e-ESPOIR: a user-friendly web-based tool for disability evaluation

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Abstract. e-Espoir (www.espoir-handi.com) is a web-based database aimed at the evaluation of physically disabled people. The tool is designed to be used on the client's side by health care specialists and patients, through two distinct interfaces. Differing from previous projects, the platform implements a user-friendly application easily customizable by the user. The system's plasticity intends to ensure a strategic evaluation according to the specific impairments and needs of each handicapped person. The user interface is mainly composed by pictogram-based questionnaires and dynamic forms to permit an intuitive utilization even for non-specialist people. The objective of this work is to improve the management of the multidisciplinary health care cooperative network and promote an active involvement of the patient, by allowing the self-evaluation.

Keywords. Web-based application, strategic evaluation, physical disability.

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1. Introduction

1.1. Issues of disability management

The development of a handicap web-based database becomes more and more necessary owing to population ageing and the health care of disabling pathologies. Statistics show that 1 in 10 people need personal assistance due to a disability more or less severe [1]. However, there is a lack of overview and medico-social multidisciplinary collaboration because of the absence of joint references and tools between the professionals [2, 3]. These observations justify the emergency of scientific studies about means to get information through a more efficient way, especially the means to share data that come from varied contexts.

A consensual organization of the medical assistance for handicapped people can be represented by a system in which the patient is located at the centre to receive health care from a collection of health specialists [4]. In the field, the professionals have to contend with two main obstacles. At first, each health care field uses different evaluation and communication tools. The consequence is both a limitation of interdisciplinary exchange and a decrease of functional reactivity because of the redundancy of data recording. At second, the disabled person does not have an active participation in her/his own evaluation. However, no one has a better practical knowledge of her/his impairment than the individual that deals with the deficiency in everyday life. So, a research on an active involvement process of the various actors (proper patient, family, doctors, paramedics...), in order to carry out a strategic and customized analysis of the motor disability, seems necessary at a medico-social level (multidisciplinary health network), economic level (rationality of the financial costs) and ethic level (assertion of the position of the patient and social and medical actors). The current tools are still very limited. They are essentially based on a rigid form template, inspired from the paper format, which impede the construction of a customized strategy to fulfill the questionnaires [3]. They are not adapted to a self-evaluation because they are difficult to understand by non-specialist people [5]. Finally, they disregard important parameters such as pain and skin disorders.

1.2. Solution proposed

In order to improve the disability management, this article presents the e-ESPOIR (*"Evaluation Stratégique et Personalisée par Outil Informatique en Réseau"*) web-based application that permits a customized and strategic evaluation of neuromuscular deficiencies. The objective is to enhance the organization of the multidisciplinary system of health cares for handicapped people. The main challenge this work attempts to resolve is to construct a tool which is accessible for the ordinary people but still maintains useful information for the health professionals. This new management of chronic deficiencies is intrinsically linked to the plasticity of the computing systems and to the centralization/distribution of the information access through the communication networks [6, 7].

From a scientific point of view, this approach consists in elaborating an innovative methodology for the accompaniment of disabled people. The originality is based on a tight collaboration between patient, relatives and professionals. At a social 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 medical level, the challenge

is to make the multidisciplinary assistance easier 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 the one hand, the goal is to create a real clinical record in order to prevent the repetition of the same questions in various services, to avoid superfluous examinations and to complete questionnaires that depend on the medical context. On the other, a really new aspect is to allow the patient and her/his relatives to have an access at some levels of the computing system and, consequently, to be directly involved in her/his evaluation. At last, the tool will also be useful for epidemiologic studies aimed at medical, social and industrial entities related to the handicap issue, in order to improve the health care delivery.

2. Technical description of the tool

2.1. Clinical and social materials

The site content is elaborated from the OSE/UKNDS questionnaire, the HOLE/FIM questionnaire and some elements of the GEVA referential. OSE *("Outil Simple d'Evaluation")* is a form, illustrated by pictograms, used for the assessment of multiple sclerosis symptoms [8]. It is a francophone adaptation of the *United Kingdom Neurologic Disability Scale* (UKNDS – ex GNDS) [9]. It permits the doctor to easily evaluate the evolution of the patient's disease [10]. The form is composed by a selection of thirteen items which are the main symptoms of the disease (cognitive functions, sensorial and motor systems, psychological state…). The assessment system is based on a five level scale from which the sick person has to select the pictogram which is the most representational of her/his state. The scale extends from the normal state to the high impairment case, with three intermediate situations. For instance, in figure 1, the middle disturb level is selected for the "vision" item.

Figure 1. A typical item of the five levels scale of OSE form for the evaluation of multiple sclerosis.

HOLE *("Handicap Outil Léger d'Evaluation")* is another form for the generic evaluation of symptoms and medico-social situations of disability [11]. Its structure is an adaptation of the *Functional Independence Measure* (FIM) which is designed to be used following different reading levels according to the user's profile (professional vs. patient) [12, 13]. HOLE was created to convey an overview of the global health state and functional capacities of the handicapped person. This tool was a first step towards a patient evaluation shared between the professional and the patient her/himself. Indeed, the questionnaire is based on easy medical language and illustrated topics to facilitate the comprehension and usage by an average person (figure 2). Nevertheless, it also maintains a high medical value to be used by the professional to improve her/his diagnostic.

Figure 2. An excerpt of HOLE form, for the communication and skin disorders/pain topics.

Finally, GEVA is a referential of evaluation used, in an official way, in *Maisons Departementales des Personnes Handicapés* (French centres for the assistance of disabled people). This is an evaluation guide composed by eight chapters (social, home, job, health, psychic, functional capacities, compensation roadmap, assessment overview), which permits to store useful elements to construct a customized plan of compensation for the autonomy loss by the handicapped person. On the one hand, this last tool has the advantage of being really exhaustive in regard to the evaluation of the socio-medical state and needs of the individual. On the other hand this completeness brings a high complexity to complete a ponderous document, which is not always within the reach of everyone and is confined to a too rigid template.

2.2. System implementation

2.2.1. Global architecture

e-ESPOIR is based on a client-server computing architecture (figure 3). So, the tool is completely available on the client's computer through a web browser. This type of access makes possible the dichotomy between a simple user interface and a professional interface and brings a better flexibility in system administration. e-ESPOIR is more than a simple web-site, it is a web-based application. Its architecture is composed by four components: the frontend, the backend, the document component and the database. This kind of architecture was chosen to permit isolate functionalities and to facilitate the maintenance of the system. Indeed, from this organization each component can be individually updated, with the only caution in the linkage between these components. Another advantage of this architecture is to ensure the scalability of the tool to a configuration in which each component could be located in its own server.
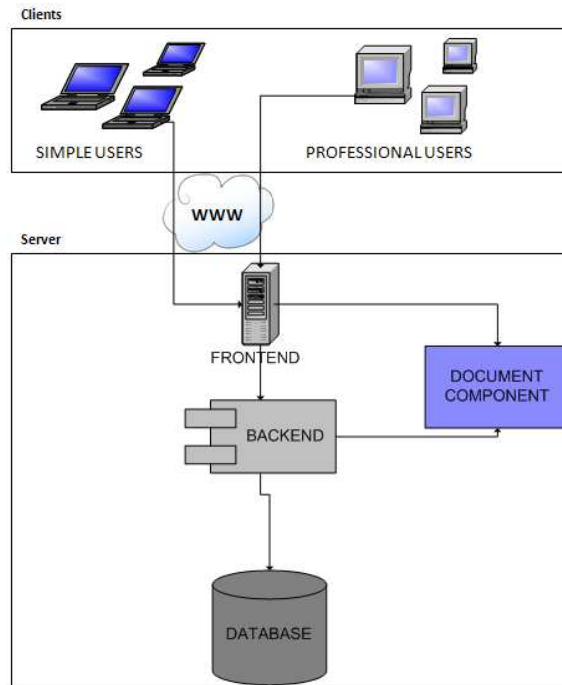
Figure 3. Client-server architecture and four components of e-ESPOIR web-based application.

2.2.1.1. Database

The site working relies on a database of questionnaires, result recording and identification module. The technology used to implement this database is *Microsoft SQL Server*. In order to record the data following the constraints described afterward, tables were created and linked each other according to the requirements of the application. A caution was applied to construct tables as normalized as possible for an easier upgrade of the database.

The database architecture is organized according to HOLE topics (feeding, hygiene, locomotion …). For the data modeling each topic is described in terms of a short and an extended questionnaire. The short one only records answers on a five level scale, inspired on OSE model. The detailed questionnaire has a more complex structure. Each topic is subdivided into items and a general comment. An item contents a true or false value. For some items, a true answer is complemented by a rating system and a possible comment (see section 2.2.2, for an illustration of the data acquisition interface).

In terms of security, the access to the clinical data stored into the server is limited. Only accredited users are allowed to consult patients' data. For this purpose, the identification module ensures a connection between a patient login and her/his personal data. Also, the ID number permits discriminate a simple user from a professional user. This distinction is important to load a different interface for specialist vs. patient and to provide a professional with restricted authorization to consult her/his patients' data only.

2.2.1.2. Frontend

This is the application component visible by the user. It is highly dependent on a lower layer that deals with the site's logical structure (the backend). The frontend is

composed by the visual of the pages and some logics relative to the data insertion by the user. After, the data recording and management processes are transferred to the backend. The visual user interface is mainly organized into pictogram-based questionnaires and dynamic forms in order to make easy the health record filling and to permit the user to customize her/his evaluation profile according to her/his specific needs (see section 2.2.2, for more details). Also, the frontend uses global functionalities of internet, such as cookies. These cookies are variables saved on the client's side. For instance, they are used in this project to ensure a user login during a certain period of time. The technological tool employed to implement this part is *ASP.NET*.

2.2.1.3. Backend

This component makes the connection between the frontend layer and the database layer. The backend has two main functions. On the one hand, it transmits the data acquired through the user interface to the database. On the other, it constructs and provides structures directly exploitable at the frontend. This three layers web application architecture has two important advantages. At first, the user never accesses the database directly, which increases security requirements. At second, it facilitates the task of someone who is working at the frontend. Indeed, s/he does not worry about formatting the data that come from the database, because this process is carried out by the backend that provides a perfectly usable and familiar structure. This module is programmed in *C#* language.

2.2.1.4. Document component

This is the simplest component but, also, the one that consumes the most computer resources. The site has the functionality to issue documents, such as a review of questionnaire answers. Since they are only simple documents, a file generation via *Microsoft Interop* (library to issue *Word* files) was chosen. The documents are created in real time, according to the user request, through predefined templates. After the issue, the files are serialized and saved into the database or downloaded to the client computer. This process consumes some resources of the machine where the site is running. However, the site is prepared to move forward to other technologies (*Microsoft Reporting Services,* for instance) if it is justified by the workload or the kind of documents issue.

2.2.2. User interface

Two kinds of interface are implemented, one for the patients and another one for the professionals. The simple user interface allows four main operations. The patient can fill in questionnaires, make some requests (e.g., issue and upload documents), consult results of the questionnaires and create a relation with her/his attending physician. The professional interface also permits to execute queries and consult data of related patients, as well as to complete items about these patients. Moreover, the health care specialist has the permissions to add more relevant questions, according to the patient profile, with the purpose of increasing the interactivity of the evaluation. In order to avoid mixing a self-evaluation from a specialist assessment, both are identified into the database by the specific ID of each user. The advantage of allowing two types of evaluation is the possibility to correct or to refine the point of view of the handicapped person vs. the professional in case of discrepancy.

Figure 4. Frontpage of the e-ESPOIR web-based application.

Figure 4 shows the homepage of the site. The user can choose the language interface between English, French and Portuguese. The main menu, displayed into a written and a pictorial mode, has five topics: "Home Life", "Social Life", "Medical Record", "Social Record" and "Account Management". To be able to use the web-application, the user first has to register, through the "Account Management" menu. The registration is different whether the user is a patient or a professional. If the user is a patient, s/he has to answer some questions that permit to bring an overview of the patient situation (identity, disease, civil status, profession, specific needs, home environment and user name/password). If the user is a professional, s/he only has to fill in the items related to the login identification access. Also, the management menu permits to create a link between a handicapped person and a health specialist, for the patient data access and questionnaire edition by the professional, and to issue or to upload documents.

The "Social Record" part is constructed from the section 1 and 3 of the GEVA referential. The items to answer concern the education, the family, the profession and the wage situations of the disabled person. Through the "Medical Record" menu, the user has access to a thesaurus with respect to the medical state of the patient. The content of the "Social Life" is based on a radar chart displaying seven social quantitative parameters (public life, relatives, friends, human assistance, using of communication means, management of personal businesses, outdoor mobility). The

bigger the plot area, the greater the social activity. Finally, the "Home Life" menu is divided into two sub-menu levels: "Daily Activities" and "Home Adaptations". The latter implements questions of the GEVA section 2, which is related to the evaluation of home and personal environment adaptations regarding the loss of autonomy.

(a)

(b)
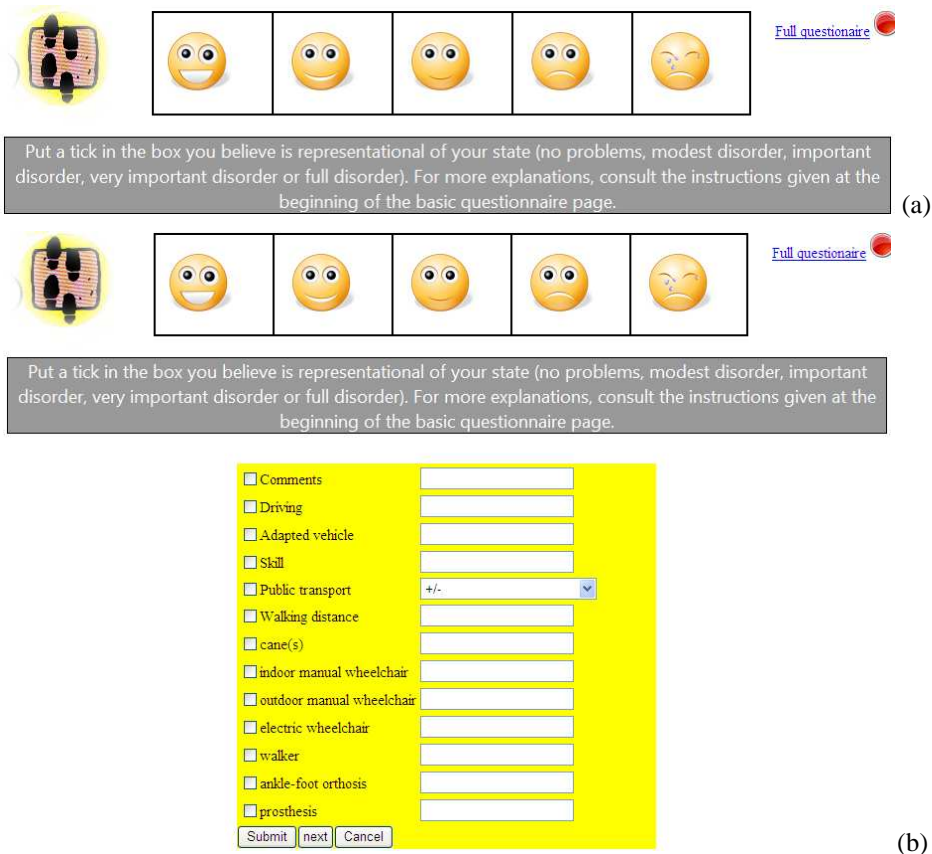
Figure 5. Example of the full questionnaire design: at the outset, the items are displayed in form of a basic questionnaire (a), afterwards the user can make the decision to make visible the full questionnaire itself (b).

The "Daily Activities" sub-menu is the most original and dynamic part of the e-ESPOIR evaluation tool. In this section, the patient is completely free to choose the topics s/he wants to answer and the detail level he wants to reach for each topic. To do that, s/he has the choice between a basic and a full questionnaire (figure 5). The "Basic Questionnaire" sub-menu takes up the HOLE topics (table 1) and implements the five level disturb scale of OSE (none, modest, important, very important, full disorder). So, by taking a quick look through the page, the user can have an idea of the global disorder level for the main symptoms of the physical deficiency. Also, this page is used to bring an overview of the patient's state, seeing that it is automatically updated when the user fills in the items through the "Full Questionnaire" sub-menu. Indeed, this last menu permits to fill in the full questionnaire itself and the basic questionnaire related to the chosen topic (see figure 5b, for an example with the movements/locomotion topic). The full form ensures an exhaustive evaluation of the patient's state for a determined symptom.

Personal cares	Sphincter control	Transfers	Movements	Communication	Diverse
- Feeding	- Stools	- Bed /	- Stairs	- Expression	- Pain /
- Look	- Vesical functions	sofa	- Mobility	- Comprehension	sensitivity
- Washing		- WC			- Skin
- Top dressing		- Bath /			diseases
- Bottom dressing		shower			- Mood
- Toilet using					

Table 1. Evaluation topics of the "Daily activities" menu.

If the patient takes the decision to fill in the full questionnaire for a specific topic, it means that this symptom is particularly relevant in her/his everyday life. So, this is a clue that the professional has to carefully take into consideration for her/his diagnostic assessment and health care delivering. The customization of the questionnaire answering and edition, in order to go deeper into certain topics and not into other ones, is the key idea to construct a strategic evaluation of the disabled people needs that the tool attempts to do.

3. Conclusions and perspectives

The challenge of this work is to create a web-application to improve the multidisciplinary evaluation of disabled people. To do that, the tool is based on a subtle balance between a usual terminology and a technical relevance. The interface is also constructed to increase the user accessibility. This user-friendly platform is designed to transform the passive patient into an active actor. On the contrary of the other projects, e-ESPOIR takes the advantage of the computational plasticity to ensure a dynamic and interactive evaluation. The patient as well as the professional can customize the questionnaires in order to achieve a really strategic evaluation. The future works will focus i) on promoting even more intuitive assessment items (for instance, via animated avatars) and ii) the creation of an anonymity database for epidemiologic studies.

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