This paper describes the development of a specialized epidemiologic/clinical data registry form for Acquired Immune Deficiency Syndrome (AIDS). Data is collected on all AIDS suspects and proven cases reported to the STD Program by local physicians, clinics and hospitals. The completed AIDS Registry Form is optically scanned and automatically filed using the Medical Information Management System (MIMS) software program. By utilizing simple, automated data retrieval and tabulation methods, cross-comparison of epidemiologic/clinical data can be performed. Uniformity of information among AIDS victims may then lead to common factors contributing to the prevalence of this most serious disease syndrome.

Introduction

Historically Sexually Transmitted Disease Programming has been primarily a public health function in America. The focus of this programming has been fourfold. Epidemiological follow up of positive tests and contacts to known cases, case management and case finding activities to determine source and spread of disease; basic clinical services extended to the high-risk group for early detection of disease, treatment of contacts, and clinical management of cases; and education of the high-risk group to prevention technique; and the accumulation and analysis of morbidity data to determine disease prevalence among various population groups and areas of service. During the last decade, this program focus still formed the core of sexually transmitted diseases as a viable subspeciality in the practice of medicine. Although the majority of the STD program functions remain the responsibility and expertise of public health, new sophisticated methods of control need to be developed. Clinical services for the sexually transmitted diseases require new protocol standards of performance. Methods of quality assurance and peer review can insure the appropriate practice of these standards in the diagnosis, treatment and clinical management of the STD's. In conjunction with these diverse programming needs, accurate data for research is required.

Computer science technology is the logical recourse in satisfying these STD program data requirements. Previous collection methods were manual, time consuming, therefore expensive, and limited in their scope of application. Clinical quality assurance programs were sometimes operational under protocol or standardization. However, the audit of records required manual selection through randomization techniques and a complete audit of all records in accordance with protocol was impossible. Data collection and analysis for both clinical and/or epidemiological research were only completed for minimal time intervals (as program priorities permitted) or required special funding for long term studies. A method of rapid and inexpensive data entry and retrieval in a manner that could be absorbed by a program in the routine operation of that program and within the scope of limited funding was required. Since a majority of the program staff to these sexually transmitted disease programs had no prior computer training, the system had to be "friendly" in language and comparatively simple in application and function.
Medical Information Management System (MIMS) was initiated to monitor the health status of astronauts. (4) The MIMS program was designed to manage all the various aspects of information relevant to patient care. It can be used to recall an individual patient record, to search for pre-selected data among a large number of patient records, and to provide aggregate data in a concise understandable visual method. The primary advantages of MIMS is that the user can define the categories and file structure of data; define, update and edit records without regard to the length of the original data field; retrieve any combinations of selected data items from multiple data bases; and generate statistical information from the data system. (5)

The MIMS program was based upon fts status as the preliminary source of data entry into the system. This program to the data upon entry. The physical configuration of this system also provides for the capability of retrieving and researching data from a remote site by using a portable duplex terminal via the same telephone connector system.

Although the MIMS program interfaces with an optical scanner at the point of data entry, it may be utilized with any mode of data entry. Also, although the data retrieval is performed at a hard copy terminal, it can be retrieved at a cathode-ray tube terminal with accessory printer. (6)

Currently there are two types of data entry forms being utilized in the MIMS system. For the last three years the Cincinnati STD Prevention/Training Center Clinic has been using the medical record form. This record is a two-sided data form containing 302 base items. Twenty of these items are individual patient demographic information, 323 items refer directly to clinical investigation and patient management, and 39 items are demographic in intent and for clinic use, i.e., research studies and special demographic information. All data items must be entered by making a mark in the appropriate box with either a number two pencil or pencil type pen. To insure confidentiality, patient records are entered into the data system and referenced individually only by specific patient number. Each record contains a unique number until the patient ceases to make further clinic visits. Patient number is then retired with the record. The second data entry form is being used on a selective basis at the Baltimore STD Prevention/Training center Clinic. This is the epidemiologic report form. This form contains 206 data base items relative to the interview, field investigation, and case management of clients seen either for syphilis or gonorrhea. This form is meant to be used in conjunction with the medical record data form. If a client is first seen in clinic as a volunteer, positive test result, or case contact, he/she will first receive the medical record form. During the subsequent epidemiological interview and resultant case management of that patient, his/her same patient number will be entered on the epidemiologic report form and followed through completion of the case. This process for the first time forms a concrete link between clinical and epidemiological disciplines on an individual patient basis. By using these two data base forms, substantial data may be selected for cross-comparison and study.

In this paper, I am proposing a third data entry form for use in the MIMS program. The Acquired Immune Deficiency Syndrome (AIDS) registry form is completed by the STD program staff person assigned to the AIDS project. Area health providers (physicians, clinics, hospitals) are urged to report all proven and/or suspect AIDS cases currently under clinical investigation, hospitalization or treatment. Complete client confidentiality is assured and physician permission for the STD staff person to perform case follow-up is obtained. An initial telephone case report is made from the health provider to the STD program. Thereafter, the AIDS staff person consults individually with the physician, patient's medical record and the patient personally in order to...
complete the registry and perform all the necessary epidemiologic case investigation and follow-up.

Acquired immune deficiency syndrome (AIDS) presents a puzzling set of symptoms and is of unknown etiology. Those affected are usually (75% of cases so far) homosexual males. The remaining 25% are recipients of blood donations, drug abusers, infants or sexual partners of known or suspected AIDS victims, and Haitians. (9) Epidemiologic observations increasingly suggest that AIDS is caused by an infectious agent which can be transmitted sexually or through exposure to blood or blood products. The possibility of sexual transmission of AIDS between partners, one of whom may be an asymptomatic carrier of the infectious agent has also been shown. (10) Sexual histories reveal the incubation period for AIDS varies from a few months to more than two years. (11) During this "pre-AIDS" or "latent" period, the AIDS victim may be unknowingly infecting multiple sexual partners. Investigation of the first AIDS cases reported began in June 1981, and by June 1983 over 1,400 cases have been reported to the Center for Disease Control with a 38% case mortality rate. (12)

Given these unknown medical and epidemiologic circumstances and their impact upon the AIDS epidemic, the necessity for accurate and uniformly complete patient data for AIDS suspects and/or cases becomes imperative. All data base items in this AIDS registry form can be subject to the same type of data retrieval and analysis as performed using the STD medical chart and epidemiological report form through the MIMS program.

Discussion

The Medical Information Management System (MIMS) is an interactive data entry and retrieval program which is: inexpensive to operate, utilizes a non-technical ("friendly") language; requires minimal operational training, functions rapidly with error-free data entry; has the capability of studying individual site data and aggregate data from multiple sites; and retains the flexibility of allowing the user to design and revise programs used in data retrieval.

After three years of application, the MIMS program has greatly enhanced multiple facets of sexually transmitted disease programming: routine clinical quality assurance in which all charts are audited in accordance with programmed criteria; demographic, clinical, diagnostic, and epidemiologic patient data are routinely collected and analyzed automatically and on a scale not feasible manually, retrieval and cross-comparison of clinical and epidemiologic data permit STD research to be integrated regularly in the STD program.

Application of the MIMS program to the AIDS investigation and case management registry seems a logical recourse in the effort to solve this most serious and fatal health problem. When a sufficient sample data is collected or proven AIDS cases and AIDS suspects, data retrieval and cross-comparison of cases can be performed. Substantive common factors in history, exposure, sexual practices, and symptomology may emerge a majority of AIDS victims. This would then provide information concerning the variety of medically and epidemiologically baffling questions concerning the AIDS problem.

References