

COMPUTERS IN USE — DESIGN OF A SYSTEM FOR THE STUDY OF A CHRONIC DISEASE

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This paper will show how a conventional commercial method of data processing, using a mini computer, can be applied to establish a computerized system for the study of a chronic disease. Inflammatory bowel disease (IBD) is a long term disorder whose cause and cure are unknown (Thayer, 1980). IBD is usually diagnosed sometime between the patient's late teens and early thirties, and lasts for the duration of the person's life (Grace & Priest, 192). Dealing with a chronic disease like IBD highlights the necessity for using modern technology to increase the available body of knowledge about it.

Using the proposed method in nursing practice will place the nurse in the role of data collector, user of technology, and key person for future scientific study. The method describes the logical and technical development of a system, excluding details about programming and actual file creation on the computer. The proposed system consists of four parts: a permanent file, an update file, an index file, and an output or access to the file.

The availability of data from large numbers of patients makes it possible to examine nursing problems that previously could have been studied only in small sample populations. The proposed system creates files for any number of patients, and makes the information available to the nurse for study.

Literature Review

A review of the literature pertaining to information systems in both nursing and medical practices, and the significance of the problem of IBD led to the conclusion that while computers have been used in some areas of nursing and medicine, they have not been used to establish a comprehensive, longlasting file of records for patients with severe chronic diseases, such as IBD. Much has been said about the need for computers to be used in nursing practice with little having been done (Edmunds, 1982; Johnson & Stegen, 1982; Muirhead, 1982; Powell, 1982; Pritchard, 1982; Sorkin & Bloomfield, 1982). The nurse's expanding role now necessitates the availability of computers

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that will facilitate the retrieval of data accurately, efficiently, and quickly (Reeves & Underly, 1982). The nurse becomes the central figure and must learn to put information into the computer and to obtain useful information from it.

In nursing and medical practice, computerization has first advanced where it is most needed and cost-effective: in areas of medical records, statistics, monitoring laboratory values, and in the administration of patient care services (Cook, 1982; Doyle, 1980; Groves, 1980; Groves & Davidson, 1980; Meldrum, 1981; Reeves & Underly, 1982; Reilly, 1982; Turner, Jones, & Streeter, 1980). The use of mini computers for equipment inventory (Howlett, Kenyon, & Kinder, 1981), for calculating the nurse's workload (Henney & Bosworth, 1980), for ordering supplies (Reeves & Underly, 1982), and for sorting nursing education records (Marks, 1981) has been documented. It has been suggested that computers be used to determine hospital staffing needs and to compile work-related data on the nursing staff (Reeves & Underly, 1982).

A computer was used to index a diabetic clinic population, in terms of age, sex, treatment, and complications (Watkins, Sutcliffe, Pyke, & Watkins, 1980). The records were updated at regular intervals and were compared with records of a like patient population that had been obtained in another country.

A computerized disease registry that records all patients seen in a clinic according to disease, age, and sex was compiled (Meldrum, 1981). The registry enables patients to be contacted for one problem even if their reason for seeking help was another problem. Computers can be used to examine a patient's history, to see what makes him ill, and to determine which patients improved most using certain treatments (Turner et al., 1980). Computers can specify the number of patients seen for a given disease over a period of time, and can quickly retrieve the data, along with related statistical analyses (Turner et al., 1980).

Advantages of using computers for keeping medical records include more accurate documentation, neat notations that cannot be misinterpreted, efficiency, and time and money saved (Reeves & Underly, 1982). No literature was found that cited the use of computers to establish a scientific, patient-oriented long term data base.

IBD is a chronic inflammatory gastro-intestinal disorder. The term IBD is commonly applied to diagnoses of ulcerative colitis and Crohn's disease (Anderson, 1982). The manifestations of the inflammatory process can be severe, and may affect multiple aspects of a person's life. While the prevalence of IBD has been established as be-

tween 90-300 per 100,000 population (Mendeloff, 1980), the disease is on the increase (Farmer, 1980). Although the given prevalence does not indicate that IBD is a problem of great magnitude, the extent to which IBD patients use hospital services does indicate its severity. In British Columbia, from April 1981 to March 1982, 7,054 hospital discharges, involving 48,045 hospital days were IBD cases (British Columbia Ministry of Health, 1983).

The cause and cure of this chronic life-long condition remain unknown (Anderson, 1982). There has been speculation about the etiology that involves genetic factors (Cullen, 1982), injurious substances (Beck, 1982), hypersensitivity of the individual (Goodacre, 1982), viruses or bacteria (Baker, 1982), and infectious agents (Tyrrell, 1982); but none of these possibilities has been confirmed. More research is needed to find the cause and cure of IBD, so that the needs of sufferers can be met (Anderson, 1982).

Development of the System

Several steps led to the development of the system. A problem has always existed in the area of history taking. Gathering standardized information that could become a data base for scientific study for nursing purposes has rarely been done. Patients seeking treatment for IBD have been assessed with general history forms. On subsequent visits, they are assessed with the same form again. General forms with headings such as history of present illness, medication, and effect of disease on lifestyle collect non-specific information that may overlook significant factors about the patient. In addition, these forms lack information regarding details of past problems and interventions. The problem of lack of continuity of information becomes more acute. Most of the information collected in these depends upon the education, experience, and point of view of the nurse present. A high rate of staff turnover may also make it impossible to collect consistent, objective information.

Another factor that has been considered in the development of this system is the mobility of information. Regardless of the initial geographical location of the patient, by having all information available in the master file, the proposed system is able to "carry" the patient's information to his or her next location. Economic conditions continue to force many people to move and relocate. The flexibility of an information system that is intended to answer today's demands creates new independence and aids in the continuity of care.

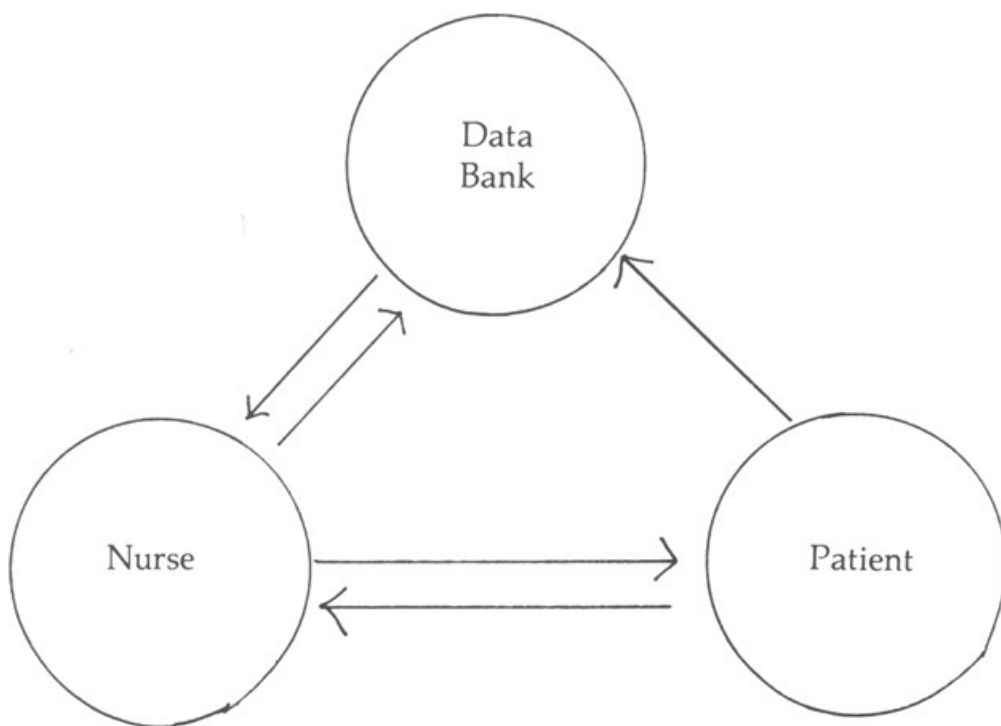


Figure 1. Data flows independently of patient location.

A data collection tool that addresses the specific requirements of the IBD patient was developed. Great consideration was given to making the system "dynamic" — that is, having the flexibility to adapt itself to changes that occur over time, or to changes from the demands of the nursing profession. New categories to be monitored can easily be added to the system, and those that become insignificant can be deleted.

The distribution of IBD cases is proportional to the distribution of the Canadian population (IMS, 1983). This factor gave rise to the idea of having one central data base where all of the information is housed, and, that communicates with many satellite clinics on terminals which have 2-way input/output into the system. For the first time, a nurse in a remote centre would have access to the information of a large centre. In phase I, the data base will be established and, in phase II satellite centres will become participants in the information exchange.

Available hardware was examined. The search led to the conclusion that the proposed system will use an IBM personal computer XT unit that will have an initial capability up to 128 K memory, disk drive 1-320 K, one 10 megabyte hard drive, one Monochrome display screen, one printer, and will use 2.0 DOS, a COBOL compiler, and one asynchronous communications 2.0. If needed, this system can be

increased to 640 K memory, 20 megabyte hard drive, and disk drive that can be increased to 640K (IBM, 1983).

This configuration will have a memory large enough to contain all necessary programs. It will also have a large storage capacity on disk, it will produce printout reports, will contain a ready made software compiler (COBOL) with versatility for processing data and scientific work. The system is also capable of connecting with satellite IBD clinics in remote areas, and communicating with hospitals and other medical facilities about the personal record and permanent file.

The decision to use commercially available software with a COBOL compiler was made because it enables the system to have built in routines and commands for scanning each record thoroughly, and because it has other features that facilitate the programming process of this system.

The low cost of developing and maintaining the system was a major consideration in the choice of both the hardware and the software. It may surprise nurses and administrators to learn that leasing the above hardware and built-in software costs approximately \$300 per month for the data centre, and \$150 per month for each satellite centre (IBM Configuration Guide). Programming, an expense incurred only once, is estimated at approximately \$10,000. Maintenance of the systems would be done by one operator/programmer. In comparison with this cost, usage of central processing unit time for one hour is \$800 for commercial use, and additional charges are incurred for storage of information and usage of the system (UBC, 1983).

The Permanent File

The permanent file contains and stores the permanent records of the IBD patient. To date, no permanent file exists with data about IBD patients. Valuable information about individuals once treated for IBD is lost. The permanent record enables the information to be gathered and housed for later analysis. The permanent file consists of all records of individuals seen for IBD.

The format of each record is that of the data collection tool. The record contains a patient identification code and a secondary protection code. The codes protect the patient's identity while allowing records to be recognized and made accessible to researchers. Each question on the tool is defined as a category and the number of categories appears following the secondary protection code. Each category maintains the same number in all records for easy identification. Each category will consist of an identification number, the total number, the total number of updates, and will be followed by the updates.

<u>code number</u>	<u>second safety code</u>	<u>number of categories entered in the record</u>
<u>category number</u>	<u>no. of entries in category</u>	<u>Information #1</u>
		<u>Information #2</u>

EXAMPLE: Weight in Kg.

<u>0 1 0</u>	<u>0 0 3</u>	<u>8 1 0 2 2 2 0 5 5 2 5</u>	= FEB. 22/81	55.25 Kg
		Y Y M M D D W W W W W		
		<u>8 1 8 0 1 2 0 5 1 5 0</u>	= OCT. 12/81	51.50 Kg
		<u>8 2 0 3 1 5 0 4 8 7 5</u>	= MAR. 15/82	48.75 Kg

Y = year
M = month
D = date
W = weight

Figure 2. Structure of a record.

Figure 2 illustrates the structure of a record and category. The example presented illustrates the weight category, its number, the number of updates, date of update, and the information collected in kilograms. Similar information in all specified categories will be recorded for each patient. Figure 2 shows how the patient responds to nursing care by keeping track of the present state and keeping in mind the past history.

Additional categories can be incorporated by assigning a new category number and adding it to the tool. Deleting information from the master file, when it is no longer needed, could be automatically done by the program.

The quantity of information that will be collected from a patient during his lifetime is difficult to estimate because of the variability of the disease process. Therefore, collecting the data on disk drive, maximizes the system's ability to house information. Large volumes of information can now be stored.

Benefits of a permanent file include accurate history taking about the patient's status, decreased time spent filling out and filing papers, and a continuous, updated account of the patient's health status. The information is stored and easily accessible for research purposes.

*Development of the Tool**

A data collection tool, designed to collect specific information from the IBD patient, was developed. The information is collected in a standardized format and becomes the basis for scientifically gathering information about the IBD patient. Much nursing literature now concerns itself with holism, a philosophy that deals with the total person and with the individual's relationship to all aspects of his environment (Iveson & Iveson, 1981). This tool employs that philosophy and collects data about the patient's family, environment, habits and attitudes.

The tool consists of two parts. Part One contains data about the patient and his family prior to diagnosis, and Part Two deals with data related to individual characteristics following diagnosis. Part One collects unchanging information about the family history, environment, dietary habits, diseases, and areas that could be implicated in contracting IBD. Part Two collects a social and changing data base, a nutritional data base, and a physiological data base. While Part One data is collected only once and stored, Part Two data is collected on each visit.

*For a copy of this tool please write to the author.

A two-part tool was developed for several reasons. First, baseline patient information is collected and stored about the patient and his family prior to diagnosis. This information does not change, and when examined may give clues about common factors implicated among persons contracting IBD. It also enables changes from the pre-illness state in each IBD patient to be followed. Part Two data allow a current, useful working data base for each patient to be readily available.

The categories of the tool are organized under the headings; social, nutritional, and physiological data bases. These headings were selected from a review of the literature of IBD, from consultation with health care professionals, and from the writer's work. They identify the major coping challenges to the IBD patient. The categories of questions allow objective data to be elicited in areas of importance. The questions have employed the work of major theorists and clinicians in the area of IBD.

The social data base includes aspects about work, travel and environment, family, and coping with a chronic illness (Friedman, 1981). A detailed nutritional data base assesses the kind and quantity of food consumed and the effects of the food on the patient. The patient is asked about his use of natural laxatives such as pecans, tapioca, fruit, and wheat bran. He is asked about his intake of peanuts, almonds, yogurt, sesame seeds, and certain spices because they are known to alter intestinal flora and might have effects on the disease (Le Sassier, 1978). Vitamin intake is also assessed. The intake of tea and coffee, which aggravate the disease in some people (Given & Simmons, 1979), is determined.

The physiological data base addresses symptoms of the disease such as weight loss, diarrhea, diarrhea alternating with constipation, anemia, pain, sleep difficulties, arthritis, iritis, abscesses, fissures, fistulas, and skin problems (Farmer, 1980). In addition, current allergies, exercise, and intake of medications are covered.

The data collection tool ensures that the same questions are asked consistently each time the patient is seen, and that the answers are recorded in a standard manner. The information is banked in the permanent file. Availability of data in a large population, over a period of time, will contribute a broad knowledge base from which to draw conclusions.

The Update File

The first time a patient is seen, both parts I and II of the data collection tool are used. Both historical and patient update information are collected. On subsequent visits, only part II, the patient update infor-

mation from is used. The information collected in the update file is then transferred, by program, to the permanent file. The format of the update file is the same as that of the permanent file.

The Index File

A major dilemma of computerized health records involves the desire that information be available for study and the need for anonymity of the patient. The index file cross-references the patient's real name and personal information with his code. His code is a number unique to the individual. Access to the index file is limited to those giving direct care to the patient, and to those needing clerical information. Information may be retrieved in the form of a printout or on the screen of the video display terminal. It may be a complete patient history or one or more categories from the patient tool.

Advantages of the System

The patient contributes information to the system and receives benefits from the system. Advantages for the patient over conventional record-keeping include comprehensive individualized monitoring, prompt treatment of problems, and rapid transfer of records. The system enables patient problems to be monitored closely and changes to be spotted quickly, and treated promptly. Significant weight changes, for example, could be identified over a period of time. In the conventional manner of following patients these might be missed.

Patients who did not return for an appointment could be located and contacted in order to find out why they did not return. Once a month, the system could be programmed to identify all patients who missed appointments. The person with access to the index file could then identify the individuals, and, if necessary, schedule an appointment. Perhaps the symptoms have improved or he objected to some aspect of his care. These areas could be pursued with him, his record updated, and his plan of care changed to best meet his needs. As more information is known about IBD, patients can be better cared for.

New Directions in Nursing

Nurses who use this system will find data that is objective, collected consistently, and has validity as the basis of scientific study. The system makes data available that has a common denominator for the study of trends among IBD patients, that can be used to generate clinical research. Avenues of study opened through this system include the ability to isolate one variable and to compare it with other variables within the same patient, and to compare one patient's condition with another patient's condition.

It is also possible to study several variables as a group and to examine their inter-relationship. It might be noted, for example, that those patients who use stress management techniques or who exercise regularly report less intake of medication or a lower incidence of diarrhea than patients who do not. If this were the case, learning stress management techniques and exercise could be built into the care plan of the IBD patient.

Previously, physiological, psycho-social, and nutritional aspects of the IBD patient were not studied together in a large population. This would be an interesting avenue to study.

Conclusion

A system in which the nurse uses an IBM mini-computer to manage collection and retrieval of data about the IBD patient has been described. In her 1982 editorial comment, MacPhail states, "The greatest need in nursing as a discipline is to develop the scientific base of nursing practice for the purpose of improving nursing care" (MacPhail, 1982). Implementing the proposed system will comply with this vision of the future nurse.

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RÉSUMÉ

Les ordinateurs au travail — conception d'un système pour l'étude d'une maladie chronique

Le présent article décrit comment une méthode de traitement des données peut être appliquée, à l'aide d'un mini-ordinateur, à un domaine de la pratique infirmière en vue de favoriser la recherche et d'accroître les connaissances infirmières. On envisage un système composé d'un fichier permanent, un fichier de mise à jour et un fichier d'index, et d'un dispositif de sortie ou d'accès au fichier qui est utilisé par l'infirmière pour consigner des données au sujet d'un malade atteint d'une affection intestinale inflammatoire.

Les affections intestinales inflammatoires sont courantes et l'on n'en connaît ni la cause ni le traitement. Le système, tout en protégeant l'identité du malade, permet à l'infirmière d'obtenir des données recueillies auprès d'un grand nombre de sujets, pendant une longue période de temps et d'utiliser ces données à des fins de recherches sur la maladie et les soins infirmiers qu'elle requiert.