

I. DATA, SOURCES AND METHODS

The studies described in *The Impact of AIDS* use a wide variety of sources and methods to collect and analyse data and arrive at conclusions concerning the impact of HIV/AIDS on particular sectors of the economy. Each methodology has its own strengths and limitations, as described below. The choice of methodology and research design has direct implications for the quality and usefulness of the results. Larger, more representative samples are more likely to produce findings that can be broadly generalized, whereas qualitative studies that rely on small samples and anecdotal accounts are of less statistical value. The reader is cautioned that the quality of the studies reviewed in this volume is uneven. Moreover, since people in many societies associate the disease with shame and stigma and are reluctant to discuss it, investigation of a subject as sensitive as HIV/AIDS presents problems for the researcher. That concern underlies the difficulty of measuring the exact magnitude of the impact of HIV/AIDS and the need to design and implement more rigorous and more appropriate research.

Chapter I examines the types of methodologies common to studies of the impact of HIV/AIDS and identifies areas where future research is urgently needed. In some cases, the methodology was appropriate for only one sector; in other cases, the same methodology could be applied to measure the impact in several sectors. Some research combined several methodologies and assembled data from a variety of sources. Many studies, especially those that served as the basis for the analysis in chapter III on households and families, used retrospective interviews with subjects, although a few studies with longitudinal surveys were available. Data collection from official government records formed the basis for some investigations, especially in the education and health sectors. Studies on firms and agricultural enterprises focused mainly on company records of employment, productivity and health. In the macroeconomic studies of the impact of HIV/AIDS, virtually all efforts employed economic modelling, although the models differed

according to the inputs selected and assumptions underlying the model. Finally, a number of studies used evidence that was not easily verifiable or quantifiable, such as semi-structured interviews and focus groups. That approach was often a supplement to other lines of evidence.

Part I of the report is an attempt to provide a comprehensive survey of studies that were available from published and electronic sources as conference papers, United Nations reports and communications from individual scholars. Some of the studies were preliminary reports on research in progress and were not formally reviewed and published or did not give a full account of the research carried out. Part II of the report presents summaries of selected studies, with particular attention to the methodology and scope of each study. Overall, the body of data is enormous and changes rapidly. As the implications of the epidemic for all facets of human life become ever more apparent, the need for research to guide policies and programmes escalates.

A. METHODOLOGIES OF STUDIES

1. *Demography*

For countries that are severely affected by HIV/AIDS, the demographic impact of HIV/AIDS was assessed by comparing population estimates and projections based on realistic assumptions about the course of the epidemic with hypothetical estimates and projections that make no allowance for the existence of AIDS. The latter are derived from the application of the DESA Population Division standard computer projection program, on the basis of assumptions regarding the future course of mortality that are similar to and consistent with those made with respect to countries that are still largely free from the HIV/AIDS epidemic. The process for deriving estimates and projections that explicitly incorporate the effect of HIV/AIDS is more complex and involves several steps (see Buettner, Sawyer and Zlotnik, 2003). HIV and AIDS estimates were produced by the Joint

United Nations Programme on HIV/AIDS (UNAIDS) so that the results of the projections are consistent with those estimates.

For the 2002 revision of the United Nations official world population estimates and projections (United Nations, 2003d, 2003e, and 2003f), the impact of the HIV/AIDS epidemic was explicitly modelled for 53 countries, up from 45 in the *World Population Prospects: The 2000 Revision*. In most of those countries, HIV prevalence in 2001 was estimated to be 2 per cent or more among the population aged 15-49. In addition, a few populous countries with lower prevalence levels were included because they had a large number of persons (at least one million) living with HIV.

2. Households and families

Most of the studies in chapter III were based on retrospective surveys, which use a single interview with respondents and require them to recall events that occurred in the past. If respondents forget some events, results may be biased. Retrospective studies also make it difficult to establish causality. For example, malnutrition in children may be associated with loss of income due to AIDS-related medical expenses, but it cannot be determined whether the children were already malnourished before the disease depleted the income of the household or whether the loss of income caused their malnourishment.

Longitudinal, or follow-up, surveys interview the same respondents at more than one point in time and thus allow timely recording of events, such as AIDS deaths. This type of survey reduces errors caused by memory lapse, but is more expensive to conduct and is subject to attrition of respondents. The present volume provides examples of follow-up surveys, including a study of economic activities in households in Burundi, Côte d'Ivoire and Haiti conducted by the International Children's Centre in the early 1990s and a study in Rakai, Uganda that looked at the ownership of durable goods in households with and without an adult AIDS death. The use of a control group in the Rakai study was a methodological improvement that allowed comparison of the two groups of households and made it possible to

show the actual effect of AIDS-related mortality on the economic fortunes of households. A study in Thailand further subdivided households into those with no death, those with an adult AIDS-related death and those with an adult death not related to AIDS. The study demonstrated that AIDS-related deaths were more costly to households than non-AIDS-related deaths, although both suffered the loss of earnings of the deceased.

A problem with the use of surveys when studying HIV/AIDS in households and families is that an adult death, particularly the death of the breadwinner, may cause the family to break up. Some family members may migrate out of the area, and young children may be adopted by relatives. Consequently, families that have suffered AIDS deaths may no longer exist and may be underrepresented in the survey sample.

3. Firms

The methodology employed by most of the studies on firms includes examination of company records for information about employment, absenteeism and productivity; interviews with company officers, managers, supervisors and doctors; and economic modelling to determine future workforce needs. Most studies were commissioned by the company involved. There may be many additional studies of this type, but the results are generally not available to the public. The methodology is often not documented in detail, and the outcomes of interest are related to company profitability, focusing on such concerns as workers' insurance and benefit costs, medical care and the costs of recruiting and training new employees to replace those who have died of AIDS.

Studies of firms may have empirical data on the HIV status of employees through medical insurance records and company-wide testing, permitting assessment of the actual impact of the HIV/AIDS epidemic. In some other sectors, where there is no independent confirmation of the HIV/AIDS diagnosis, the cause of death may only be assumed to be AIDS.

Company records can measure the direct costs of HIV/AIDS, but other indirect costs are less measurable and less quantifiable. The latter in-

clude the morale and motivation of workers in a setting where their co-workers are becoming ill and dying.

4. *Agriculture*

Methodologies to measure the impact of HIV/AIDS on agriculture have included such approaches as household interviews and focus groups of farm owners and managers. In the case of such agricultural enterprises as tea estates and sugar mills, the methodology is similar to that for firms. For example, a study of a sugar mill in rural South Africa used clinic and hospital records, employment records and household interviews. It was one of the most comprehensive research studies involving agricultural workers as a result of the combination of methodologies employed.

An approach unique to research in agricultural areas is known as rapid rural appraisal. It is a qualitative survey methodology that uses a multidisciplinary team to formulate problems for agricultural research and development. Its chief characteristics are the short period of investigation, the use of informal data-collection methods and the relatively low cost of the research. Rapid rural appraisal relies on expert observation coupled with semi-structured interviewing of farmers, local leaders and officials. This type of research has been carried out in Uganda, the United Republic of Tanzania and Zambia, among other places. The principal advantage of the method is that it produces quick answers to research questions, but the disadvantage is that the superficial nature of data collection may lead to biased results.

Many studies of agriculture included no control group that would have allowed researchers to estimate what portion of the findings was due solely to the HIV/AIDS epidemic. For example, a study in Zimbabwe examined the impact of HIV/AIDS on the agricultural production of AIDS-affected households. However, it did not include a sample of families not affected by AIDS, so the difference between the two types of households could not be measured. Another problem common in agricultural studies was the lack of knowledge of the HIV status of individuals.

5. *Education*

The studies on education understandably focused on areas where data were available—the supply of education (the numbers of teachers and resources available) and the demand for education (the numbers of children by age). The quality of education was rarely assessed, although it was implicit in some studies that experienced teachers provided higher-quality education, so their loss to AIDS compromised quality. School records were an important source of data, as were interviews with school administrators, teachers and parents.

Focus group discussions were used in a number of studies. In Zambia, focus group discussions with members of AIDS-affected households explored the conditions that led parents to take their children out of school. Focus groups may help make it possible to understand the impact of HIV/AIDS as individuals directly affected by the epidemic perceive it. For example, a study in the Ondangwa East and Ondangwa West regions of Zambia used focus groups and in-depth interviews to examine the reality faced by teachers and school principals.

Modelling techniques helped to predict the impact of HIV/AIDS on education supply and demand. The methodologies require the projection of the demographic impact as a first step and take into account the age and sex structure of the projected population. This type of methodology was developed by the United Nations Children's Fund and was widely used to estimate the supply of teachers and the number of school-age children who would not have teachers owing to HIV/AIDS.

A study of educator mortality in the KwaZulu Natal province of South Africa combined several methodologies, using an analysis of annual school survey data, a random sample survey of 100 schools and an examination of the mortality, pension and medical records of educators. Another study, in Botswana, Malawi and Uganda, used both qualitative and quantitative methods, including interviews with education managers, teachers, students and others; focus group discussions; and

an assessment of records on absenteeism, drop-outs and grade repetition from a sample of 41 schools in the three countries.

Several studies used data from the Demographic and Health Surveys (DHS) in many countries to identify orphans in the samples and to compare their educational attainment with that of non-orphans. DHS data are particularly useful for cross-national comparisons because their research design and questionnaires are similar. The Multiple Indicator Cluster Surveys sponsored by UNICEF also provide comparable information on education for a large number of countries.

6. Health

In the health sector, the most common methodologies used in the studies cited were the examination of hospital records and the collection of data from ministries of health as well as household surveys. The studies in the sector focused on health expenditures related to HIV/AIDS, including public and private expenses; allocation of funds to treatment and prevention; and sources of donor funding. In several cases, workshops were organized to elicit expert opinion on costs and expenditures for treatment. In Côte d'Ivoire, for example, physicians, leaders of non-governmental organizations, epidemiologists, health economists, a traditional practitioner and representatives of the National AIDS Control Programme met to discuss the costs of treatment for various types of patients.

One study of five developing countries used a combination of methodologies that collected objective and subjective information about AIDS expenditures. The countries were Brazil, Côte d'Ivoire, Mexico, Thailand and the United Republic of Tanzania. Sources of data for one or more of the five countries included financial reports of public expenditures or budgets; country workshops to estimate treatment costs; special health-sector analyses; a database of public hospital claims; and household surveys.

Household surveys were generally used to learn about private expenditures for the care and treatment of AIDS patients paid for by members of the family.

Although the supply of health workers is a major issue in the battle against HIV/AIDS, no studies were available that examined the impact of the epidemic on the health workforce.

7. Economic growth

All the studies of the impact of HIV/AIDS on economic growth used economic modelling techniques. In general, the task is to estimate how the economy would have performed in the absence of AIDS and contrast that result with an estimate of economic performance given the estimated or projected number of HIV/AIDS cases. The economic outcome studied is typically growth in total gross domestic product (GDP) per capita and/or growth in total GDP. Some studies employed cross-national data, either for a single time period or a time series. In those analyses, regression analysis was used to estimate the effects of one or more indicators of the volume of HIV/AIDS infections or deaths on economic outcomes, controlling for other variables that previous work had identified as having an important effect on economic growth. Other analysis employed an economic model fitted to the data of a particular country and, often, projected for 10 to 15 years in the future.

Some studies used a model that was further elaborated to posit a dual-sector economy, with a well-paying and productive formal sector and a low-wage, low-productivity informal sector. Other, more complex, variations of economic models were used to analyse how the impacts of HIV/AIDS on different sectors of an economy were related to the overall economic performance.

B. NEED FOR FURTHER RESEARCH ON THE IMPACT OF HIV/AIDS

An examination of studies that have been conducted so far reveals an urgent need for research that can shed more light on the effects of the HIV/AIDS epidemic. Where possible, longitudinal or follow-up studies with multiple rounds of interviews should be conducted to allow for ongoing examination of the cumulative effects of the epidemic. Larger and more representative samples of households and communities would

make findings more useful, as would studies in urban and peri-urban areas, which are currently underrepresented in AIDS research. An effort should be made to design research studies with control groups to make it easier to isolate the effect of AIDS. Qualitative research methods, such as focus groups, can bring a useful added dimension to quantitative studies.

Study design is of paramount importance when investigating an epidemic such as AIDS, since its impact may not be observable and quantifiable until it begins killing large numbers of people. Studies should at least acknowledge the lag time of the disease and the future effects, insofar as it is possible to incorporate them into the research design.

Although over the last two decades numerous studies on a wide variety of topics have been conducted on the effects of HIV/AIDS, enormous gaps in knowledge still exist. An important need in future studies of HIV/AIDS is the determination of the HIV status of individuals. In most of the studies reported on here, the actual cause of disease and death was not available, so it was often assumed that deaths were AIDS-related without having clinical evidence. Furthermore, testing for HIV is not common in many areas, and other ways of capturing HIV status should be explored.

More efforts should be made to understand what happens when families dissolve after an adult AIDS death—if and where they migrate, whether individually or as families. The fate of children orphaned by AIDS needs special attention, especially with regard to their nutritional status, educational achievement and long-term welfare.

In the case of firms and businesses, studies commissioned by the company concerned need to be shared with planners and policy makers so that the results can contribute to solutions.

In the health sector, documentation of care and treatment is often available from hospitals and clinics, but that approach may miss AIDS victims who do not have access to health-care facilities or

who cannot afford treatment. More information is needed about the allocation of resources between prevention and treatment of HIV/AIDS and between HIV/AIDS and other diseases. Data are also lacking on the costs of care and treatment being borne by households and families on the one hand and by service providers on the other.

In the education sector, the effect of HIV/AIDS on the viability of school systems needs to be examined. The education sector competes for funds with other sectors, including the health sector, and the burgeoning demand for AIDS-related health care may squeeze education budgets and put all children at risk of receiving an inferior education.

In addition, more information needs to be analysed by gender. The death of a mother has very different implications for her young children than the death of the father. Gender data on orphans makes it possible to determine whether girls in families affected by HIV/AIDS are more disadvantaged than boys in terms of educational attainment and other indicators of well-being.

Finally, most of the available studies were carried out in sub-Saharan Africa. There are exceptions—for example, comparative studies of Demographic and Health Surveys and some studies in Thailand—but more research is needed in areas outside the African continent. The lack of such studies can be explained by the relatively low prevalence rates in countries in Asia and Latin America. However, studies in those regions are important for the insights they will provide on the spread and impact of AIDS under diverse socio-economic and cultural conditions.

The timely analysis and dissemination of the results of research is vitally important so that policy makers and programme officials can respond to the best available research. Improved knowledge and information about HIV/AIDS is an important step in conquering the epidemic, but conditions are changing so rapidly that failure to make studies available can render the results less valuable to planners.