

THE EVOLUTION OF A SURVEY IN A RAPIDLY CHANGING ARENA:
THE ECONOMIC IMPACT OF AIDS ON HOUSEHOLDS

Mary Ellen Rider McRee¹ and Richard Widdows,²
Purdue University

Acquired Immune Deficiency Syndrome (AIDS) has had a tremendous impact on our country. This project was conducted to develop a questionnaire and method of data collection to determine the economic impact of AIDS and Human Immunodeficiency Virus status on households.

The purpose of this poster is to highlight the results of a piloted questionnaire designed to focus on the economic impact of (Acquired Immune Deficiency Syndrome) AIDS on households.

THE ISSUE

AIDS is a multi-dimensional problem with serious economic implications for patients, their families, and friends. In the Fall of 1988, stories abounded on the billions of research dollars available with funds specifically targeted toward social science research.

A full profile of costs experienced by effected persons had yet to be developed. Therefore, the project proposed to develop a survey instrument and method of collection that protected the confidentiality of the AIDS patient population. The time line proposed for carrying out this initial project was four months.

THE PROCESS

An extensive review of the literature and participation in a colloquia and its steering committee activities of the Social and Behavioral Sciences Initiative (SBSI) for the university's Center for AIDS Research were conducted. Seed monies were offered, sought, and awarded by the Center.

With seed monies, the consumer researchers were able to discuss the newest of research with medical researchers, medical economics researchers, clinicians, case managers, administrators of Medicaid from various states, government research organization program officers, and representatives of various AIDS social service organizations.

A questionnaire was developed for review by regional experts in the delivery of AIDS programs and services. Version one was reviewed by the coordinator of the local AIDS project who also

heads the regional support network for AIDS patients. Version two was reviewed by the administrators of the leading AIDS social service organization in the state.

A pilot was conducted using the revised questionnaire. Respondents were contacted through sources identified through colloquia, the revision process, and various other contacts. An initial pilot mailout was unsuccessful. Responses from reviewers and respondents about the importance of the project encouraged the reviewers to proceed. Permission to use existing grant monies for soliciting completed questionnaires was received. A graduate student already in the employ of a major AIDS social service organization was made available to collect data. Monies were paid to the social service organization who then paid the 28 respondents. The final questionnaire will be used in a larger funded project currently under development.

CONCERNS FOR FUTURE RESEARCHERS

Through this process, it became quite evident that various components of the research process quickly changed. In effect, these factors changed the focus of the research and the research process. What changed?

1. Knowledge about the disease and drug therapies changed rapidly. The disease continues to be considered an epidemic. Drug therapies have lead the focus of the disease toward chronic illness characteristics.

2. The public policy debate over the funding of research changed. A question of values arose when asking, is AIDS more important than cancer or any other chronic disease in the receipt of research dollars?

3. The researchable population changed both by location and by socio-demographic characteristics. The predominance of the traditional homosexual population gave way to local populations of intravenous drug users, teenagers, pediatric cases, and bisexuals.

Despite the rapid changes, the topic continues to be one where consumer economists can make major contributions. AIDS and other chronic illnesses impact heavily on consumption and financial management needs of households. For this reason, ACCI members have a professional responsibility to be involved in the research.

¹Assistant Professor/Extension

²Associate Professor