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TIMY—A Center-Oriented Transplant Information Management System

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THE INCREASING numbers of transplants performed at the University of Pittsburgh mandated the development of a computerized data storage and retrieval facility. The manual processing of data proved to be inefficient in meeting the daily departmental needs. Throughout the design the intention was to create a system for everyday clinical use as well as for scientific purposes. Highest priority was given to two distinct features, user friendliness and flexibility.

It was clear that tasks addressed to the system cannot depend on the available data base structure and report facilities but that the data base and reports have to be adjustable with reasonable time and efforts to the ever-changing needs of the clinical and scientific transplant team. The designers' roles within the Transplant Department proved to be of great importance in meeting these requirements.

In this report we describe the development and design of our center-oriented computerized kidney transplant information management system (TIMY). A scoring system for equitable allocation of kidney transplant organs[1] is an integral part. Similar systems are currently in use for the liver transplant program and to some extent for the heart transplant service.

SYSTEM DESIGN

Using the DATAEASE data base program (DATAEASE International, Trumbull, CT), TIMY was designed and implemented by using an IBM AT computer with a 30-megabyte hard disk. As a distinct feature, many of the data entry fields are choice fields, which helps to eliminate data entry errors (Fig 1). Additional precoding of choices allows convenient statistical analysis. System modifications required to customize the data base according to the needs of the individual transplant center can be readily accomplished.

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01-ACTIVE
02-INACTIVE, MEDICAL PROBLEM
03-INACTIVE, PATIENT REQUEST
04-INACTIVE, INCOMPLETE EVALUATION
05-TRANSPLANTED HERE
06-TRANSPLANTED ELSEWHERE
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Fig 1. As a distinct feature, many of the data entry fields are choice fields, which helps to eliminate data entry errors. The precoding of choices allows a convenient export to statistical software packages.

The system design covers the candidacy, transplant, and follow-up phases. Data can be entered in the appropriate forms (Figs 2 to 4) with easy movement between the various patient records. In addition addresses and telephone numbers of referring physicians, patients, and their home dialysis centers are stored in specific files and used for printing the weekly candidate list.

Various established reports are available for clinical and research tasks. Included are comprehensive candidate listings, regular summary reviews, and statistics (Figs 5 and 6). Additional reports can be designed for impromptu informational requests by using the software query language, which does not require a programmer to initiate them.

The data base is available to the transplant coordinators via a laptop computer. Therefore

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TRANSPLANT INFORMATION MANAGEMENT SYSTEM - KIDNEY REGISTRY - DEMOGRAPHICS

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ID# _____ LAST NAME _____ FIRST NAME _____

DATE OF BIRTH _____

SEX _____ RACE _____

BLOOD GROUP ABO _____ RH _____ LEWIS ANTIGEN A ____ B ____

HLA TYPE A__,__B__,__Bw__DR_,__DQ__,__DRw__,__ TISSUE TYPING #____

DIAGNOSIS _____

DATE DIAGNOSIS WAS FIRST MADE _____

COMMENT _____

****

IF PATIENT LOST TO FOLLOW-UP, ENTER DATE OF LAST FOLLOW-UP _____

IF PATIENT DIED, ENTER DATE OF DEATH _____

PRIMARY CAUSE OF DEATH

_____

SECONDARY CAUSES OF DEATH

2._____

3._____

4._____

5._____

COMMENT_____

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Fig 2. Every patient entered in the TIMY kidney transplant management system has a pertinent record with demographic data. Most of the data is entered in precoded choice fields, which minimizes data entry errors and greatly facilitates later analysis.

TRANSPLANT INFORMATION MANAGEMENT SYSTEM-KIDNEY REGISTRY-CANDIDATE DATA

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ID# _____ LAST NAME _____ FIRST _____

CURRENT RECORD ___ CANDIDACY FOR GRAFT #_ ABO _____ ALIEN _____

PHYSICIAN CODE_____ DIALYSIS CENTER CODE_____ SEND LETTER_____

DATE REFERRED_____ PREFERENCE_____

LIST STATUS _____ URGENCY_____ LOGISTICS _____

INSURANCE_____ SECONDARY _____

AGE_____ AGE GROUP _____TOTAL PREGNANCIES_____ LIVE BIRTHS_____

HEIGHT__ft__in OR ___cm WEIGHT___lbs OR ___kg

PRA HIGHEST____ DATE ____ PRA RECENT____ DATE ____

HAAb____ HBsAg_____ HBsAb _____ HBcAb _____

CMV_____ HIV ELISA TESTING __ WESTERN BLOT __

PRE-KTX BLOOD TRANSFUSIONS WHOLE BLOOD_____ PACKED RED CELLS_____

WASHED CELLS__ FROZEN/FILTERED PLASMA____ PLATELETS___ BUFFY COATS___

IF LIVING DONOR, ENTER # OF DONOR SPECIFIC TRANSFUSIONS ___

DATE OF LAST PRE-KTX TRANSFUSION _____

START OF DIALYSIS _____ TYPE_____

NEPHRECTOMY _____ DATE_____ REASON_____

SPLENECTOMY _____ DATE_____

ADDITIONAL DIAGNOSIS

HEPATIC _____

PULMONARY _____

CARDIOVASCULAR _____

JUVENILE DIABETES MELLITUS _____

ADULT DIABETES MELLITUS _____

DIABETIC TREATMENT _____

COMMENTS _____

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Fig 3. Form for candidate information. Additional forms exist for patient address, referring physician, and dialysis center.

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TRANSPLANT INFORMATION MANAGEMENT SYSTEM-KIDNEY REGISTRY-TRANSPLANT DATA
**************************************************************************
ID# _____ LAST NAME _____ FIRST _____
NUMBER FOR THIS GRAFT (GX#)__   TRANSPLANTED ORGANS_____
DATE OF KTX _____  SERVICE _____  DONOR# _____  TRANSPLANT ID# _____
AGE AT KTX ____
--------------------------------------------------------------------------
IMMUNOSUPPRESSIVE BASELINE _____ CyA STARTED DAY _____
--------------------------------------------------------------------------
DONOR LOCALITY _____  OTHER _____

HARVEST MODE _____  COLD STORAGE _____

MACHINE _____  PERFUSATE _____

ISCHEMIA TIME  WARM DONOR____min  COLD___hr___min  WARM RECIPIENT__min

RECIPIENT SURGEON _____ 1st ASSISTANT _____ DONOR SURGEON _____

--------------------------------------------------------------------------
INTRA-OPERATIVE-BLOOD-TRANSFUSIONS  WHOLE BLOOD___  PACKED RED CELLS___
        WASHED CELLS___  FROZEN/FILTERED PLASMA___  PLATELETS___
**************************************************************************
DONOR INFORMATION
 LAST NAME _____ FIRST _____ SEX _____
--------------------------------------------------------------------------
 WEIGHT__lbs or__kg  AGE _____  RACE _____
 BLOOD GROUP ABO _____  RH _____  LEWIS ANTIGEN  A___ B___
--------------------------------------------------------------------------
 RELATIONSHIP_____  DONOR KIDNEY SITE_____
--------------------------------------------------------------------------
 CAUSE OF DEATH _____  CANCER _____
--------------------------------------------------------------------------
 HBsAg____  CMV_____  VDRL_____  HIV ELISA_____  WESTERN BLOT____
 OTHER INFECTION _____  IF YES, SPECIFY _____
--------------------------------------------------------------------------
 RECENT BUN _____  RECENT CREATININE ___
--------------------------------------------------------------------------
 TISSUE TYPING #_____ HLA TYPE  A__,___B__,__Bw__DR__,__DQ__,__DRw__,__
 DATE OF SERA_____  CROSSMATCH___  TEST TYPE _____
                    AUTOLOGUS CONTROL_____ TEST TYPE _____
**************************************************************************
RESULTS OF SCORING SYSTEM
  WAITING____  PRA____  HLA____  URGENCY____  LOGISTICS____  TOTAL____

OVERRIDER _____  IF YES, FULL EXPLANATION HAS TO BE GIVEN IN COMMENTS
     INCLUDING ID#  OF OVERRIDDEN PATIENTS. EXPLANATION HAS TO BE KEPT IN
     ADDITION AS A HARD COPY FOR ALL TIMES WITH SCORING PRINTOUT ATTACHED
     WITH SCORING PRINTOUT ATTACHED TO IT!

COMMENTS:_____
**************************************************************************
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Fig 4. Data entry form covering the essential information related to the transplant event and the particular donor. For survival and status information additional forms are existing.

pertinent patient data can be reviewed from any telephone connection, which facilitates the coordinators work during nights and weekends. The dynamic nature of the data requires constant updating, so the coordinator can review any pertinent data changes since the last printing of the candidate list.

The system structure encompasses the data necessary for reporting to government agencies as well as to the UCLA and Collaborative Transplant Study (CTS) Kidney Transplant Registries. The electronic data transfer via diskettes or modem to the UCLA Kidney Transplant Registry and to the CTS study at

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**************************************************************************
  TRANSPLANT INFORMATION MANAGEMENT SYSTEM - KIDNEY TRANSPLANT REGISTRY
                    CANDIDATE LIST AS OF 07/07/87

*  BLOOD GROUP O  *
PAGE   1
**************************************************************************
 Doe,   John     ID#:  999-99-9999        DATE REFERRED: 12/01/86
  ABO: O   AGE: 53.6   SEX: MALE          DOB: 01/01/34   HT: 173  WT: 77.9
  CANDIDACY FOR GX#: 1   STATUS: ACTIVE          URGENCY:
  DIAG: Diabetic Nephropathy              DIALYSIS: Hemodialysis
  PRA HIGH:  2.0   DATE: 01/01/87         PRA RECENT:  0.0   DATE: 04/07/87
  TISSUE TYPING #: 77777    HLA TYPE:     A  2, 3   B  7,62    DR  3,5
  HAAB: Neg   HBsAg: Neg    HBsAb: Neg    HBcAb: Neg    CMV: Neg
  INSURANCES: Blue Cross/Blue Shield      NEPHRECTOMY: None
  COMMENTS: Patient had myocardial infarct in 10/85
  ADDRESS:  1122 Beechwood Ave, Pittsburgh, PA. 15219
  PHONE HOME: (412) 999-9999              PAGER: (412) 999-9999
  PHONE WORK: (412) 999-9999              TYPE:  VOICE
  RELATIVES:  (412) 999-9999 - Susan - aunt
  RELATIVES:  (412) 999-9999 - Jack  - sister
  DIALYSIS CENTER: ABC    PHONE: (412) 999-9999     REFERRING MD: TES
**************************************************************************
 Doe,   John     ID#:  999-99-9999        DATE REFERRED: 05/15/86
  ABO: O   AGE: 39.1   SEX: MALE          DOB: 07/08/48   HT: 193  WT: 83.4
  CANDIDACY FOR GX#: 2   STATUS: ACTIVE          URGENCY:
  DIAG: Polycystic Kidney Disease         DIALYSIS: Hemodialysis
  PRA HIGH: 54.0   DATE: 03/19/86         PRA RECENT: 41.0   DATE: 06/29/87
  TISSUE TYPING #: 99999    HLA TYPE:     A  1,28   B  7,60    DR  4,
  HAAB: Neg    HBsAg: Neg   HBsAb: Neg    HBcAb: Neg    CMV: Neg
  INSURANCES: Medicare                    NEPHRECTOMY: Yes
  COMMENTS: First kidney transplant in 3/85, rejected after 12 months
  ADDRESS:  1133 Fifth Ave
            Pittsburgh, PA. 15216
  PHONE HOME: (412) 999-9999              PAGER: (412) 999-9999
  PHONE WORK: (412) 999-9999              TYPE:  VOICE
  RELATIVES:  (412) 999-9999 - Terry - mother
  RELATIVES:  (412) 999-9999 - Greg  - brother
  DIALYSIS CENTER: ABD    PHONE: (412) 999-9999     REFERRING MD: DVT
**************************************************************************

ETC. ETC. ETC.

BLOOD GROUP A
BLDOD GROUP B
BLOOD GROUP AB

ETC. ETC. ETC.
**************************************************************************

                  CANDIDATE LIST STATISTICS
                    FOR ALL BLOOD GROUPS

          ***********************************************
              ACTIVE CANDIDATES     #     119   100.00 %

                 BLOOD GROUP O      #      57    47.9 %
                 BLOOD GROUP A      #      34    28.6 %
                 BLOOD GROUP B      #      20    16.8 %
                 BLOOD GROUP AB     #       8     6.7 %

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Fig 5. **Weekly candidate listings are printed with comprehensive candidate data for use by transplant coordinators, procurement agency, and tissue typing laboratory.**

TRANSPLANT INFORMATION MANAGEMENT SYSTEM - KIDNEY REGISTRY - 06/06/87
REPORT TO THE OVERSIGHT COMMITTEE
TIME PERIOD FOR THIS REPORT FROM 05/01/87 TO 05/31/87

KTX DATE	SECTION	ID#	NAME	GX#	ALIEN	AGE	ABO	Tx ORGANS	DIAGNOSIS	WAITING	PRA S	PRA C	HLA O	HLA R	URG I	LOG N	LOG G	TOTAL	OVER-RIDER
01/01/87	URO SURG	999-99-9999	Doe John	1	NO	41.6	O	KIDNEY ONLY	Chronic GN	3.29	6.1	2	0	0	11.39	No			
COMMENTS:																			
01/08/87	GEN SURG	999-99-9999	Doe John	1	NO	37.4	A	KIDNEY ONLY	Diabetic Nephropathy	0.67	0.0	2	0	0	2.67	No			
COMMENTS:																			
01/08/87	GEN SURG	999-99-9999	Doe John	1	NO	28.9	A	KIDNEY ONLY	Interstitial Nephritis	0.33	0.0	4	0	0	4.33	No			
COMMENTS:																			
01/11/87	URO SURG	999-99-9999	Doe John	2	NO	21.5	A	KIDNEY ONLY	Chronic GN	9.28	7.7	8	0	0	23.98	No			
COMMENTS:																			
01/13/87	GEN SURG	999-99-9999	Doe John	1	NO	29.1	O	KIDNEY ONLY	Polycystic Kidney	1.35	0.2	2	0	0	3.55	No			
COMMENTS:																			
01/19/87	URO SURG	999-99-9999	Doe John	1	NO	9.1	O	KIDNEY ONLY	IgA Nephropathy	0.14	0.0	4	0	0	4.14	No			
COMMENTS:																			
01/30/87	GEN SURG	999-99-9999	Doe John	1	NO	47.2	O	KIDNEY ONLY	Goodpasture Syndrome	3.43	0.2	6	0	0	9.63	No			
COMMENTS:																			
01/30/87	URO SURG	999-99-9999	Doe John	1	NO	60.3	O	KIDNEY ONLY	Endstage Renal Disease	4.86	3.7	0	0	0	8.56	Yes			
COMMENTS: Donor was CMV positive, this patient was 1st CMV positive on list.																			

STATISTICS FOR THE PERIOD: 01/01/87 TO 01/31/87

ALIENS	# = 0	(0.00 %)	OVERRIDERS	# = 1	(12.50 %)
NON ALIENS	# = 8	(100.00 %)	NON OVERRIDERS	# = 7	(87.50 %)
NOT ENTERED	# = 0	(0.00 %)	NOT ENTERED	# = 0	(0.00 %)

Fig 6. The Oversight Committee, a community board established to review the transplant activities in Pittsburgh, receives every month a listing of the performed transplants, patient data, scoring results, and eventually overriding statements.

the University of Heidelberg, W Germany, is currently being implemented.

For scientific projects additional data entry forms can be easily developed and implemented into the system. Using the DATAEASE query language, the researcher or clerical staff can design customized reports including basic statistics. Further analysis can be accomplished by exporting the data for use in different statistical software packages. This process is greatly facilitated through the use of precoded choice fields.

SCORING SYSTEM

To facilitate the allocation of the best-suited transplant candidate when a donor organ is offered, an integral, computerized scoring system was developed as an objective allocation method.[1] The results do not mandate but augment the decision-making process of the surgeon. Currently, in Pittsburgh the Transplant Organ Procurement Foundation is running this scoring system for the kidney transplant program.

Various factors were thought to play an important role in the assessment of a suitable candidate. Of these, the five most significant are used in the scoring system: time of waiting, quality of HLA antigen match, presensitization state with panel reactive antibodies (PRA), medical urgency, and logistical factors. Because the donor and recipient should be of the same blood group with only rare exceptions, renal candidates are grouped as to whether their blood type is O, A, B, or AB. Candidates who weigh less than 27 kg or are 10 years or younger are listed separately. Sera from all candidates of the appropriate blood type and size are match against lymphocytes from the donor of the offered kidney. A negative crossmatch, connoting the absence of antidonor cytotoxic antibodies in the recipient serum, is a necessary condition for placement on the list of potential candidates.

The waiting score is determined as a rank order of waiting time that is established from the date of referral for consideration of transplantation. A maximum of ten points is awarded to the candidate waiting for the longest period, with fewer points given for shorter waits.

The quality of antigen match points is determined by the grade of histocompatibility at the HLA-A, -B, and -DR loci. Two points

are given for each antigen matched, with a score of 12 being possible.

The present state of alloimmunization, as defined by the most recent PRA antibody level, is used for calculating the PRA score. One point is given for each 10% PRA value up to a maximum of ten points.

The medical urgency score is used in cases where dialysis is not a feasible option for the patient so that organ transplantation within a short period of time is essential. This is necessary, for example, in patients whose access sites for dialysis have been exhausted. A total of ten points can be assigned to such a patient.

A maximum logistics score of six points can be awarded for logistic factors based on the ease and rapidity with which the transplant could be performed. For example, if a kidney was offered near the end of its permissable storage time, logistic points might be given to a candidate whose proximity to the hospital and history of recent dialysis could permit prompt organ transplantation.

DISCUSSION

TIMY has proved to be very effective in our everyday clinical and scientific use. In comparison to previous data management systems available in our department, user friendliness and flexibility are greatly improved. This led to departmentwide acceptance of the system as a useful tool. The availability via telephone connection from a laptop computer is of great importance for the clinical transplant coordinators. The easy customization of reports proved to be very valuable to our clerical staff in accommodating the various requests from insurance companies and other agencies. The medical staff participating in research can design their data entry forms to compliment the existing system. The standard framework of the data base can be used and expanded to meet the particular study needs.

As stated earlier the result of the scoring system does not mandate but facilitates the selection of an appropriate candidate for this particular donor organ. Certainly additional medical circumstances like cytomegalovirus status of donor and recipient, size limitations, etc, have to be considered. When there is a deviation from the computerized scoring result, an explanation is documented. Scoring results and overriding explanations are routinely reported to community boards for review purposes (Fig 6). Since its introduction in 1986 this computerized scoring system has proved to be a very valuable tool in the transplant candidate selection process.

A similar scoring system is routinely used for candidate selection in our liver transplant program.[2] A system for heart transplantation is currently under evaluation.

REFERENCES

1. Starzl TE, Hakala TR, Tzakis A, et al: JAMA 257:3073, 1987

2. Starzl TE, Gordon RD, Tzakis A, et al: JAMA (in press)