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## The Social Costs of HIV/AIDS: A Comprehensive Study

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## The Social Costs of HIV/AIDS: A Comprehensive Study

**The Social Costs of HIV/AIDS:  
A Comprehensive Study**

**WHARTON RESEARCH SCHOLARS PROGRAM:**

SEJAL PATEL

**FACULTY ADVISORS: IAN MACMILLAN AND JAMES THOMPSON**

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## **I. INTRODUCTION**

HIV/AIDS is a global pandemic that currently affects over 150 million people around the world (Barnett and Whiteside 9). Over 40 million individuals have the disease; until a cure is found, the socio-economic impact of HIV/AIDS will continue to escalate (Barnett and Whiteside 364). This is especially true in Sub-Saharan Africa, where most of the epidemic is concentrated. South Africa alone represents 13% of the world's total HIV positive population (Avert 1). Aside from the casualties resulting from AIDS-related deaths, the social impact from AIDS should also be considered. HIV/AIDS is labeled as a socio-economic disease, meaning the disease affects the social structures and economies of those nations heavily infected. The AIDS problem is compounded in poor countries as a lack of infrastructure and funding make the challenge of fighting AIDS much more difficult. HIV continues to affect the most socially productive sectors in society, those between the ages of 15-50 (Barnett and Whiteside 1).

Given the latent nature of the disease and the lack of strict reporting regulations in Africa, one can conclude that the total reported number of HIV infections is vastly underestimated. This in turn suggests that the costs associated with the disease are also underestimated. Given the growing global prevalence of HIV/AIDS, an in-depth study of the relevant costs associated with the unchecked epidemic can provide useful information to policy makers who determine ultimately how much funding should be allocated to further study the disease. The relevant costs associated with HIV/AIDS that are currently considered, namely health-care expenses and wage losses from leaving the workforce, represent only a fraction of actual costs incurred. Measuring the comprehensive costs of

HIV/AIDS becomes even more important for third world nations, as the rapid spread of HIV/AIDS in these countries will be especially problematic for their less-than-stable economies. Therefore, the study that will be the basis for my project will be designed to take place in sub-Saharan Africa, with a particular emphasis on the two most heavily infected countries: Botswana and South Africa.

Little is known about the total HIV/AIDS costs incurred by individuals, families and society. Documenting these costs is important for several reasons: developing feasible disease management strategies, allocating research dollars for biomedical research and development, and understanding, in-depth, the cost burden distribution. The ultimate goal of the project is to encourage people, communities and governments to mobilize in light of these findings.

## **II. BACKGROUND RESEARCH**

Kennedy Gaichiri, a Wharton Research Scholar alum, conducted research to identify the South African province most in need of public health intervention at the firm/industry level. His research was used in conjunction with a project Dr. Ian MacMillan had undertaken. Professor MacMillan undertook a project to develop a workforce health management system that would allow companies to optimally determine drug/nutrition regimens for a population of workers in firms located in countries with high HIV positive workforces. One specific component of his project included the development of a software system that would take limited input data about individual workers and infer the most cost effective model for distributing limited nutrition and drug supplies to maintain the vitality of infected workers.

James Thompson, Director of the Societal Wealth Program at the University of Pennsylvania, along with Dr. MacMillan, has done research specifically looking at the direct and indirect costs of HIV/AIDS with respect to employees at the firm level. Such costs include re-hiring costs, decreased productivity and/or quality of work, and paid sick leave.

### **III. RESEARCH QUESTIONS**

First, I focused on exploring different HIV/AIDS social impact studies to assess which cost measuring technique is most appropriate. After I found an appropriate study, I then proceeded to determine exactly how it was conducted. I looked at logistics, data collection, and analysis procedures. Some examples of the logistics I explored include costs of the study, sample size and time frame of the study. The need for such research is practical because if approved, a research project of this nature will likely cost between \$1.2-\$1.4 million to implement.

### **IV. FINDINGS**

#### **A. FINDING A COMPARABLE STUDY**

The first step in designing the AIDS proposal was to find an appropriate study that could be replicated for HIV/AIDS. There have been several AIDS impact studies done in the past. A common element among these social impact studies is the use of a “macroeconomic” measurement technique. The vast majority of HIV/AIDS related

studies previously completed use complex economic equations to assess total costs. For example, the One-Sector Neoclassical Growth Model (also known as the human capital approach) views GDP as a function of total factor productivity, capital accumulation, the growth rate of labor, and labor productivity (Haacker 5). By “tweaking” the parameters of the equation, economists at the International Monetary Fund hope to capture the economic impact of AIDS as it relates to a shrinking and less productive workforce. The Neoclassical Growth Model estimates parameters for

$$Y = AK^{\alpha}(\epsilon_H P_H L)^{\beta}(\epsilon_U P_U L)^{\gamma},$$

formulas such as the one above to assess output. Here, Y represents GDP and the right-hand side variables relate to the labor market. Using the equation above, the total estimated costs of the epidemic in 2000 amounted to 2.3-4% of GDP, with direct costs equaling 1.8-3.6% of this estimate (CADRE 13). Though these commercial forecasting models may be able to provide a ball-park figure for the social impact of HIV/AIDS, there is probably a high degree of uncertainty surrounding the actual estimates. This approach is also used by organizations such as the Center for AIDS Development, Research, and Education (CADRE) although with slight modifications to the GDP equation (CADRE 12). The Dual Economy approach, also used by the International Monetary Fund, is similar to the Neoclassical Growth Model with the exception that it uses both skilled and unskilled labor as factors of total GDP (Haacker 6). Still, this approach also generalizes the effects of the epidemic and is likely to underestimate the true costs of the disease. There are inherent difficulties involved in modeling work of this nature because several assumptions are necessary. First, labor force mortality estimates



are translated into ‘efficiency units’ using average wages as weights, a common procedure but one that underestimates the productivity contribution of experienced workers in lower skill categories, and the impact of replacing such workers with younger employees (CADRE 14). Secondly, although there is an attempt to take account of differential cost impacts across sectors of labor losses, it is not clear that this takes into consideration the varying skill compositions in different sectors (CADRE 15). A third questionable assumption is the fixing of morbidity losses due to the onset of full-blown AIDS in HIV+ workers with surprisingly no differentiation on the basis of skill class (CADRE 15).

A better approach to modeling the social costs of HIV/AIDS is to use a “bottom-up” approach. By assessing the total costs of HIV/AIDS at a micro-level and aggregating the costs, a more realistic assessment can be made when compared to the macro-level GDP figures from before. Thus, my goal became to find a social impact study that used this “bottom-up” approach that measured the costs of HIV/AIDS at a micro-level. The micro-level, in this case, refers to measuring the costs of HIV/AIDS at the household level. In the search for such a study, we came across a comprehensive multiple sclerosis study conducted at Duke University in 1994. The study assessed the household costs related to multiple sclerosis and aggregated the findings to determine the annual costs. As expected, the results were both unrealized and compelling; the US government responded to the findings by increasing funding to multiple sclerosis research.

The 1994 study was modeled after a similar study led by Dr. Robert Inman in 1976 which also calculated the economic losses resulting from multiple sclerosis. Given the vast similarities between multiple sclerosis and HIV (average age of onset, high cost

of treatment, physiological similarities etc.), one can safely use the mechanics of the multiple sclerosis study as a basis for a new HIV study. Although there were a few crucial costs that were neglected in the 1976 study but captured in the 1994 study, the 1976 study included a diary given to each participant and his/her spouse to document every cost, emotional reaction etc. to the disease for the given time period. This component of the 1976 study was left out of the 1994 study but should be included in the HIV/AIDS proposal as the findings in Dr. Inman's journals shed light upon previously unrealized costs. Thus the 1994 Duke University MS study, with the journal component of the 1976 MS study, became the basis for framing the proposal for the HIV/AIDS impact study.

## **B. MULTIPLE SCLEROSIS STUDY**

The next step was to contact the head researchers of the Duke University study. I was able to reach Dr. Kathryn Whetten Goldstein, Director of the Health Inequalities Program at the Terry Sanford Institute of Public Policy at Duke University. The other two researchers, Dr. Frank Sloan and Larry Goldstein, are no longer with Duke University and couldn't be reached. By speaking to Dr. Goldstein I attained valuable insight into the construction and logistics of the study that could be cross-applied to HIV/AIDS. The following describes the logistics of the MS study:

### **i. PARTICIPANTS**

National Multiple Sclerosis Society provided researchers with a sample of their members who had MS. The sample had individuals in different stages of the disease. Individuals were contacted via mail and were over the age of 25, to include only those members who were in the workforce. Comparative data was taken from the 1992 Panel Study of Income Dynamics to compare individuals with MS with individuals with various characteristics over 25. Mean cost utilization of personal health services in the general population was also determined.

To deal with the over-representation of severely disabled MS patients in the study (as they are more likely to participate in such a study) weights were applied to total MS costs in the ratio of 0.2 for chronic progressive (severely disabled patients) and 0.8 for all other MS patients were used.

Overall costs attributed to MS were determined as separate estimates by MS types: chronic progressive vs. all others.

## **ii. SOURCES OF ECONOMIC COSTS**

### **INFORMAL CARE (UNPAID ASSISTANCE)**

Unpaid personal assistance to patients of MS and job retraining by persons of the general population was determined from data from the 1992 Health and Retirement Study and the 1993 Asset and Health Dynamics of the Oldest Old. Regression analyses computed based upon per ADL (activities of daily living) cost and applying those estimates to the general population.

Alternative methods for analyzing informal care were used as well. If an individual received both formal and informal care, the hourly wage paid for formal care was applied to the informal care. If the respondent received informal but no formal care, the mean hourly wage from 1992 Panel Study of Income Dynamics (PSID) was used (\$12.95/hour).

#### **FORMAL CARE (PAID ASSISTANCE)**

Formal care expenses were calculated based upon reported hourly payout.

#### **EQUIPMENT/ALTERATIONS (HOME ALTERATIONS SUCH AS RAMPS, LIFTS ETC.)**

These costs include baseline costs for home purchases and/or renovations in addition to the following assumptions made in these calculations: useful life of 7 years for equipment, 10 years for a vehicle, and 30 years for adaptations to home. Equal payments would be made for these alternations over the life of the equipment with a real interest rate of 3%.

#### **EARNINGS LOSS (BY MS PATIENT)**

Expected earnings of individuals without MS were derived using population-based predicted labor force participation and wage numbers using the PSID. Individual specific earnings losses were estimated by subtracting actual from predicted work hours and multiplying by the predicted wage. These calculations were made over the working-life of the individual and discounted (real discount rate of 3%) back to 1994 to estimate the present value terms of an MS individual's earnings losses. Separate estimates were

made for eight subgroups by occupation and gender. A weighted mean was then calculated using the proportion of each group from the sample size. Past loss (prior to 1994) and future loss over time was based upon the current value of personal services and equipment expenditures and current lost value which came from total loss earnings.

#### **PERSONAL HEALTH CARE (HOSPITAL, PHYSICIAN, PRESCRIPTION DRUGS)**

Personal health care costs were estimated as the product of the fraction of individuals using a particular service by the mean number of units of the service (i.e. hospital days) and by the national mean cost of the unit.

#### **INFLATION**

Costs incurred before 1994 were inflated to 1994 dollars using the CPI.

### **iii. SOURCES OF COMPENSATION**

#### **INCOME SUBSIDIES**

The subsidies considered include: private disability insurance, unemployment compensation, worker's compensation, benefits, supplemental security income, Social Security when < 65, and food stamps.

Compensation was also computed for other services, equipment and earnings loss. For services other than informal care, the survey obtained information on out-of-pocket expenditures. The subsidy was computed as the differences between estimated expenditures and out-of-pocket expenditures. For equipment, the survey obtained

information on both total and out of pocket outlays and the subsidy was calculated as the difference. For earnings, direct questions on all sources of family income – including private and public income subsidies were asked.

#### **iv. FINDINGS OF MS STUDY**

The combined annual total per capita cost of MS was \$34,104. Of this, 19% was for informal care and \$24,421 was borne by MS individuals/families/friends. MS individuals bore 71% of the costs for services and insurance/public subsidies financed the remaining 29%. Mean lifetime cost in 1994 dollars was \$2.2 million (calculated by capital value calculations) and total costs amounted between \$6.8 - \$11.9 billion. Overall, almost a fifth of the total cost was for informal care and only 44% of the combined costs were for personal health care services.

Differences between Dr. Inman's 1976 MS and the 1994 study include: the additional expenses of alternations to home and vehicle, the purchase of special equipment, the use of less limited health service estimates, and a direct measure of informal care cost rather than measuring earnings losses of a spouse. The 1976 estimate for the average lifetime cost of MS was \$151,000 (Inman55).

#### **V. ADJUSTING FOR HIV/AIDS**

The description above outlined the exact costs considered for multiple sclerosis; though MS and HIV are comparable diseases, certain costs are/are not relevant for the AIDS impact study. For example, the costs associated with equipment and home

alternations are substantial for MS patients in the US but will likely be negligible for HIV/AIDS patients in sub-Saharan Africa. When assessing the social costs of AIDS, we will look at direct costs, indirect costs and also consider additional costs for which specific measurement techniques are not yet known.

The direct costs that will be considered include formal care (paid assistance), loss of wages (patient), personal health expenses, asset sales and funeral expenses. Formal care, wage loss and personal health expenses can be documented and accounted for by using the journal technique found in Dr. Inman's 1976 study and/or the survey technique used in the 1994 study. Asset sales and funerals sales can likewise be accounted for by documentation according to the journal technique and/or survey and the appropriate appraisal of assets. Asset sales and funeral expenses are considered because they are specific to the HIV epidemic in sub-Saharan Africa. To pay an AIDS patient's expensive anti-retroviral treatment, doctor's bills etc., families often have to sell or liquidate assets such as livestock, bicycles, radios etc (Barnett and Whiteside 191). These costs are substantial considering the average annual income of a family in sub-Saharan Africa is approximately \$1800 (Wikipedia: South Africa). Though the "sale" of an asset is more a transfer of wealth and not necessarily a cost, we choose to acknowledge it as a cost at the household level. The ultimate purpose of this study is to recognize the huge financial costs of HIV/AIDS at a very micro-level to demonstrate that families cannot afford the cost burden of HIV/AIDS. Funeral costs are also necessary to consider because of the role of funerals in African culture. For many families, funeral costs can amount to more than the entire cost of treatment including medication, doctor's visits, food etc. (Palitza 3). According to the Joint Economics, AIDS and Poverty Program at the University of

KwaZulu-Natal, the average cost of a traditional funeral ceremony in South Africa is around \$4,900 (Palitza 3). It is often seen as socially inappropriate to not have an elaborate funeral for a loved one and thus a substantial amount of household wealth is liquidated to afford such a procession.

Indirect costs include informal care (spouse's wage losses), psychological costs, and business costs. Psychological costs can be measured by the Multiple Sclerosis Quality of Life Inventory Test. The MSQLI test was developed by the National Multiple Sclerosis Society and consists of a series of straightforward questions related to quality of life, emotional state and mental stability (MSQLI 1). The questions asked in the survey are not unique to multiple sclerosis and therefore, can be easily translated and tailored to a South African audience. Business costs stemming from HIV/AIDS include: employee productivity losses (as measured by the MSQLI test), on the job accidents (as measured by small enterprise surveys), absenteeism (as measured by small enterprise surveys), and increased health care costs such as insurance, early retirement withdrawals etc. (as measured by small enterprise surveys). Such data is already being collected and analyzed by James Thompson.

Other additional costs that will be given consideration is the overall decline in productive human capital and the orphan burden. Though there is no established mechanism by which we can measure these additional costs, a buffer should at least be included in the final assessment to address these issues. As AIDS continues to take the lives of those within the 15-50 age range, more and more children are becoming orphaned. As of 2003, approximately 1.1 million AIDS orphans were living in South Africa alone (AIDS Foundation 4). These orphans have traditionally been adopted by



extended family who are expected to absorb the additional costs of these children (Barnett and Whiteside 2008). However, as more and more children are orphaned, these extended family networks will not be able to afford to take them in. Therefore the increased household expenditure due to orphaned children needs to be documented and aggregated. The second additional cost to consider is related to future generations of uneducated children. Families with HIV positive individuals are increasingly pulling their children out of school to help pay for related expenses and take care of family members at home (Avert 6). Additionally, teachers are increasingly becoming recognized a fast growing “risk group” for HIV/AIDS. Most teachers are women, and women are socially and physiologically more susceptible to HIV/AIDS than men (Farmer 24). As of 2004, approximately 4,000 teachers died of AIDS in South Africa and 2,300 were infected (McElligott 5). The combination of fewer educated children and a shrinking teaching workforce will result in a generation of children in sub-Saharan Africa who will not be productive workers. In the future, firms cannot reasonably expect to find local human capital that can meet the demands of a competitive global market. The future costs associated with this decline in productive human capital need to be discounted to today if an accurate assessment of the social costs of HIV/AIDS is to be made.

To offset some of the costs associated with HIV/AIDS, some forms of compensation need to be considered. Insurance benefits for skilled labor workers, health insurance, death insurance, early retirement benefit withdrawals etc. can be documented by either the family or the firm. Government subsidies to anti-retrovirals also need to be considered and documented at either the family or government level. Though government subsidies aren't as common in sub-Saharan Africa, in countries such as Brazil, the

government pays for all anti-retroviral treatment at no cost to the patient (Seligman and Resende 12).

The scope of the project also needs to be reconsidered for HIV/AIDS. Though patients with MS were randomly selected to participate and both progressive and non-progressive patients were used, the patient sample for the HIV/AIDS study will be strictly non-progressive. That is, a cross-section of patients will be taken who have been diagnosed with HIV at  $t=0$ ; these individuals will continue to be monitored through time as the disease progresses from HIV to AIDS.

Once the structure of the project was determined, the next step was to identify how the data is to be collected and analyzed. Dr. Whetten-Goldstein and her team used the services of Mathematica Policy Research to construct the surveys that were administered and then analyze the data. Mathematica Policy Research has several experienced researchers and statisticians who have worked on social impact studies of this nature in the past. After speaking with the executive director at Mathematica, we were told that they would be willing to construct a survey related to HIV/AIDS for the purposes of our research. The AIDS survey would be similar to the MS survey; however, recognizing that the surveys would be administered in sub-Saharan Africa, the questions would be simple and culturally appropriate. MPR currently employs two South African researchers who specialize in regional data collection. For the multiple sclerosis questionnaire, Mathematica surveyed patients regarding: general household information, health assessment, cognition, caregiver information, medical services, household production (cooking, cleaning etc.), employment, disability, health insurance and housing. The assessment of the HIV/AIDS data would not be done by Mathematica,

however, but would instead be handled by University of Pennsylvania faculty. Dr. Robert Inman has previously been involved with work of this nature where he analyzed and quantified both qualitative and quantitative data. Given that the AIDS impact study will most likely include a journal assessment, Dr. Inman's specialty in extracting quantitative data from such sources can be of use.

Essentially, three different methods of measuring costs can be used. First, Mathematica Policy Research will be used to develop a detailed questionnaire/survey to measure the comprehensive costs of HIV/AIDS at the household/business level. Second, the National Multiple Sclerosis Society Quality of Life Inventory Test can be administered, evaluated and quantified to translate the psychological impact of the disease to actual business costs. Third and finally, the journals of patients can be assessed by faculty such as Dr. Inman to shed light on previously unidentified/unclassified costs.

## **VI. OTHER CONSIDERATIONS**

When speaking to Mathematica Policy Research about the feasibility of the proposed project, the scope of the social impact study came into question. Though the proposed project was feasible, the director questioned as to whether grant sponsors such as the Gates Foundations would fund such a large project given that this initiative was new with no previous track-record. To address such a concern, the Mathematica team suggested that if finding grant sponsorship was difficult for this reason, two smaller pilot projects could be run first. The first pilot project would be to continue Dr. MacMillan's firm-level workforce health management system project. The second pilot project would involve studying medium-size enterprises across industries in South Africa, with both

skilled and unskilled workers, to determine the costs of HIV/AIDS at the firm level. The key idea for the second pilot is to identify which industries are most at risk from the pandemic.

## **VII. CONCLUSIONS**

HIV/AIDS is a disease process that has caused innumerable social and economic losses in the world and on the African continent in particular. Even with relative global awareness of the current pandemic, not enough is being done to rescue affected societies. The above analysis confirms that HIV/AIDS presents problems to every level of society. Given the huge social and economic costs of HIV/AIDS, treatment, education and prevention should become a top priority for those nations most heavily affected. Poverty, a lack of solid political infrastructure, and inadequate funding, however, make this difficult task much more challenging. What the country's future will look like will be determined, to a large extent, by what policies and initiatives are undertaken today to combat HIV/AIDS both by the local government and the international community. To increase awareness about the future economic impact of AIDS, a study documenting the vastly underestimated costs of the disease is crucial. To document the comprehensive costs of the disease is a challenging task that requires a lot of thought and planning before execution. The purpose of my research is to lay the foundation upon which a thorough research proposal and project can be built to meet this challenge.

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