A WEB-BASED PLATFORM FOR THE THERAPEUTIC EDUCATION OF PATIENTS WITH PHYSICAL DISABILITIES

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Abstract

The therapeutic patient education (TPE) aims at helping patients and relatives to understand diseases and treatments, and collaborate in healthcare by taking an active role in the management of a chronic disease, in order to improve the quality of life. This model has been largely developed in the French speaking European countries, which have adopted a series of laws and regulations to ensure the patient can access and comprehend easily the information related to his/her state of health, with the objective of transforming him/her into a fundamental care giver that will work in partnership with the health professionals. This transition from the classical patient compliance to empowerment is a revolutionary concept in terms of patient education. As in any form of education, individuals are involved in a long-term learning process, in which they have to acquire knowledge, competencies and develop behavioral skills to deal with their disease and become as autonomous as possible.

In practice, this consensual idea is not so easy to implement. A patient with a chronic disease is surrounded by several health professionals who use their own technical language, which impedes the interdisciplinary exchange of information between specialists and from the care giver to the patient. In addition, the current tools in TPE are essentially based on a rigid form template, inspired by the paper format, which challenges the construction of a customized strategy to evaluate the patient needs. These are not adapted to a self-evaluation by patients because they are difficult to understand by non-specialists. At last, they usually focus on a determined disease instead of taking into account the global state of the individual and therefore disregarding important parameters such as pain or mood.

In order to enhance the TPE, we have developed a web-based application that permits a customized and strategic evaluation of neuromuscular deficiencies as a whole (http://enterface13.net/am/). The main challenge of this project is to construct a tool which is accessible for ordinary people but still maintains useful information for health professionals. The user interface is mainly composed by pictogram-based questionnaires and dynamic forms to allow an intuitive utilization even for non-specialists. The originality of the platform is based on a tight collaboration between patient, relatives and professionals. At a socio-educative level, the tool is used to share data and to be a language interface to facilitate the communication between health, social and administrative specialists. At a medico-educative level, the multidisciplinary healthcare cooperative network is improved thanks to a multi-users access, a customization of the application using, and different reading and consulting levels of the data (from an overview to a detailed analysis). On one hand, the goal is to create a real clinical record in order to prevent the repetition of the same questions in various services and to complete questionnaires that depend on the medical context. On the other hand, this approach promotes an active involvement of the patient, by allowing for self-evaluation.

Keywords: Web-based application, therapeutic patient education.

1 INTRODUCTION

Statistics reveal that one out of ten people have need of personal assistance due to a disabling pathology [1]. The population ageing alarms for the need of health care reinforcement, particularly regarding chronic, incapacitating pathologies. Although the treatment of this kind of disabilities is evolving remarkably at a medical level, it usually disregards the social recovery which can prove decisive for people with a chronic condition.

1.1 Therapeutic Patient Education

The therapeutic patient education (TPE) helps patients develop and maintain the skills and competencies needed to manage their chronic disease in a collaborative healthcare treatment, taking an active role in the recovery along with relatives, health professionals and every social intervenient.
TPE is a model in development in which the patient learns to adapt to behaviours leading to an improvement of his/her quality of life. The TPE model covers the social aspects commonly overlooked in health treatments, namely in situations in which the patient doesn’t fully comprehend the disease, the risks and the treatment [2]. Although TPE thrives at equipping the patient with the knowledge and ability to understand every step of his/her recovery, this paradigm blocks at the language barrier between health professionals and the common patient, the latter unable to absorb a technical, potentially complex dialect. Additionally, the current tools in TPE are limited to a rigid paper format, non-customizable template which doesn’t consider the self-evaluation by patients nor important health parameters such as pain or mood. TPE also requests a regular contact between the patient and the health professionals in care of him/her, which can prove too demanding and unappealing in terms of schedule. Other juridical related issues prohibit the share of medical information to the patient, opposing the TPE paradigm. There is, however, a larger development of this model in the French speaking European countries, allowing the patient access to the information regarding his/her state of health through the adoption of laws and regulations enabling so.

1.2 A Web-Based Solution

The flexibility and power of communication granted by the information systems, namely web-based platforms, are getting larger and larger throughout the years. This characteristic makes them a great asset in the technological enhancement of the TPE. We have thus developed a user-friendly, multilingual, web-based application which allows for a personalized and strategic evaluation of neuromuscular disabilities through a set of pictogram-based questionnaires and dynamic forms. This web-based tool thrives at helping in the collaboration between patient, relatives and health professionals by maintaining a regular contact and sharing information regarding the patient’s health condition in a simple, accessible language without disregarding his/her own self-evaluation. The main challenge of this platform is to provide both patient and health professionals with medically useful information about the patient’s physical and psychological condition without consuming too much time in the process. The solution presented is based on a set of simple and straight-forward answer questionnaires inspired by efforts such as OSE (Outir Simple d’Evaluation) [3][4], HOLE (Handicap Outil Léger d’Evaluation) [5], e-ESPOIR (e-Evaluation Stratégique et Personnalisée par Outil Informatique en Réseau) [6] and some elements from the reference guide for disability evaluation – GEVA (Guide d’EVAuation des besoins de compensation de la personne handicapée) – regarding the patient’s social life and daily activities. The Web application works on a socio-educative level, allowing for a dynamic examination of the global health status of the patient through a language that facilitates the communication between health, social and administrative specialists. At a medico-educative level, the application provides a multi-users access, allowing each health specialist to contribute to the evaluation and customization of their patients’ forms and a multidisciplinary healthcare cooperative network.

The project is a result of an interdisciplinary collaboration between computer science engineering and medical specialists, assuring the accuracy of the platform in both technology and health slopes. Its goal is not to replace or limit the personal contact among patients and health professionals and its use assumes that a previous medical appointment was made between them.

The Web-based application is developed with the Joomla Content Management System resorting to HTML5, CSS3 and the programming languages PHP (server-side) and Javascript (client-side). The data storage and administration is done by a MySQL DataBase Management System.

2 SYSTEM IMPLEMENTATION

The application has a user registration system, in which it must be specified whether the user is a patient or a health professional. This specification will affect the user interface (UI), providing the health professionals with tools to find registered patients and request assignments to them. A patient requested assignment this way can either ignore or accept the request, the latter giving birth to a patient/health professional link allowing the share of the personal and medical data within the platform. This connection grants shortcuts for both patients and health professionals to respectively allow self-evaluations and evaluations, as shown in Fig. 1 and Fig. 2.
Fig. 1 – List of patients in care of the health professional

Fig. 1 presents the patient list in the perspective of a health professional connected with them. Through this menu, this professional has direct hyperlinks to, from left to right, message each patient, view their profile and social life, inspect and evaluate their daily activities, check their charts, reports and finally, remove the link between themselves and the patient.

Fig. 2 – List of medical staff monitoring the patient

The patient UI grants him/her the query of his/her own evaluation. Fig. 2 presents some of the shortcuts the patient can use for this query, organized in a list of medical staff monitoring him/her. The report and chart logos by the health professional name direct the patient to, respectively, their daily activities full questionnaire reports and basic questionnaire charts. This list presents itself a shortcut for options available through a main menu of the application UI.

2.1 Social Life

An essential element of the patient’s recovery is related to the social life he/she undertakes. The platform’s effort to create a simple, straightforward way of collecting and presenting the social life’s status of the patient results in a form in which he/she describes, from never to very frequently, the periodicity of nine events regarding his/her social activity, as shown in Fig. 3.

Fig. 3 – Patient’s social life events and periodicity

The data collected this way is represented in a radar-like chart, in which each vertex presents an event from the patient’s social life. The distance between each vertex and the chart’s centre is proportional to the frequency of the event in his/her social life, as Fig. 4 points out.
The area of this chart is as large as the frequency of the patient’s social activity. This type of chart emphasizes the autonomy level the disabled person has over his/her insertion and participation in society.

2.2 Daily Activities

In order to gather a full overview of the health condition and functional skills of a person with a neuromuscular disability, a set of questionnaires were developed regarding important aspects of the day-to-day activities. These aspects are inspired by the HOLE [5] topics for medico-social disability symptoms evaluation, presented in Fig. 5.

The patient can self-evaluate each daily activity's topic by answering a full and/or a basic questionnaire. The first consists on a small form of straightforward questions which cover the details of the activity in question. In the basic questionnaires, the patient is requested only to describe the limitation felt when addressing each daily activity, from No Problem to Full Disorder. The latter questionnaires are more adequate for activities in which the patient does not require to go into much detail. Fig. 6 and Fig. 7 present, respectively, a full and a basic questionnaire example.
As Fig. 6 points out, the full questionnaires are very undemanding of the patient’s time. It takes virtually no effort to comprehend the questions and the answers are mostly closed to a few options. Nevertheless, these questionnaires carry important medico-social information regarding the patient’s health status.

Fig. 7 demonstrates how easy it is to fill in the daily activity’s basic questionnaires. The patient simply defines his/her limitation in each activity by selecting an entry in the table. A cross referencing between the activity and the disorder level generates a horizontal bar chart.

A particular highlight of this platform is the fact that every questionnaire and even every question are not mandatory. Some disabilities demand different focus than others on the daily activities, which means the patient and the health professionals must dialogue in order to define which questionnaires they consider worth answering in. The application compiles a table in which the patient can take a look at the questionnaires and respective questions answered this way, organized by activity, as shown in the example in Fig. 8.
The health professionals can view and evaluate their patients’ daily activities in a similar way. However, in order to spare the former the constant search for each questionnaire the latter have answered in, the application compiles a list of each patient’s recent activity in the platform. Fig. 9 presents the template of a patient’s recent activity.

Fig. 9 – Patient’s Recent Activity

The recent activity records the latest questionnaire entries for the last 30 days, if any, labeled with answer date and icons highlighting each activity.

The evaluation of the patient’s daily activities is made by answering the same questionnaires. This application provides the health professional with the patient’s corresponding self-evaluation right by the evaluation form. This feature is available for situations in which the health professional might consider the patient’s opinion regarding the latter’s daily activities. Fig. 10 and Fig. 11 present, respectively, the health professional’s full and basic questionnaire evaluation forms.

Fig. 10 – Daily Activities – Full Questionnaire (Professional Evaluation)
Just like in the patient’s self-evaluation forms, the latter figures expose how simple, fast and straightforward the professional evaluations are within the platform.

Another great feature of this Web application is the questionnaire editor, allowing the health professionals to add new questions to each form for a specific patient and even to specify answer choices for each of those questions. Fig. 12 presents the questionnaire editor template.

The added questions can be either open, Boolean (yes or no) or closed, that is, with a set of defined answer choices.

2.3 Patient Reports

A key aspect of this project is to make possible a share of information between professional and disabled person. The latter can have an access to the specialist’s evaluation and the specialist can consult the patient’s self evaluation, as well. Therefore, the application allows both of them the analysis of the reports generated through the evaluations of the full questionnaires in each daily activity, just as revealed in Fig. 13.
The patient reports’ template grants an easy comparison between self-evaluation and professional evaluation by placing them side by side, revealing the latest answer to each question, if any, as well as its answer date. The user can dynamically navigate through different questionnaire reports and professional evaluators, conferring the opinion of a different health professional. The eldest reports are archived, nevertheless they can be examined in table format.

The direct comparison of self-evaluations and professional evaluations can lead to interesting results, like opinion divergence between patient and health professionals about the former’s condition. This disagreement can motivate a dialogue to assert the motives behind it. A differential in evaluations can be explained by some over-confidence or under-confidence by the patient about his/her own limitations, or even a mislead understanding by the health professional about his/her patient’s social and health condition.

2.4 Patient Charts

In order to allow a graphical observation of the patient’s status, the platform offers a dynamic, customizable set of charts which enhance several important aspects of his/her condition and recovery evolution. Naturally, this information is accessible by both patients and health professionals, assuring the medical data share between them.

To enhance the current condition of the patient, the application generates a radar-like chart which converts the basic questionnaire answers into a numerical value, proportional to the patient’s limitation in each daily activity. For situations in which some daily activities are not worth considering in the analysis, the platform offers an activity filter, allowing the user to dynamically exclude/include activities from the resulting graph. Fig. 14 presents the chart generated through the patient’s answers in the basic questionnaires.

![Patient's Full Questionnaire Report](image)

**Fig. 13 – Patient’s Full Questionnaire Report**

![Patient's Basic Questionnaire Chart (Self-Evaluation)](image)

**Fig. 14 – Patient’s Basic Questionnaire Chart (Self-Evaluation)**
The observation of this chart instantaneously brings out the full limitation status of the patient. The larger the chart's area is the more severe are the patient's limitations in his/her daily activities.

The Web-based application can also generate a similar chart with the health professionals' evaluations. Additionally, an overview report can be generated by overlapping the patient's self-evaluation and the health professional's evaluation charts, such as the one shown in Fig. 15.

![Fig. 15 – Patient’s Basic Questionnaire Chart (Overview)](image)

In a perfect scenario, the chart above would reveal no discrepancy between the overlapped evaluations. However, situations in which the patient has a different opinion about his/her social and health condition than his/her professional staff can happen. The reasons can come from lack of understanding about his/her current limitations to mislead information traded between patient and health professionals about the former's condition. This situation should be addressed with an increase of communication to ascertain an accurate understanding of the patient's health status.

A temporal evolution of the patient's global health condition throughout a vast period of time can be analysed with help of vertical, coloured and customizable bar charts. The application compiles the answers in the daily activities' basic questionnaires and presents the average disorder of the patient in a monthly basis throughout the previous twelve months, as shown in Fig. 16, regarding the self-evaluations. The platform can also generate similar charts for the professional evaluations and even overlap the former with the latter, strongly enhancing the comparison between both.

![Fig. 16 – Patient’s Temporal Evolution Chart (Self-Evaluation)](image)

The chart above effectively translates the patient's global social and health condition evolution. The lower the bars are, the better the patient fares regarding his/her limitations. The colour gradient, from green to red, aids the interpretation of the chart. For instance, a chart mostly coloured in green-like tones reveals a good management of the patient's disorder, while a chart filled with reddish toned bars can be seen as a severe, limiting health condition. In addition, a growth of the chart's bars on a monthly basis can be interpreted as a bad management of the patient's disorder, which could be a sign that a dialogue with the health professionals is necessary to solve the worsening tendency. On the contrary, a decrease of the bars over time may indicate a better management of the disease, resulting in a successful increase of the patient's quality of life.
3 CONCLUSION AND FUTURE WORK

The developed application allows both patients and health professionals keep in touch regularly through a message system, forms and charts regarding the social life and daily activities. Although the terminology in the platform is extremely accessible, it grants both of them medically relevant data about the patient’s global health and social status and temporal evolution, enhancing the comparison between self-evaluation and professional evaluations. The Website navigation is fluid and user-friendly, with virtually unlimited server storage space, granting no restrictions in the number of users and records.

Thanks to the interdisciplinary collaboration between computer science engineering and health professionals, the platform ensures rigour in both technology and medical fields. Additionally, this link allowed the test of the platform from the point of view of the health professional users. The efforts to guarantee the satisfaction of the health specialists greatly strengthened the project.

Overall, the main purpose of this project is to provide a didactic tool to help patients to understand their disease and to take an active part in the management of their health condition. Although the use of the application by several patients and professionals has been delayed because of juridical questions about medical data confidentiality, the platform will be ready for tests at a larger scale in the near future.

REFERENCES


