Transplant Information Portal

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<td>VARIMED Ltd</td>
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Keywords: medical informatics; web enabled, patient management

1. Introduction

The Transplant Information Portal (TIP) primarily provides the infrastructure to permit the effective integration of distributed and heterogeneous data to provide a better-informed transplantation operation (the right information at the right place at the right time). The use of international coding (ICD10, WHO, ATC) is making the TIP more suitable for European level co-operation. TIP was developed with respect to CEN patient record architecture, and the medical data structured in HTML is very handy. It structured as a folder - file role down system in one database so the translation into any language is very easy. The folders serving as a hub for the main activities and the files following the workflow of the participating health care professionals. The submitted patient data will stay in chronological order on each web page as added information like any archived paper or hard copy in the hospital basement. A recipient-donor-matching program (Select 4.5, BioStar, Hungary) was also integrated into the TIP.
2.1 Objectives

For the development of the TIP XML (eXtended Mark-up Language) software was used that allowed to build a customised web based patient record. The patient information entered into TIP stored in an XML format. TIP was implemented in Hungary on June 1, 2001 and proven it is an excellent tool for transfer data via Internet and control the accessibility with a state of art authorisation /authentication method able to control who can view and/or modify and what and quick query of the database. The participating health care professionals are using user name and password for the entry and the system administrator assigning for different level of authorisation of the user groups: transplant co-ordinators, nurses, technicians, and physicians (nephrologists, immunologists, transplant surgeons). Everyone is permitted to access data belonging to his or her own role down folders or files she or he is authorised to access. The Dialysis Card, Transplant Card and Professional Card (Bull Hungary Ltd.) can be seen as an electronic identification with additional data storage.

2.2 Work description:

As of today VARIMED Ltd. with Praxis Medical System are providing services via the Transplant Information Portal for 19 dialysis centres from the Fresenius Medical Care Dialysis Centre Ltd., and four transplant centres from Budapest, Debrecen, pecs and Szeged organised by The Hungarian Transplant Association. One tissue typing laboratory from the National Institute of Haematology and 15 donor hospitals co-ordinated by the Anaesthesiology and Intensive Care Association of Hungary with MEDANINFO Ltd. In the near future the Slovenija-Transplant is planning to implement TIP also.

The initial development was funded trough FP4 RETRANSPLANT (HC 4028 & IN 4028) project sponsored by European Commission - Directorate General XIII, Telecommunications, Information Market and Exploitation of Research, Telematics Application for Health. The TIP also received grant from the Ministry of Education, Republic of Hungary, Research and Technology Development Fund, Information and Communication Technology Application Programme (IKTA 4 068/2001). The total development costs were 120,000 Euro. The major benefit of the TIP the management of a complex data, the transparent procedures and rules that determine who are the potential receivers of an organ and what will be the priority rule between them. The TIP is available on the market, the interested parties could purchase it for 10,000 Euro independently from the size of the end users. The TIP can be implemented on a less expensive software solution to operate the software. The WEB Server includes; Microsoft Windows NT 4.0 operating system, an Internet Information Server (ISS) server 2, and the mail server is an Exchange Server. The database managed by Microsoft SQL Server 7.0, and the application server was an Allier’s Cold Fusion Server 4.5. Nevertheless it can be used with any type of database management system like Oracle or Interbase or combination of them.

2.3 Description of users type

Organ transplant is an increasingly successful and viable treatment for patients suffering from chronic end stage diseases and from irreversible failure of organs such as kidney, liver and heart. It offers new life to thousands of people throughout the World. In response to the steeply rising demand for transplantation, both the number of transplant centres and the
number of patients on waiting lists have grown rapidly. Graft rejection is still a major problem in kidney, liver, and heart transplantation. The financial cost of organ transplant made it imperative to develop health telematics tools for the patient selection and matching and early identification and treatment of graft rejection. The fast and efficient communication between the many medical actors is both a paradigm and a challenge for health telematics. It is a basic rule in organ transplant that donor organs are matched to recipients by national or multinational organ-sharing organisations. Kidney transplantation was selected as a generic model since it is the most frequently transplanted organ and follows well established guidelines. Recipients are well identified in dialysis centres and the donors at the donor hospitals. The patient selection and matching is taking place in the tissue typing laboratories and than the selected patient list will be distributed among the transplant centres. The transplant centres will decide which patient will be called for transplantation, but without detailed knowledge of the actual health status of the patients. The participating organisations still using traditional communication pathways: telephone, telefax, e-mail and they are not able to share information on the same patient among all health care providers at the same time.

2.4 Description of proven economic benefit

In most studies the cost effectiveness of the hemodialysis remained within a narrow range of 55,000 to 80,000 Euro/ life years (LY) despite considerable variation in methodology and imputed costs. The cost-effectiveness of home hemodialysis was found to be between $33,000 and $50,000/LY in the USA. Kidney transplantation, however, has become more cost-effective over time, approaching $ 10,000 /LY in the USA and 11,000 Euro/ LY in Europe. In Hungary the cost of the kidney transplantation 13,000 Euro/LY and yearly turnover of kidney transplant is approximately 300, the total cots around 4M Euro. The cost saving benefit of the TIP is the reduction of the Cold Ischemic Time (CIT) and significant reduction of the consecutive graft failure due to the quick, controlled and accessible information available on the donor organ and on the recipient patient. If the TIP could reduce graft failures with 10%, than from the same amount of money used in Hungary for kidney transplant in 2002 an additional of 25 patient could undergo transplantation (325,000 Euro). It is the reason why we have to convince the different institutions are holding the relevant information in the organ transplant procedures to use the Transplant Information Portal and share patient information via Internet. First of all there is ample evidence of a transplantation to become a standard and widespread practice used to solve an increasing number of kidney diseases. The number of solid organ transplant doubled between 1988 and 1998 with survival rates improving. Second, there is also ample evidence of a chronic organ shortage, and the waiting list more than tripled in the same ten years. This crisis situation resulted in a very strong rationalisation movement world wide and in Europe also. The Governments being more and more interfering with local practices, and pushing hard for the use of IT to achieve a better co-ordination and further standardisation of the different actors and practices in organ transplant. Quick tour around the web planet broadly supports that the TIP is one of the IT tool can help in this rationalisation process.

2.5 Description of proven benefits in terms to access to care

The diversity of hospital organisations participating in organ transplant, the complexity of clinical protocols and procedures, as well as the different preferences of various user groups
make it extremely difficult to effectively serve the needs of the health care facilities are participating in organ transplant. On the transplantation professional side, four different actors appear on the map: the organ taking institution (donor hospitals) and the organ transplantation institution, the typing laboratories (immunology, biology), and dialysis centres. The relevant information for the donor, and for the possible recipients has to be processed quickly. As for the donor, the problem is he/she can decease anywhere, including remote areas, and then the organ taking operation has to proceed quickly at the closest medical facility possible, where the brain death was announced. The possible receivers for each organ of the donor have to be identified through a selection procedure based on the priority listing system for each organ, crossed with biological matching engine held by national transplantation organisations. For each of them, section of information are persuaded on the shared medical information (security accessed) space called Transplant Information Portal, that is actually made of a variety of information located in different databases.

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2.6 Description of references

