Abstract

COSTAR was originally designed for use in an ambulatory care clinic. This paper describes the adaptation of COSTAR for use in the Kidney Transplant Unit of the Massachusetts General Hospital. With few changes, the system was modified to make it compatible with the needs of the Transplant Unit that include the clinical care of both inpatients and outpatients as well as administration and research. COSTAR was chosen over other available file management systems because the time-orientation of the COSTAR record make it ideally suited to the tracking of time-dependent episodes in this population. The directories were modified to include the highly specialized medical vocabulary associated with renal disease and transplantation. Forms specific to rejection and complications of transplantation were developed. The flexibility of the Medical Query Language permitted the development of many features to meet special reporting needs.

Introduction

Kidney transplant patients are markedly different from the typical patient seen in an ambulatory care clinic for which most computer-based record systems were designed. In ambulatory care a patient may be seen on average 1 or 4 times a year for well care. Transplant patients, in contrast, are followed closely and frequently with extensive monitoring accumulating a considerable volume of data which can span ten years or more and include periods of hospitalization. The diversity of information collected on the transplant patient includes dialysis history, tissue typing, rejection, monoclonal antibody monitoring, infections and complications, as well as the spectrum of diagnoses, tests, medications, and demographic data. In addition, donor information including items such as the ischemia time of the donor kidney is included in the recipient's record.

The Transplant Unit of Massachusetts General Hospital (MGH) asked the Laboratory of Computer Science (LCS) to recommend a computer-based information system to meet the needs of their practice. Over a period of several weeks, each of the members of the transplant team was interviewed by a physician and computer scientist from LCS and asked to describe their data requirements. The first kidney transplant at the Massachusetts General Hospital was done in 1963. To date, over 580 transplants have been performed at MGH. Currently, approximately 50 kidney transplants are performed annually. The members of the Transplant Unit include specialists in surgery, nephrology, infectious disease, immunology, pathology, nursing, psychiatry, dietetics, and social work. Each of these specialists collects different sets of data on the patient; however there is considerable overlap in many of the items recorded. A central repository for this data would decrease duplicate data recording and would facilitate access to the central record by the individual members of the team. Communication of information among the group would be facilitated by the legibility of a computer-printed record over the hand-written notes in a traditional medical record. The laborious task of thumbing through a thick, often poorly organized paper record is eliminated in an automated system where selected information can be retrieved and displayed with ease.

Requirements of Transplant Unit Information System

The first requirement of the system was that it facilitate the clinical care of the transplant patient. As Pollak has noted "the treatment of patients with chronic renal disease demands that the physician understand and handle a complicated interplay of many events. Effective treatment by chronic dialysis and transplantation has increased the complexity of tracking clinical events and interrelating clinical laboratory and therapeutic data." An accumulated data base of clinical experience with transplant patients represents a valuable aid to clinical decision making. Confronted with a new patient, the response to alternative therapies in similar patients seen in the past can help in deciding which actions to take.

A second requirement of the system was that it serve the research needs of the Transplant Unit. Often, research data is collected as a separate activity from the delivery of clinical care. Research data that is collected, passively stored, and never used in the active day-to-day care of the patient suffers from not being re-examined. The use of one record for both
clinical care and research insures that the research data is not a passive archive but will be reviewed by the clinician in the ongoing care of the patient thus closing the feedback loop and assuring the quality of the data. The physician sees the record the next time the patient comes in for a visit and has the opportunity to correct erroneous data.

The Choice of the COSTAR System

After a careful appraisal, COSTAR, the Computer Stored Ambulatory Record, was chosen over other available file management systems for use in the Transplant Unit. At first glance, this is a surprising choice since COSTAR was originally developed to be a complete medical record system for use in a group practice in the care of ambulatory patients. However, the time-orientation of the COSTAR record make it ideally suited to the tracking of time-dependent episodes in the transplant population. It is a generalized package divided into a number of modules with a built in flexibility that allows it to be used in a variety of settings. With few changes, the system was modified to make it compatible with the needs of the Transplant Unit. Although a custom tailored system written specifically to meet the specifications of the Transplant Unit was a possibility, building the system from scratch would be time consuming and prohibitively expensive. Adapting an existing database management system to suit the Transplant Unit's requirements was chosen as the most cost effective solution.

In COSTAR, the medical vocabulary of terms that are allowed in the patient record are encoded in the "directory". Each medical group may define the lexicon of terms appropriate for their practice. The Transplant Unit started with the COSTAR directory in use in the Primary Care Unit of MGH so that laboratory tests, medications, and diagnoses used in both Units would each have the same code. This basic directory was then enriched to include the highly specialized vocabulary associated with transplantation.

In most settings where COSTAR is in use, a self-encoding form called an encounter form is used to collect and record information pertaining to an ambulatory patient visit. For the Transplant unit, a series of forms was designed to capture not only the ambulatory clinic visits but also the hospital stay of the transplant patient. Information relevant to the transplant procedure, rejection episodes and complications. The hospital stay is a data-rich period that offered a challenge as to how best to distill the multitude of data items available down to a reasonable number. A daily hospital form is used to capture the key events that occur for a patient in a given hospital day. Figure 1 shows a sample copy of a Transplant encounter form.

Many months were spent in the development of the directory and the design of encounter forms. The reason this task demanded so much time is due to the unusual nature of the data (pertaining to specific chronic disease rather than the well care typical of an ambulatory setting), the sheer volume and complexity of the data, and the need to carefully define and encode data that would form a research database.

The process of abstracting data from the records of the past 500 transplants onto encounter forms and inputting them to the COSTAR system is an enormous task that has only just started. Again, this is atypical, most COSTAR sites begin by prospectively recording information on their patients rather than going back and encoding detailed archival information.
One problem encountered is that COSTAR does not permit the entry of encounter dates prior to 1/1/70. Since the Transplant Unit has transplants dating from 1963, a solution was worked out for entering the pre-1970 data that involves using an encounter date in 1970 but inputting the actual date under an administrative code. This awkward solution allows the Medical Query Language to correctly assess the date of occurrence; however, the canned COSTAR routines (flow charts, encounter reports, and status report) continue to be encounter date based.

More adaptation was needed in the area of printed reports. The standard COSTAR output documents are the status report which summarizes the current condition of the patient, the encounter report which lists the information captured at a particular visit, and the flowchart which displays the course of clinical findings over time. COSTAR allows for the setting up of special purpose flow charts, an option that was extensively used in the Transplant Unit's system. Flowcharts summarizing tissue typing information on donor and recipient, the immunosuppression history, and the course of serum creatinine, BUN, blood pressure, and weight over time were developed. Wherever possible, the existing COSTAR reports were used.

The use of the Medical Query Language

The Transplant Unit had been using a standard report format to review patients seen in clinic at a weekly meeting. The use of status report and the clinic encounter report for each of these patients was suggested as a replacement for the report format in use before the introduction of COSTAR. Rather than use one of the canned COSTAR reports, they requested that COSTAR present the data in the same form the Unit were previously using. The Medical Query Language (MQL) was used to generate this report. MQL is a high-level procedural language designed for use by non-programmers. It is anticipated that MQL will be widely used by the members of the transplant team to "browse" through the data base and get answers to their research and practice administration questions. The flexible data retrieval and display MQL offers make it possible to retrieve and display the data for the weekly clinic summary report in a format close to the one formerly used. MQL is used as a true report generator with the clinic summary query being hooked to the COSTAR print option driver. On demand, the query can be made to search for patients seen in the clinic during the week and print a summary according to the prescribed format. Figure 2 shows a sample clinic summary report.

Abnormal Laboratory values are flagged with an asterisk (*). Changes in medication dosage are indicated by the notation: previous dosage "->" current dosage.

Figure 2. Clinic Summary
MQI is also used to prepare a report summarizing the transplant (Figure 3). Items included are the renal disease leading to transplantation, date of onset of disease, dialysis history, transfusion history, tissue typing data on recipient and donor, sensitization, donor information, and ischemia time. This query is attached to the COSTAR display option driver so that members of the Transplant Unit can display this information for individual patients as needed.

Figure 3. Transplant Summary

<table>
<thead>
<tr>
<th>Transplant Unit</th>
<th>Transplant Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>MGH Transplant Unit</td>
<td>Know how to do it</td>
</tr>
</tbody>
</table>

- **Recipient**
  - **Age**: 38
  - **Sex**: Male
  - **Race**: White
  - **Height**: 70
  - **Weight**: 150
  - **Blood Type**: O
  - **Diagnosis**: Renal Failure
  - **Cause of Death**: Heart Failure
  - **Type of Transplant**: Living Donor
  - **Source of Donor**: Family
  - **Hospital**: MGH
  - **Cause of Death**: Heart Failure

- **Donor**
  - **Age**: 40
  - **Sex**: Male
  - **Race**: White
  - **Height**: 70
  - **Weight**: 150
  - **Blood Type**: O
  - **Diagnosis**: Renal Failure
  - **Cause of Death**: Heart Failure
  - **Type of Transplant**: Living Donor
  - **Source of Donor**: Family
  - **Hospital**: MGH
  - **Cause of Death**: Heart Failure

The Transplant Unit also requested that COSTAR be made to plot clinical values over time on a graph. MQI was enhanced to permit the plotting of up to two values across time on a graph. A general purpose query was written and attached to the COSTAR display so that interactive plots are now available.

Figure 4. Plot of Serum Creatinine Post-Transplant

**Conclusion**

The experience of the Transplant Unit shows that COSTAR can be used in a setting quite different from the ambulatory care environment for which it was designed. The addition of the vocabulary of transplantation to the directory, the design of special purpose encounter forms, and the use of the Medical Query Language to generate custom reports and plots made this possible.

**References**