total detected cases this rate is 9% (5). However, there was no significant difference between cases who were received antiretroviral therapy and others for one year per person total indirect cost and its all cost items. So we can generalize our results to total cases with different pattern of ARV use.

We suggest inferential analytic studies on the determinants of AIDS and death among the HIV positive patients that can be useful for cohort cost studies in which we can better reflect damaging aspects of HIV-infections (19). Finally as indirect cost have significant portion in total costs of disease, both direct and indirect costs, when obtainable,

should be used to assess the economic consequences of HIV infection and treatment interventions.

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Conflict of interests

The authors declare that they have no competing interests.

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