KidsETransplant: A Platform for Liver-Transplanted Children

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Abstract

In Switzerland all children' liver transplants are centralized at the University Hospitals of Geneva (HUG) since 1989. Approximately 125 children have received transplants since then, and their survival chance is higher than 90% - one of the highest in Europe. Maximizing the chances of success requires that patients understand and comply with follow-up treatment. The KidsETransplant project aims at helping the child - and his family - to better understand his health situation, to get access to shared resources and to be able to better communicate with healthcare professionals and other patients. This paper describes the various components that have been designed and developed for reaching these goals as well as the evaluation process that will be performed during the life of the project. Initial evaluation and feed-back from early users will be provided in the revised version of the paper.

Keywords:

Child, Liver transplant, Compliance, Web, Serious games

Introduction

In Switzerland all children' liver transplants are centralized at the University Hospitals of Geneva (HUG) since 1989. This center of excellence has now taken care of more than 125 children.

Follow-up after a transplant is done partly at the HUG and partly with the personal pediatrician/gastroenterologist: patients have to come to the HUG three, six and twelve months after their operation, and then annually. In between hospital visits the follow-up is made by their regular doctor at home.

Understanding of the disease and compliance with follow-up treatment are especially important in order to maximize the success chances after liver transplantation. In order to avoid complications, such as graft rejection, patients must take a regular course of medications for the balance of their lives. However, children, especially around 10 to 15 years-old, are less likely to follow the heavy constraints of the treatment. Tools for enabling them to better understand the issues related to the treatment are, therefore, welcome, and serious games have been shown to increase understanding of diseases and treatments in various situations [1].

Materials and Methods

Organization

A multidisciplinary working group was setup composed of clinicians closely implicated in the care of these patients, computer scientists and media experts to design and implement the KidsETransplant platform. Patients and their parents have also been invited to give their comments as they will be the principal users of the platform.

Concept

The project has 3 components:

1. a website providing reliable medical and practical information;

2. an interactive discussion forum for the patients and families followed at HUG;

3. a mobile application to access electronic medical records.

The website is the information center: it contains general information about liver diseases, treatments, care process, and healing, among other topics. The interactive forum will permit exchanges and dialogue among the children and their parents. The forum is based on social networking principles recognizing the value of community-based nonprofessional support.

The mobile application aims to be *the* personal interface for the child and his family. The main target group is the children themselves so it must be attractive (3-D serious gaming), resembling the media and toys they like to use.

The aims of this platform are:

a. for children/patients to better understanding their condition and the benefits of post-transplant care;

b. to empower children/patients and their families to take control of their medical problems;

c. to improve adolescents' compliance with their therapy;

d. to decrease medical complications (especially liver rejection) among adolescents;

e. to improve transmission of information between patients, families and their health care professionals by making the patient the cornerstone of the network;

f. to be an important technical innovation, nationally and globally. While the electronic medical record exists in Europe and North America, we are not aware of it being matched with 3-D serious gaming. If results are conclusive, it can be of interest to other pediatric sub-specialties treating chronic diseases, such as endocrinologists' treatment of children with diabetes.

The platform will be evaluated in the following process: at enrolment stage, each child and his family will complete a questionnaire. Follow-up questionnaires will be completed every 12 months, enabling the platform coordinators to gather information on patient perceptions, the platform's advantages and disadvantages, and whether patient and family awareness has increased.

Website

The Web platform contains two sections:

- A general information section about liver diseases, their consequences, their treatments;

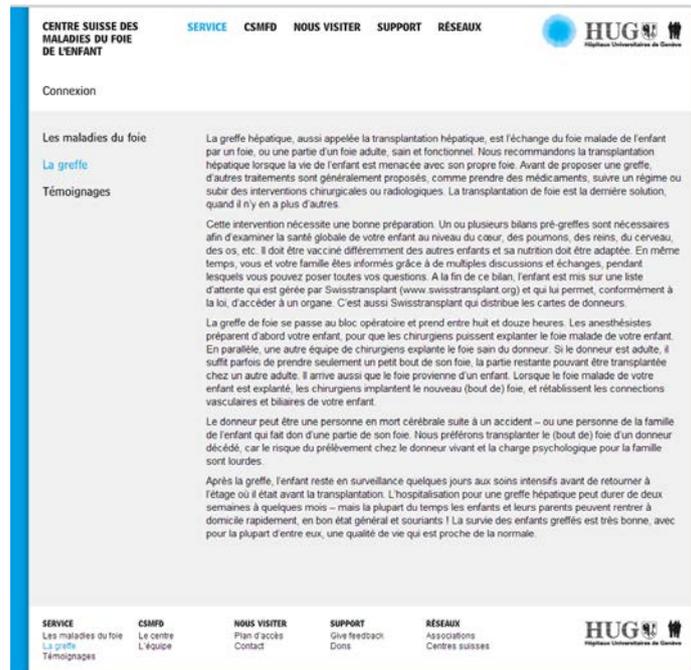- A general information section about the Swiss center for liver disease in children.

Figure 1- Web site home page

Interactive forum

The interactive forum will permit exchanges and dialogue among the patients and parents in a social networking environment.

Access to the forum requires a strong authentication in order to safeguard personal medical data. The SMS challenge, in which a person enters his login and password and receives back on his mobile device an SMS containing a single-use code to validate the login, was chosen as the most secure method.

Mobile application

The mobile application aims to be the main tool for the child. It is on this platform that he will find information on his health status, his medications, and his schedule. In order to appeal to the kids and maximize utilization, a classical web-based application was abandoned in favor of a "serious games" approach close to what children are using on various game consoles. This makes development of convivial and attractive user interfaces possible.

The basic idea of the interface is that the child navigates in his own virtual room. Objects are placed in natural locations: clicking on the objects triggers actions like "open the agenda", "look at some results", etc. (Figure 2). The interface displays information from the child's own medical record [3], such as laboratory curves, exact medication plan, or date of next visit.

Some customization of the room is possible: posters can be modified, and personal images can be displayed on the walls. A Post-it® can be added on the wall enabling the child to note important information. These post-its can then be – if the child wishes so – discussed with his doctor.

Figure 2- Virtual Room of the child: workplace and panel of available games

In the medication summary page, the child can add reminders to take his drugs, and be notified by SMS if he wishes. Such a facility will be very useful as the medication plan is quite complex and varies according to treatment plan.

The games, shown on the right hand side of Figure 2, are designed to make the platform more attractive and more likely to be used regularly.

The mobile platform is implemented using the Unity Game Engine. This engine has been selected for its capabilities and is availability on multiple platforms.

Currently two different platforms are supported for the navigation in the room: Microsoft's Windows and Apple's IOS (iPad devices). Support for Google's Android platform is expected to be available in 2013.

Access to the room is of course also protected by strong authentication. The same mechanism is used as for the Web platform.

Results

At the time of submission, results are only partial and based on the preliminary feed-back of a focus group of children and their parents. The first patients are being enrolled before end of 2012, with the expectation of having 10 to 20 children using the platform by March 2013. Real evaluation of the benefits of the platform will only be available after March 2013.

Preliminary feed-back on the mobile platform has been enthusiastic with the children willing to use it as soon as possible.

Planned improvements to the platform will include the addition of pop-up text boxes associated with particular objects in the child's virtual room, and quizzes to add another level of challenge to the patient's gaming experience while helping the clinical team track patient understanding of his therapy.

The questionnaire for evaluating the impact of the platform on its users is ready. Each user of the platform will have to fill it before getting access to the platform. The about thirty questions are designed for getting an initial picture of the relations between the children, their families and the care givers as well as the way they are following the evolution of the disease and the treatment. Users will have to fill it again every year and a comparison of the answers will be made for assessing the impact of these new tools.

Acknowledgements

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