COMPUTER SUPPORT OF CARDIOVASCULAR SURGICAL REGISTRIES*

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Summary

In support of our services and research goals we have developed computer-based systems to register and follow-up aorto-coronary bypass, prosthetic valve and pacemaker patients. We have used a minicomputer database management system which has software facilities which allow it to flexibly handle evolving needs.

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Introduction

University teaching centres with large cardiovascular surgical programs are faced with two significant problems:

1. The service problem. The need for efficient patient documentation and effective long term follow-up methodologies.

2. The research problem. The specific interests of individual researchers and the constant review of surgical mortality and morbidity necessitate that consideration be given to the creation of efficient data gathering, data retrieval and data analysis processes.

The large patient populations typically treated and followed at these centres are both a rich source of research material and a constant source of work load for already busy staff.

Our work on surgical registry and follow-up systems is an attempt to create comprehensive support technology (composed of hardware, software and appropriate personnel) to both assist in the service-related activities and to provide sufficient resources and quality controlled data in order that research can be carried out in a meaningful, unburdenesone way.

Scope

Our computer support of cardiovascular surgical registration and follow-up includes the following areas at the present time:

1. pacemaker registration and follow-up
2. prosthetic valve registration and follow-up
3. aorto-coronary bypass registration.

We are currently evaluating extension into other areas, such as vascular surgery, and into greater depth in existing areas such as studies relating to myocardial preservation techniques.

Beyond our own in-house pacemaker-related work, we are in the process of designing a province-wide system for pacemaker registration. All major centres in the province of Ontario are cooperating in the design of the dataset, the appropriate forms, and the methodology of implementation.

Volume

At the present time our prosthetic valve and aorto-coronary bypass registries are each composed of approximately 2,000 patients operated on at Toronto General Hospital.

We have been registering and following our pacemaker patients on a smaller computer system since 1972. We currently follow over 1,000 pacemaker patients, having implanted over 2,000 pacemakers since the computer-based registry was begun. We perform approximately 8,000 follow-up visits or transtelephone transmissions of electrocardiograms every year.

We currently perform approximately 400 aorto-coronary bypasses and approximately 200 prosthetic valve procedures annually. Approximately 450 new pacemakers are implanted or replaced each year.

Methodology of Patient Data Collection

When we first began our computer-based systems we opted to backlog a minimum of information on each patient on whom surgery had been performed to date. The amount of information collected varied for each specific surgical program. The data collection forms used for prosthetic valve and aorto-coronary bypass backlogging are included as Figures la and lb and Figure 2, respectively. The patient identification form is the same for all surgical programs.

When in 1972 we began our computer-based pacemaker registration and follow-up program, we opted to log each patient on the system as the patient showed up for his first post-implantation or follow-up visit. It thus took approximately six months before all active patients were registered on the system. No backlogging was done in
At the present time we are switching from our older PDP-8 based pacemaker system to our Varian database management system (see below). This time we have decided to backlog all existing patients using a simplified subset of the data on the PDP. Detailed data collection will occur prospectively beginning with the first follow-up visit following the initiation of the new system.

For routine data collection we have tended to rely heavily on optical mark-sense forms. Examples of these are included and their characteristics and price are documented elsewhere.6

At the present time our aorto-coronary bypass program is limited, a basic form serving both retrospective and prospective patient registration.

In the case of our prospective scheme for prosthetic valve registration and follow-up, our approach has been more comprehensive and a series of optical mark forms have been created covering the pre-operative, operative and post-operative phases of patient care as well as patient follow-up documentation and mortality documentation. The follow-up form is included here as a representative example (Figure 3).

We have recently completed a completely new set of data collection forms, mostly of optical mark-sense variety, relating to our pacemaker follow-up system. In addition to the standard patient identification form there are forms for: pre-operative clinical assessment; operative procedure documentation, from which it is intended to generate the operative note; follow-up documentation, which will serve the purpose of both clinic visits and transtelephone transmission of electrocardiograms; patient termination of care; and a form which documents the state of the explanted pacemaker. This form set is available from us on request.

There already exist various additional datasets which are linked to the surgical registration and follow-up data, such as invasive hemodynamic data, echocardiographic findings, etc. These additional datasets are recorded independently and able to be associated with surgical data via the tools provided under the database management software.

In addition, work is underway to extend especially the aorto-coronary bypass registry to include follow-up. An example of our current form is enclosed as Figure 4.

Any of the surgical datasets can be extended by the simple expediency of creating additional forms and providing the appropriate linkages of this information to the existing surgical data.

Service Aspects

The primary service uses of the system at the present time are the generation of reports (for example, pacemaker reports include operative note generation, and the production of letters summarizing patient status to referring physicians) and the production of global management reports and clinic schedules.

One useful global report is produced weekly for our Emergency Department and contains a brief summary on each paced patient. This printout can be referenced when a pacemaker patient arrives at the Emergency Department in order to determine the type and state of the pacemaker quickly. This report has completely obviated midnight raiding of the Pacemaker Centre’s pacemaker charts, preventing the loss of valuable records.

Software is being produced as part of the newer pacemaker system which enables the system to generate standard patient follow-up schedules, allowing the physician to modify these as required. The follow-up schedules can be based on the specific model of pacemaker implanted in the patient, the status of any advisories on his pacemaker, or on any patient-related problems which require more or less frequent follow-up.

Summaries of each patient encounter will be produced for inclusion in the patient chart. Address labels for letters to patients or their physicians are produced by the system as well.

In the aorto-coronary bypass and prosthetic valve follow-up programs, a program can query the database for all patients whose anniversary of surgery is occurring and letters requesting patient visits to the follow-up clinic or alternatively the mailing of follow-up questionnaires are initiated automatically.

Since telephone numbers are also kept available on the system, when follow-up letters fail and first and second notices have no effect, telephone follow-up can be initiated to at least gain basic information about patient life status.

As with pacemakers, follow-up frequency can be based on any patient or device related parameter such as the type of valve, patient symptoms, or the time since surgery.

Research Aspects

At a departmental level, on-going evaluation of both short and long term mortality and morbidity is a common goal. Individual researchers associated with each surgical program have specific research interests. It is intended that data on the system support the department-level goals and that, at least, the individual researchers be given significant assistance in obtaining patient cohorts or in considering the feasibility of given cardiovascular surgical research projects.

Individual researchers have wide-ranging interests. Relating to pacemakers, there are studies of the real cost and longevity of various pulse generators, of efficient and effective modes of follow-up, and of the overall indications for and success of cardiac pacing. In the area of prosthetic valve research, the relationship of the timing of surgery relative to onset of symptoms and a resultant long term morbidity, the longevity of specific valve types, and the long term status of the left ventricle, are, to name a few, projects of interest. In the aorto-coronary bypass area,
the patency rates, long term functional status, and pre- and post-surgical ventricular function are examples of the specific research interests.

Relating to both aorto-coronary bypass and prosthetic valve surgery, there is a significant interest in myocardial preservation techniques, an area currently under consideration as one for which we may significantly expand our data collection scheme.

Where the research interests are not adequately served by current data collection forms or data collection methods, is quite straightforward to introduce newer more detailed forms which can be used, perhaps in conjunction with other data collection procedures, to add additional data to the database to meet the needs of a given study. Integrating this new data with the existing database is easily accomplished.

The Data Collection and Management System

The system is able to accept information on optical mark forms, on interactive CRT or hard-copy terminals, on magnetic tape (for instance, produced on a key-tape facility, or through direct input of numerical values using a digitizing pen).

The database management system handles the problem of integrating new data with old, of relating different datasets to a single patient when different procedures are performed on that patient, and of adequately indexing information so that reasonably speedy access can be provided to the data kept in the database.

DIEST (Data Independence Extensions to TOTAL) package1 provides a further feature of allowing the researcher to alter the type of information collected, the forms used for data collection, or the methods of internally relating data in response to changing needs. In short, the system is able to be restructured to meet evolving requirements.

A Query system is provided for data retrieval. Using the query system a researcher (several have been trained in a relatively short period of time to use this facility) is able to specify criteria (using boolean, arithmetic, and inequality operators) for selecting records from the database.

Once records have been selected in this way and saved in a file, it is possible to run easily specified reports in order to print out the data retrieved. The report generator (identical externally to MARK IV) provides mechanisms for formatting the output, sorting the output into sub-groups, and producing basic statistical information such as mean and standard deviation. Counts of the number of records retrieved before printing can be obtained as well.

We are currently developing a basic statistical analysis package which will give us the ability to analyze the data produced by the Query system. This statistical package includes t-test, paired t-test, correlation, regression, and life table analysis. We are currently studying various data display techniques which would be of value in our research and currently support the PLOT-10 package for the purpose of simple data display. There are also utilities provided for printing out subsets of information in a form compatible with larger systems. For instance, it is our practice to do more complex statistical analysis on our university computer facilities. For this purpose a tape can be produced whose information is readable by standard statistical analysis packages.

Cost

The cost of this system to the Division of Cardiovascular Surgery can be broken down as follows:

1. The cost of sharing the central computer facility along with a contribution to the computer maintenance contract ($8,500 per annum).

2. The cost of an interactive terminal and the sharing of an optical mark reader and printer ($1,200 per annum).

3. The cost of forms for recording information (approximately $1,000-$2,000 per annum).

The cardiovascular surgical database system is basically an add-on to existing divisional running costs. To date the work has been funded primarily in a research format, all support coming from external granting sources.

Computer support of pacemaker registration and follow-up, however, is supported as a hospital budget item and currently supports no outside support. Many pacemaker service functions are supported on the computer, or will be under the newer version of this system.

Among the three areas approximately one full-time user port is required to provide adequate access to the computer. The cost of forms in the new version of the pacemaker follow-up program has not been completely specified.

Conclusions

We have created a comprehensive support system for the registration and follow-up of aorto-coronary bypass, prosthetic valve and pacemaker patients. Relying heavily on optical mark-sense forms, we have evolved data collection procedures which have been used both retrospectively in registering previously operated on patients and prospectively recording information on new patients. The system used provides facilities which serve both service (such as report generation) and research (such as data analysis) needs within a busy teaching hospital.

Although we have not yet done a formal cost-benefit analysis, it appears that the total costs associated with proceeding this way are significantly less than would be associated with acquiring even two more staff persons presuming it was decided to carry out at least some of these functions manually.
The overall system has been successful in terms of maintaining an adequate patient information base suitable for service and research purposes. We believe that such a system is a serious alternative to hiring clerical staff and attempting a manual system. As well, it provides significant capabilities which would be difficult to achieve in any manual alternative.

References


## PATIENT IDENTIFICATION FORM

1. **NAME:** Surname  
   First name and initial

2. **ADDRESS:** Street, Apartment  
   City  
   Postal code  
   Province or State

3. **TELEPHONE NUMBER:**  
   Area code  
   Unknown

4. **SOCIAL INSURANCE/SECURITY NUMBER:**  
   Unknown

5. **HOSPITAL:**  
   Unknown

6. **IDENTIFICATION/CHART NUMBER:**  
   Office use only

7. **INSURANCE NUMBER:**

8. **DATE OF BIRTH:**  
   Day  
   Month  
   Year

9. **SEX:**  
   M = Male  
   F = Female

10. **PRINCIPAL OUTSIDE PHYSICIAN:**  
    Surname  
    First name and initial  
    Street, Apartment  
    City  
    Postal code  
    Province or State

11. **OTHER OUTSIDE PHYSICIAN:**  
    Surname  
    First name and initial
    Street, Apartment  
    City  
    Postal code  
    Province or State

12. **CODED INFORMATION:**

### PROVINCE CODE:
- Newfoundland NFD
- Nova Scotia NSC
- Prince Edward Island PEI
- New Brunswick NBR
- Quebec QUE
- Ontario ONT
- Manitoba MAN
- Saskatchewan SAS
- Alberta ALB
- British Columbia BCO
- Yukon Territories YUK
- North West Territories NWT

### STATE CODE:
Use standard two letter coding.
<table>
<thead>
<tr>
<th>Operation Number</th>
<th>Day</th>
<th>Month</th>
<th>Year</th>
<th>Shunt</th>
<th>Surgeon</th>
<th>Hospital</th>
<th>Date</th>
<th>Position</th>
<th>Model and Size</th>
<th>Check One</th>
<th>Other Procedures (see code)</th>
<th>Coded Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Prosthetic Valve Registry**

**Operative Profile**

NAME: Surname
First name and initial

IDENTIFICATION/CHART NUMBER:
TORONTO GENERAL HOSPITAL  CORONARY BYPASS REGISTRY

1. NAME: Surname
   Given name

2. CHART NUMBER: 

3. STABLE CORONARY PATIENT: Yes [ ] No [ ]

4. UNSTABLE CORONARY PATIENT: Yes [ ] No [ ]
   If yes: a) Crescendo angina Yes [ ] No [ ]
   b) Acute coronary insufficiency Yes [ ] No [ ]

5. LATEST PREOPERATIVE CORONARY ARTERIOGRAM:

6. LEFT VENTRICULAR ANGIOGRAM: (Grades 1 to 4) [ ]

7. PROPRANOLOL THERAPY: Yes [ ] No [ ] Unknown [ ]
   If yes, number of days discontinued before surgery [ ]

8. DATE OF OPERATION: [ ] [ ] [ ] da mo yr

9. REVASCULARIZATION:

10. INTRA-AORTIC BALLOON PUMP: Yes [ ] No [ ]

11. POSTOPERATIVE DEATH: Yes [ ] No [ ]
    If yes, date: [ ] [ ] [ ] da mo yr

   Classification:
   a) Operative death [ ]
   b) Early death (30 days) [ ]
   c) Late death [ ]

   Cause of death:
   a) Cardiac, coronary [ ]
   b) Cardiac, non-coronary [ ]
   c) Other [ ]
   d) Unknown [ ]

12. PROCEDURES OTHER THAN ACB: (see code) [ ] [ ] [ ] [ ] [ ] [ ]

13. POSTOPERATIVE CORONARY ARTERIOGRAM:
    If yes, date: [ ] [ ] [ ] [ ] [ ] [ ]

14. REDO OPERATION: Yes [ ] No [ ]
    If yes, date of redo: [ ] [ ] [ ] da mo yr

15. PHYSICIAN COMPLETING FORM: [ ]
    DATE: [ ] [ ] [ ]

FIGURE 2

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<table>
<thead>
<tr>
<th>PATIENT IDENTIFICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>SURNAME:</td>
</tr>
<tr>
<td>FIRST NAME AND INITIAL:</td>
</tr>
<tr>
<td>PHYSICIAN COMPLETING FORM:</td>
</tr>
<tr>
<td>DATE OF FOLLOW UP:</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>NYHA FUNCTIONAL CLASS:</th>
<th>See code</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUBJECTIVE RESPONSE TO SURGERY:</td>
<td>A=Greatly improved B=Moderately improved C=Slightly improved D=Same E=Worse</td>
</tr>
<tr>
<td>EMPLOYMENT STATUS:</td>
<td>A=Full time B=Part time</td>
</tr>
<tr>
<td>C=Unemployed D=Housework</td>
<td></td>
</tr>
<tr>
<td>If &quot;B&quot; or &quot;D&quot;, percentage of time</td>
<td></td>
</tr>
<tr>
<td>If not working, A=Physically unable B=Emotionally unable</td>
<td></td>
</tr>
<tr>
<td>C=Physician's advice D=Retirement age</td>
<td></td>
</tr>
<tr>
<td>E=Employer will not hire F=Not motivated</td>
<td></td>
</tr>
<tr>
<td>MEDICATIONS:</td>
<td>A=None B=Odigitalis C=Oituretics O=Potassium</td>
</tr>
<tr>
<td>E=Heparin F=Prostacyl H=Anticoagulants</td>
<td></td>
</tr>
<tr>
<td>In=Antiplatelet agents J=Nitrates</td>
<td></td>
</tr>
<tr>
<td>HISTORY OF THROMBOEMBOLISM:</td>
<td>Y=Yes N=No</td>
</tr>
<tr>
<td>If yes, A=Cerebral B=Peripheral Total number (1-8)</td>
<td></td>
</tr>
<tr>
<td>Postoperative month of first embolus</td>
<td></td>
</tr>
<tr>
<td>SIGNIFICANT ANTICOAGULANT HEMORRHAGE:</td>
<td>Y=Yes N=No P=Possible Number since surgery</td>
</tr>
<tr>
<td>PROSTHETIC VALVE ENDOCARDITIS SINCE SURGERY:</td>
<td>Y=Yes N=No P=Possible</td>
</tr>
<tr>
<td>INSUFFICIENCY MURMUR OF PROSTHESIS:</td>
<td>Aortic Mitral Tricuspid</td>
</tr>
<tr>
<td>Grade [0-6+] NA=Not assessed</td>
<td></td>
</tr>
<tr>
<td>Varying intensity Y=Yes N=No</td>
<td></td>
</tr>
<tr>
<td>DIASTOLIC MURMUR OF MITRAL PROSTHESIS:</td>
<td>0+ 1+ 2+ 3+ 4+ 5+ 6+</td>
</tr>
<tr>
<td>Grade [0-5+] NA=Not assessed</td>
<td></td>
</tr>
<tr>
<td>OPENING SOUND:</td>
<td>A=Normal B=Abnormal</td>
</tr>
<tr>
<td>CLOSING SOUND:</td>
<td>A=Normal B=Abnormal</td>
</tr>
<tr>
<td>ELECTROCARDIOGRAM:</td>
<td>A=NSR B=Atrial fibrillation</td>
</tr>
<tr>
<td>ESTES LVM point score:</td>
<td>See code</td>
</tr>
<tr>
<td>LV strain:</td>
<td>Y=Yes N=No</td>
</tr>
<tr>
<td>Infection:</td>
<td>A=Yes B=Ant C=Inf D=Lat E=Post</td>
</tr>
<tr>
<td>SPECIAL STUDIES:</td>
<td>A=Echo TD B=Echo TD</td>
</tr>
<tr>
<td>C=Phono D=Exercise test E=Nuclear angiogram</td>
<td></td>
</tr>
<tr>
<td>HEOMOGBLIN:</td>
<td>(g/100 ml)</td>
</tr>
<tr>
<td>RETICULOCYTE COUNT:</td>
<td>(%)</td>
</tr>
<tr>
<td>LDH:</td>
<td>(IU)</td>
</tr>
<tr>
<td>CARDIOTHORACIC RATIO:</td>
<td>Calculate %</td>
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</table>

<table>
<thead>
<tr>
<th>PROSTHETIC VALVE REGISTRY</th>
<th>FOLLOW-UP FORM</th>
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</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7 8 9 0</td>
<td>X UNK</td>
</tr>
<tr>
<td>1 2 3 4 5 6 7 8 9 0</td>
<td>X UNK</td>
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<td>1 2 3 4 5 6 7 8 9 0</td>
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<td>X UNK</td>
</tr>
</tbody>
</table>

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FIGURE 3
4. Since your operation are you feeling (check only one):
   - much better
   - slightly better
   - no better
   - worse

5. If "no better", have you had pain for (check only one):
   - 1 year or less
   - 2 years or less
   - 3 years or less
   - 4 years or less
   - 5 years or less
   - more than 5 years

6. Do you have any chest pain now similar to the pain you had before your operation? (Check as many as apply):
   - after exercice (only)
   - at rest
   - with emotional excitement
   - at night

7. If yes, can you walk at a normal pace (check all that apply):
   - Without Pain
   - 50 yards or less
   - 100 yards (about 1 block)
   - 200 yards
   - 500 yards (about 1/4 mile)
   - Upstairs, 1 floor
   - Upstairs, 2 floors

8. Have you had any:
   - swelling of feet or ankles
   - shortness of breath
     - lying down

9. Are you taking any of the following pills?
   - Digoxin (lanoxic)
   - Inderal
   - Isordil
   - Water Pills
   - nitroglycerin

10. Were you working:
    - Before Surgery
    - After Surgery
    - Part-time
    - Full-time
    - Retired
    - Unable to work because of heart disease
    - Doing Housework

FIGURE 4

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