EVOLUTION OF A MICROCOMPUTER-BASED STATEWIDE
KIDNEY DIALYSIS REGISTRY MANAGEMENT AND REPORTING SYSTEM

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ABSTRACT

This paper provides a brief description of the development and application of micro-computer technology and a sampled data base management system to the specialized needs of a small, federally funded, Renal Network Council organization.

The hardware evolves from word processing equipment to business level hard disk micro-computer. The software progression is from list processing to actuarial life table reports written in compiled BASIC. The file structure and size changes from a 160K list processing file to a 1.3 megabyte random access file.

BACKGROUND

End Stage Renal Disease (ESRD) Network areas were designated by the federal government in 1978 to assure the availability of necessary services for chronic renal failure patients and monitor the quality of care these patients receive. Each network has a Medical Review Board to analyze profiles of care and conduct medical care evaluation (MCE) studies.

As networks tried to study the size and characteristics of the chronic renal failure patient caseload, they had no historical data to use. Although a federal end-stage renal disease (ESRD) management information system (MIS) had been in place and was processing 4 forms - an Initial Patient History and Treatment form, a Tissue Typing form (for kidney transplants), a Death Notification and a Semiannual Facility Survey - the lack of adequate ESRD central office funds and the relative obsolence of their hardware caused DP to fall behind schedule. Further, the terminals used were those of the Social Security Administration (SSA) and shared with other governmental units, thus reducing the on-line time available to the ESRD program staff.

When, DHEW, now HCFA, produced a census of patients for each network by facility from their MIS, the nature of certain problems became apparent: duplicate records and the inclusion of non-ESRD patients was found.

Networks needed reliable current data on patient origin to make Certificate of Need (CON) recommendations, and recommendations for new facilities to be included in the federal reimbursement program. Networks needed profiles and cross tabulations of patient care data - causes of ESRD, number of home patients, number of hospitalizations, number of diabetic or hypertensive patients, survival data, etc. In 1980, DHEW informed networks that modest funds would be made available for in-house mechanical data processing applications. These funds would have to cover the total costs of hardware lease or acquisition, software design and development and were being provided because starting in 1981, the networks were to assume the responsibility of processing three patient specific forms prior to transmission to the federal ESRD office. The effect was to decentralize the ESRD MIS and allow local validation similar to the concept in the PSRO (Professional Standards Review Organizations) program.

In 1980, New Jersey had 26 federally certified ESRD facilities and 2,074 patients. When the availability of HCFA funds was announced, the New Jersey network applied for and was awarded $14,800 for calendar year 1981.

APPLICATION DESCRIPTION

The initial purposes of this data processing application were to 1) collect, validate and enter selected data items from the 3 MIS patient-specific forms; 2) enter as baseline data a validated version of the federal census from 1979 forward; 3) utilize a word-processing capability to reduce staff time for routine multiple mailings; 4) validate the aggregate data reported on the facility survey; and 5) produce reports showing ESRD caseload characteristics. Initially 18 items were recorded on each patient as a minimum data set.

The New Jersey network subcontracted with the Middle Atlantic Shared Services Corporation (MASSC) for technical advice on hardware selection and programming services. MASSC had previous experience in maintaining a renal patient registry using a commercial time-sharing system and RAMIS data base management software, thus was familiar with the esoteric terminology and peculiarities associated with the renal program environment.

An analysis of the information processing requirements of the network resulted in the identification of the need to satisfy both word processing (WP) and limited data processing (DP) functions. The initial objectives of the network for DP applications were very basic. In addition to the periodic generation of alphabetized patient listings (by facility) there were requirements for cross tabulations of patient characteristics such as...
as sex and race by age groups; tally counts by treatment modality and setting; and patient origin (county) by age group. A certain degree of discreteness and consistency editing of data was also specified as necessary to insure a reasonable level of data base accuracy. The Network could also utilize WP capabilities to assist in its communications with the members of its Council and various Committees as well as the 26 New Jersey ESRD facilities and other ESRD Networks.

The limited underfunding, no assurance of funding continuation beyond the first year, and a Network staff of four people without any WP or DP experience created formidable constraints on hardware/software selection. In addition, the funding was not approved until March 8, 1981 and yet there were expectations of keying in the federal MIS patient file for the years 1979-1980, adding new data for 1981 and generating statistical reports and listings from the system during 1981.

The MASSC recommendation was a DEC WS-78 workstation with List Processing (LP) software augmented by Math/Sort (M/S) programming software from Symbolic Systems, Inc. The WS-78 was configured with a 16K (word) memory, a letter quality printer, and two eight inch diskettes with approximately 250,000 bytes of storage on the document diskette and 80,000 bytes on the system software diskette. (The system also had options for communications capabilities which were of interest because of federal plans for possible remote collection of ESRD data.)

The complete cost of the hardware and software was just under $10,000. The remainder of the available funds ($4,800) were used to program the edit and report programs; document the software; establish and document the operating procedures; and provide training to the Network staff. The equipment procurement and development of the application software took place during the late spring of 1981 while the Network was developing forms submission procedures with its facilities and the 1979-1980 federal patient listings were being reviewed for data entry to the WS-78.

All facilities were asked to identify the individual who completed each federal form and two workshops were held to explain how the network would collect and process the forms. All were given the federal MIS patient census for their facility, asked to check each item for accuracy and currency, then return the verified copy to the network.

After all MIS census lists were returned, the number of corrections that had to be made was in the order of 35% to 65% depending on the item; deaths were very much under-reported, many patients were not on the correct facility list, many types of dialytic therapy were not current, transplants were very under-reported. Incorrect name spellings plagued efforts to reduce the number of duplicate records. The MIS data, though known to contain errors, was then entered into the WS-78. After additional corrections to these files were made, the first Network patient listings were produced using the WS-78 LP function. It was not until the 3rd census corrections that the file approached an estimated 85% reliability level. Throughout the data conversion period, new forms continued to be received, reviewed and added to the file after passing the Math/Sort edit program which was now available. When the file was estimated to be reasonably complete, the following reports were then generated via the Math/Sort application programs which were now completed. The following reports were sent to each facility and produced in the aggregate for the State:

- alpha patient list/alive (with all data items)
- alpha patient list/deceased (with all data items)
- patient county of residence by county of treatment by facility
- number and mean age of live patients and patients not ever transplanted
- treatment modality summary report by facility
- patient age/county of residence summary report by facility
- months on dialysis at time of death/age group by facility
- number of deceased patients and mean age at time of death

The word processing application had to be limited to material that would likely be revised frequently and/or complex statistical typing where corrections were usual because the effort required to validate the patient file had been underestimated and required most of the available staff time. Initially, a part time staff person had been recruited but became full-time in short order.

In time, the volume of corrections and changes to the patient file were recognized as time consuming because of the patient search procedure required by the list processing software, i.e. alphabetically through the file until the correct record was located, then through the remainder in order to rewrite the file. In addition, the sort software required the sorted file to output to the system software disk which only allowed for 80,000 characters document storage, thereby requiring the facility files to be sorted one at a time.

The need for a Statewide alphabetic patient listing (needed to locate duplicate records with unpredictable name spellings) was met by a time-consuming process of copying data from facility disks (8) onto a Statewide disk in alpha progression. The error potential and additional processing time was deemed unacceptable. Further, the time required to back up the 8 disks became burdensome. These difficulties, plus those encountered in the complex programming required to produce new reports, and the limitations of core memory and disk storage size, all showed that a review of system requirements was due. DP needs showed that larger core memory and the necessity for fewer disks would appreciably enhance system performance. These factors led to cancelling plans to upgrade the WS-78 equipment to a DECMate ($4,000) and go to microcomputer technology.

The change to a Vector Graphic 3 with 64K RAM, two 630K floppy disks and an OKidata 80-column printer was made in February 1982 (the initial DEC WS-78 installation had been made in
April 1983). By using the communication hardware and software capabilities of these otherwise totally incompatible microcomputers, the Networks patient files were reformatted and transmitted from the DEC WP to the Vector Graphic microcomputer without any problems. Now, the entire patient file was on one 5 1/4" floppy and record accession appreciably faster, though not in seconds; going through the entire sequentially structured file took approximately 20 minutes.

At the beginning of 1982, New Jersey had 2,360 chronic renal patients (alive) and file size (including deceased patients) was approaching 4,000 records. Starting in 1982 a diagnosis (cause) of renal failure was added to each patient record, and the treatment setting and race categories were expanded. In addition to the reports which had been converted from the WS-78 system, the following reports were added to the microcomputer system:

- Live patients A/O beginning and end of year, 1979 forward/facility
- Daily transaction log (with all data items/patient)
- Home and self-care patients by number and %, by type of therapy, compared to staff-assisted/facility
- Transplant patient status by type of transplant longevity report/facility
- Expanded patient county of residence by age group report/facility
- Expanded patient race by age by sex report
- Dialysis longevity report with average years in therapy by age group/facility
- Listing of all new patients by year of first treatment
- Listing of all patient deaths by year of death
- Life table analysis
- Listing of all patients by birth date sequence (to review for possible duplicate records)
- Diagnosis report/facility

In October 1982, with over 4,000 records on file, the file had to be split onto 2 floppies because of the sort procedure which required two copies of the file to be resident on the same disk, thus restricting the file size to approximately 288,000 bytes, i.e. one half of the 596K available disk capacity.

Although the techniques of using multiple floppies to store a data base is normal on microcomputer systems, the constant insertion and removal of disks eventually takes its toll on the disks and, more importantly, on the disk drives. However, the 1982 hardware configuration and software could have satisfied the 1982 data collection, storage and reporting requirement indefinitely using this multiple-disk concept.

In 1982, HCFA initiated new directives to the Networks which emphasized the need to carry out studies of patient treatment by "tracking" them via the evaluation of historical data. This new emphasis increased the patient data items being collected from 19 to 50 items. (The additions were primarily made to allow for recording of multiple codes and dates for the same data types.) This requirement resulted in a complete redesign of the data entry screen format to accommodate all 50 items on one screen. The system also had to be redesigned to record patient movement through different treatment modalities and facilities so that "historical" data as well as a "current" status was maintained. HCFA directives also required that diagnosis codes be revised from a locally developed condensed version with a 2 digit code to a much expanded 5 digit ICD-9-CM system; editing of 70 renal related codes had to be incorporated. These new requirements again called for an upgrade in storage capability, conversion from sequential to random access files and the design of special record retrieval procedures due to the continuation of name misspellings. The system was upgraded to a Vector Graphic 4 with 5 megabytes of hard disk and 128K RAM. Since the file would now be subject to a higher volume of data changes, minimization of record accession time became a critical redesign factor.

Now, record accession is instantaneous with the introduction of the random access file structure. Machine-assigned patient numbers (4 digit) speeds data entry, data entry screen format improvements facilitate accuracy of input and the audible alarm alerts the operator to inadvertent illegal entries at the time of input.

The system has been used to provide all reports listed earlier to component facilities in the network and the State Department of Health. Additionally, the Network has responded to special requests for information not aggregated in the routine reports in a manner to allow analysis. These included requests to: total the number of patients in a specific 3 county area by treatment site and county of residence from the Department of Health in regard to a CON question; total the number of cases in treatment 16 years of age or below with a count for each facility as well as county of residence from a pediatric nephrologist at one of the component facilities; and, case load summaries according to different age groupings and race groupings for the Forum (of all 32 network chairmen) for national reporting requirements.

The system continues to have the capacity to function as an intelligent terminal to communicate New Jersey registry data to the ESRD MIS processing center. It also has a current storage capacity which can accommodate a registry of 20,000 patients and thru a local micro link network upgrade could maintain a data base of 300,000 records. This hardware potential and the sophistication of the DEMS software could provide services to other States and regions if required by possible HCFA options to reduce the number of renal networks.