

Home Monitoring and Decision Support for International Liver Transplant Children

Bianying Song^a, Mareike Schulze^b, Imeke Goldschmidt^c, Reinhold Haux^a, Ulrich Baumann^c, Michael Marschollek^b

^a Peter L. Reichertz Institute for Medical Informatics, University of Braunschweig – Institute of Technology – and Hannover Medical School, Muehlenpfordstr. 23, 38106 Braunschweig, Germany

^b Peter L. Reichertz Institute for Medical Informatics, University of Braunschweig – Institute of Technology – and Hannover Medical School, Carl-Neuberg-Str. 1, 30625 Hannover, Germany

^c Paediatric Gastroenterology and Hepatology, Hannover Medical School, Carl-Neuberg-Str. 1, 30625 Hannover, Germany

Abstract

Complications may occur after a liver transplantation, therefore proper monitoring and care in the post-operation phase plays a very important role. Sometimes, monitoring and care for patients from abroad is difficult due to a variety of reasons, e.g., different care facilities. The objective of our research for this paper is to design, implement and evaluate a home monitoring and decision support infrastructure for international children who underwent liver transplant operation. A point-of-care device and the PedsQL questionnaire were used in patients' home environment for measuring the blood parameters and assessing quality of life. By using a tablet PC and a specially developed software, the measured results were able to be transmitted to the health care providers via internet. So far, the developed infrastructure has been evaluated with four international patients/families transferring 38 records of blood test. The evaluation showed that the home monitoring and decision support infrastructure is technically feasible and is able to give timely alarm in case of abnormal situation as well as may increase parent's feeling of safety for their children.

Keywords:

Home Care; Decision Support Systems, Clinical; Liver Transplantation.

Introduction

The need of an information and communication technologies infrastructure for home monitoring and decision support is increasing due to demographical change and pervasive health care [1, 2]. Many people have the demand of home monitoring and decision support, e.g.: the elderly people, patients suffering from chronic diseases, organ transplant patients, and others. Many smart homes or ambient assisted living labs have been built to improve quality of life of patients or elderly people [3, 4]. Health-enabling technologies and sensor enhanced health information systems play a very important role in the area of home monitoring and decision support [5].

Complications may occur after a liver transplantation. In [6, 7], endocrine and bone metabolic complications in liver transplant children have been investigated. With the improvement of the survival of orthotopic liver transplantation (OLT) in children, the care of pre- and post-transplant complications is playing a more important role. Sixty percent of children as-

sessed for OLT have a problem of growth failure. Post-OLT, approximately 10% of children may be affected by drug-induced diabetes mellitus. Pre-OLT, prevalence of fractures in children is increased from 10% to 28%. Post-OLT, prevalence of fractures in children is increased from 12% to 38%. The risk of having avascular bone necrosis (4%) and scoliosis (13%-38%) in children with OLT is high.

In [8], acceptance, infection rate and adverse events of the 2009 H1N1 vaccination in liver transplant children have been investigated. One hundred twenty seven children were allocated in the retrospective analysis. In this study, the acceptance of the 2009 H1N1 vaccination was 56%. The infection rate was 4% in vaccinated children and 25% in non-vaccinated children, respectively. Moderate physical adverse events were frequent.

Tegtbur *et al* have investigated the endurance exercise capacity in heart transplant patients and patients affected by coronary artery disease (CAD) [9]. Incremental tests and a half hour constant load test have been performed in the study. In incremental tests, the maximal workload was 106.0 ± 24.7 W in heart transplant patients and 163.1 ± 41.0 W in CAD patients, respectively. In the constant load test, with a threshold of 55 ± 6 W, lactate increased from 0.9 ± 0.2 mmol l⁻¹ to 3.1 ± 1.6 mmol l⁻¹ in heart transplant patients and increased from 1.0 ± 0.2 mmol l⁻¹ to 3.4 ± 1.5 mmol l⁻¹ in CAD patients. In the constant load test, the kinetics of heart rate and lactate were comparable in both groups.

In [10], quality of life and exercise tolerance in heart transplant patients and patients with a left ventricular assist device (LVAD) have been compared. Fifty-four heart transplant patients and thirty-six patients with a LVAD were allocated in the study. As a conclusion, quality of life and exercise capacity have increased over time in both groups. Compared to the LVAD group, heart transplant patients had a higher exercise tolerance.

Hannover Medical School (Medizinische Hochschule Hannover, MHH) is a center for children's liver transplant operation. Many international patients come to MHH for treatments. The regular post-operation monitoring is very important to observe the function of the transplant liver. However, the regular control of international patients is difficult due to a variety of reasons, including different care facilities. A technical infrastructure with point-of-care devices for monitoring liver functions in the postoperative phase in home environment may improve the patients' safety. However, such an infrastructure is still

missing and the effect of the home care monitoring for international liver transplant children is still uncertain.

The aim of our research for this paper is to design, implement and evaluate a home monitoring and decision support infrastructure using point-of-care devices for international children who underwent liver transplant operation.

Materials and Methods

Study setting

Four international patients aged 6-36 months were allocated due to their stable liver function tests on discharge. The patients were from Libya, Bulgaria, Uzbekistan and Azerbaijan. All of the four patients have undergone liver transplant surgery. After the surgery and a short term stay in MHH, the patients were sent back to home country for the recovery. Three month later, the patients had to come back to MHH for the clinical examination. The time span of the three months at home was considered as the measurement time of the study. The expected frequency of blood draw was every two weeks.

The parents of the patients were prepared to join the study and do the measurements at home regularly in order to get early alarm in case of deterioration. The data gathered in the home environment should be transmitted into a database through a secured internet communication and should be checked by an authorized health care provider. The data communication is encrypted by a symmetric-key algorithm.

The whole point-of-care system can be seen in Figure 1. In this figure, a commercially available blood analyzer device (see below) including cassettes, a tablet PC, a lancet, some capillary tubes and a bottle of medical disinfectant are shown.

Before we gave the whole system to the patients and their families, we offered a training course to teach the parents how to set up the whole system, take blood from the finger of the children and follow the instructions and information of the software.



Figure 1- The point-of-care system for international liver transplant children (Picture was taken from a patient's home)

Hardware

Sensor

A point-of-care device (Alere Cholestech LDX) was used for measuring blood parameters. A variety of cassettes is supported by the Cholestech LDX device to measure different blood parameters, e.g., aspartate transaminase (AST) & alanine transaminase (ALT), lipid profile, total cholesterol, High-

sensitivity C-reactive protein (Hs-CRP), and others. In our study, AST&ALT cassette and Hs-CRP cassette were chosen. AST&ALT cassette was used to measure the function of the liver; Hs-CRP cassette was used to analyze whether the patient has an infection. The AST&ALT cassette is able to measure not only the values of AST and ALT, but also the ratio of AST/ALT.

PC

An all-in-one PC (ASUS) and a tablet PC (DELL) were used for four settings. Both PC run Microsoft Windows 7 OS. The ASUS all-in-one PC has a built-in RS232 interface which can be used for the connection of the Cholestech LDX device. The DELL tablet PC has no built-in RS232 interface. Therefore, a USB-RS232 converter had to be used.

Software

Java language was used to develop the client program. The program was used to collect and show information including questionnaire (see below) and the results of blood tests. After gathering these two kinds of information, the information can be transmitted into a database automatically. A user manual for this client program was written and delivered to the patient families.

To receive the values of the blood parameters from the Cholestech LDX device, RXTX library [13] was used for the Java serial communication. The strings received from the Cholestech LDX device are ASCII code and have to be parsed. The numeric values can be processed by searching the characters after the predefined keywords, e.g., the equals sign.

To store the relevant information, a MySQL database with five tables was used. One table was used to store the questionnaire itself (see below), the second table was used to store the families' answers of the questionnaire, the third table was used to store the results of the blood test, the fourth table was used to store the patients' information, and the last table was used to store the health care providers' information.

To facilitate the access of the relevant information easily by health care providers, a web portal was constructed. The web portal was implemented in JSP language and deployed on a Tomcat server. Only authorized health care providers are allowed to see the content of the portal.

Questionnaire

Questionnaire for assessing the quality of life

The questionnaire of pediatric quality of life inventory (PedsQL) [11] was used to assess the quality of life of the children and their parents. PedsQL has disease-specific modules for assessing the quality of life of children affected by different diseases. The patients and their parents were asked to answer the questionnaire every two weeks during the time span for measurements. In our study, three modules of PedsQL were used:

- Family impact module
- Transplant module
- Infant scales module

Questionnaire for assessing the point-of-care system

In addition to the PedsQL questionnaire, a self-developed questionnaire was used to assess the effect of the whole point-of-care system. Twelve questions concerning patient safety, cost, overall rating, difficulty of use and others were used in

this questionnaire. The patients were asked to answer the questionnaire after the usage of the point-of-care system.

Results

Implementation

The architecture of the system is illustrated in figure 2. The whole system contains three parts:

- Patient@Home
- Doctor@Hospital
- IT infrastructure

Patient@Home

The main components of the Patient@Home part are a tablet PC in which the self-developed software runs, the electronic version of PedsQL questionnaire and a Cholestech LDX device. By using the system, the results of the questionnaire and blood test can be shown on the tablet PC and after that transmitted into the database through internet automatically. To prevent data loss in case of exception of network, the data of questionnaire and blood test are additionally stored in log files in the tablet PC locally. The self-developed software for Patient@Home has a graphical user interface (GUI) which is shown in Figure 3. The software has two buttons for questionnaire and blood test, respectively. After pressing the button “questionnaire”, a window for selecting the age of the child can be shown. After the age is selected, the PedsQL will be shown in a new window (see Figure 4). After answering the questions, by pressing the button “run”, the data communication between tablet PC and Cholestech LDX device can be enabled. The information, e.g., optic check and others, originally shown on the display of Cholestech LDX device can be shown in a disabled text box of the GUI. The current measured Hs-CRP, AST and ALT can be shown additionally in form of numbers and graphs. The personal historic values of blood test can be displayed in a two dimensional figure.

Doctor@Hospital

In the Doctor@Hospital part, only a normal computer with internet access is needed. After the home measurement is done, the latest values of the patients’ blood test and their timestamp will be sent to doctors. In case of an abnormal value, the doctors are able to give timely suggestions and propose interventions to the families. The historic profile of patients’ blood test and the questionnaire can be viewed by the doctors through a web browser according to a unique identification number of patient. As an example, a web page in this part can be seen in Figure 5.

IT infrastructure

The main components of the IT infrastructure behind the patients and doctors are a database server, a web server, a decision support server and a backup server. The MySQL database server is used to store both the clinical information and the management information. The web server facilitates health care providers view the results of the blood test and the questionnaire. The decision support server checks the database periodically and sends an E-mail to health care providers in case of new results of blood test arrives. The backup server is constructed for the database for security reasons.

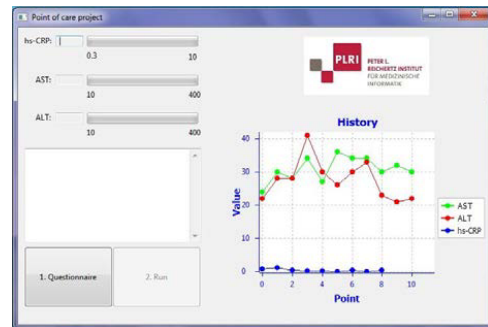


Figure 3- Graphical user interface (GUI) of the software for patients used in their home environment.

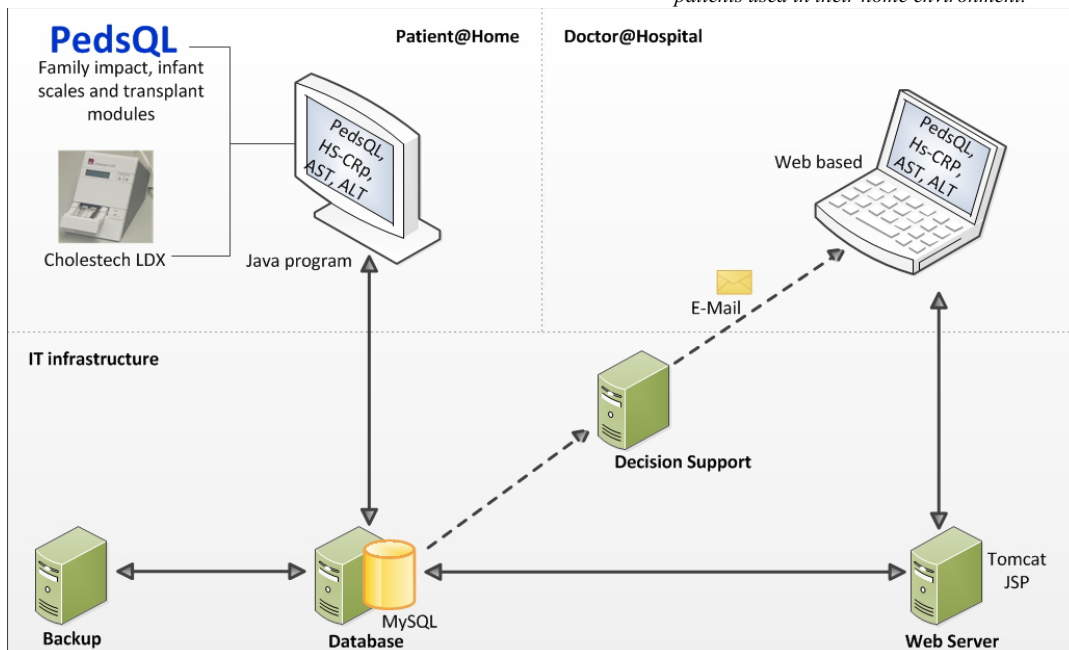


Figure 2- Three parts of the architecture of the point-of-care system: Patient@Home, Doctor@Hospital and the IT infrastructure behind patients and doctors which contains a database, a web server, a decision support component and a backup server.

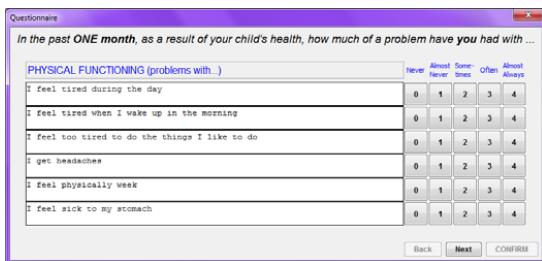


Figure 4-A screenshot of the electronic PedsQL questionnaire.



Point of care project

Welcome Herr Prof. [redacted]

[Log-out](#)

Please select a patient: [dropdown]

Current patient is: [redacted]

ID	Hs-CRP	AST	ALT	AST/ALT	Time
1	null	32.0	30.0	1.1	2012-06-19 14:15:34.0
2	0.37	null	null	null	2012-06-19 14:27:03.0
3	null	1.0	17.0	-1.0	2012-06-22 00:39:51.0
4	null	23.0	16.0	1.4	2012-06-22 11:44:11.0
5	null	32.0	25.0	1.3	2012-06-23 11:33:40.0
6	2.6	null	null	null	2012-06-24 16:29:04.0
7	null	29.0	16.0	1.8	2012-06-27 21:52:24.0
8	[redacted]	null	null	null	2012-06-29 00:42:34.0
9	[redacted]	null	null	null	2012-06-29 00:56:16.0
10	null	[redacted]	[redacted]	[redacted]	2012-06-29 01:07:32.0

[see questionnaire](#)



Supported by: [Peter L. Reichertz Institute for Medical Informatics](#)

Contact person: [Bianying Song](#)

Figure -5 A web page for Doctor@Hospital (Please not the values shown are from healthy adult volunteers).

Evaluation

The point-of-care system worked reliably in the evaluation. Answers of the PedsQL questionnaire and values of blood tests can be transmitted into the database. Altogether, thirty-eight values of blood tests have been transmitted into the database. From the medical perspective, these values are normal except one Hs-CRP value which is larger than 10 mg/L. After the abnormal Hs-CRP value was measured, the doctor from MHH suggested parent of the patient to visit a local doctor. Later, the patient was confirmed having an infection caused by Epstein-Barr virus (EBV). After a treatment, Hs-CRP value of the patient has been decreased.

There were three transmission failures in the evaluation due to unstable internet connection and all of these failures were from one patient. Yet, values of blood tests and answers of questionnaire were stored locally in the all-in-one PC and there was no data loss.

In the evaluation, one Cholestech LDX device was damaged by a patient’s misuse of a power cable. Since then, the patient cannot perform blood test at home any more.

Two patients have answered our self-developed questionnaire for assessing the effect of the whole point-of-care system. The questionnaire showed that the patients performed the blood test at their own home. The time spent for one time usage of the system is approximately 15-30 minutes. The system is able to improve the feeling of safety for the children. One parent will use the system until their baby can use it by himself and they will pay up to 2000 Euros for the system including a Cholestech LDX device, a tablet PC and the software, as well as up to 20 Euros for supplies each time. Some problems have been detected: one parent felt taking blood from the baby was difficult, the other parent felt following the instructions and information of the software was difficult.

In the evaluation, one mother of a patient gave a very positive feedback to the point-of-care system, she wrote in an E-mail:

“It was so soothing to have it here and know that everything is ok with our son. It really helps people in our situation and gives them security. Thank you for letting us use it!”

Discussion

Pervious works on home monitoring and decision support have been done for patients with a variety of diseases [1], e.g., heart failure, asthma and others. A generic home monitoring system may be considered for patients in home environment, however, specific interfaces for different point-of-care devices and questionnaires for different patients have to be developed.

Finkelstein has developed a home monitoring and decision support system for asthma patients [12]. Evaluation showed that the internet based data communication between hospital and home was reliable, the test results gathered in home environment were comparable with the results collected in clinical environment, and the home asthma monitoring system can be accepted by patients without IT experience. Evaluation in our study showed that the home monitoring and decision support system for international liver transplant children is feasible. The system may increase the parent’s feeling of safety for their children. However, unlike the results of Finkelstein’s work, the data communication between hospital and home in our study was not reliable in all cases. One of our patients suffered internet connection problems. However, Finkelstein’s study has been done only inside USA. In our study, the database server was located in Germany and the patients were international. The patient suffered from internet problem was from Libya. Some network settings e.g., firewall or others may have affected the data communication.

Our study has been done an international context, in addition to the technical issue, more issues e.g., legal issues concerning data privacy should be considered in the international context.

In the evaluation, we found that the training of patient/family plays a very important role in the successful measurement in home environment. Different culture and technical background of patients should be considered. The communication in non-

native language via oral translation increased the difficulty of the training. Careful training at multiple times may prevent problems like the misuse of power cables.

A problem concerning the difficulty of following the instructions and information of the software was reported by a parent. Until now, the instructions and information of the software were written in English, but a translation to the native language of the patient may improve the situation.

Currently, two cassettes of Cholestech LDX device for measuring three parameters (AST, ALT and Hs-CRP) have been chosen for assessing the health status of the international liver transplant children. Other parameters, e.g., cyclosporine level, are also important for the home monitoring of liver transplant children. However, the integration of other parameters is restricted by the development of point-of-care devices.

Limitation

Currently, the results of the blood test are sent from the client program to the database automatically in the background after the measurement is done, a feedback mechanism from the database server to the client program is not provided. This means that, if data are lost during the communication, they will not be resent by the client program. A feedback mechanism may improve the robustness of the software.

Until now, the analysis of the data and decision support were done manually. The current method is not suitable for large scale study with multiple participants. The function of data analysis and decision support may be designed in a more intelligent way, e.g. integration of an Arden compiler [14].

Conclusion

We developed an IT infrastructure with a point-of-care device for home monitoring and decision support for international liver transplant children. The infrastructure has been evaluated in a study with four international patients. However, the function of the IT infrastructure can still be improved. The clinical effect of the IT infrastructure has to be investigated in a large scale clinical study.

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Address for correspondence

Bianying Song MSc
 Peter L. Reichertz Institute for Medical Informatics,
 University of Braunschweig – Institute of Technology and Hannover
 Medical School
 Muehlenpfordtstrasse 23
 D-38106 Braunschweig, Germany
 +49 531 391 2127
 bianying.song@plri.de
 www.plri.de