Patient Empowerment by Increasing Information Accessibility In a Telecare System

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Abstract. Patient empowerment is important in order to increase the quality of the medical care and the life quality of the patients. In this respect, the paper describes how a telecare system can become more "friendly" with the assisted persons (elderly people or post-discharged patients) due to a specific feature addressing the patient access to information from medical texts. The according service is part of the server of a tele-care/tele-assistance system (TELEASIS) and adapts the medical text to "patient" lay person language, contributing in this respect to the patient empowerment process. This component is based on an original terminology interpretation engine which is being briefly described in this paper. The TELEASIS system has a specific interface dedicated to medical personnel allowing the addition and assignment of medical text to patients or group of patients, which can be later accessed by the patients adapted to a patient friendly language. The medial texts are saved on a central medical information database which contains different content formats (text, multimedia, videos). As a conclusion, the adapted information available for the assisted persons and the communication channels established in the system increase the possibility of patients being better informed on their health status.

Keywords. Tele-assistance, text accessibility, patient empowerment, elderly people.

1. Introduction

The traditional medical treatment or social assistance model (as elderly people care) often ignores the non-medical (emotional, social, and cognitive) aspects of living. In order to access a holistic solution of the healthcare personnel- patients relationship, patient empowerment is an answer to this challenge. Patient empowerment is defined as helping people to discover and use their own innate ability to gain mastery over their disease or status [1]) - by providing education for informed decision-making, assisting patients to weigh costs and benefits of various treatment options, setting self-selected behavioural goals, and providing information about the importance of their role in self-management.

Health care professionals are under increasing pressure to become more efficient [2]. In this respect, a collaborative way, as patient empowerment, to improve the quality of the medical care that reduces the burden of medical professionals is a must. The challenges of fostering the adoption of the new paradigm of patient empowerment

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differ substantially from those associated with the introduction of new technology. The adoption of the collaborative care approach empowers health care professionals as much as it does patients [3]. That is the reason why in the project TELASIS new functions are developed: related to increased accessibility of the patients to the medical information, or to a better understanding of the medical terms by the patients.

But we must be aware that the patient empowerment paradigm has its own pitfalls [4][5]. The healthcare professionals must promote more responsibility for the patients themselves. Medical language is very often hard to understand for regular people. Given this the communication between doctors and patients can suffer especially when dealing with remote communication that can appear in systems like TELEASIS. A research project, using a specialized classifier, tried to evaluate how easy is for regular people to access data expressed in medical language reached the following conclusion "The classifier was then applied to existing consumer health Web pages. We found that only 4% of pages were classified at a layperson level, regardless of the Flesch reading ease scores, while the remaining pages were at the level of medical professionals. This indicates that consumer health Web pages are not using appropriate language for their target audience" [6]. This can affect in a grate manner the accessibility of the patients to their health information. Having a bad understanding of their health status may have a bad influence on their heath evolution. Empowering the patients with more understanding of the medical information related to them will strongly reduce this risk.

2. A better accessibility to information

One key element of patient empowerment is enhancing accessibility to information of interest. The TELEASIS system suggests several ways to ensure this like access to a central medical information database, access to additional communication channels, interpreting medical language. The last issue will be the main topic of this paper. Interpreting medical language represents adapting or "translating" information from specialized medical language to lay or patient friendly language.

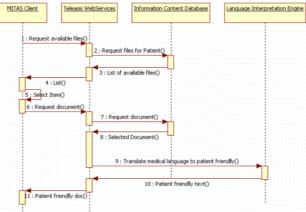


Figure 1. Getting patient friendly information

TELEASIS system is offering patients access to their health data, reports and additional medical information. All this data is stored in an information and content database. Enrolled medical stuff or other power user can add documents to this database, and can set the access rights for patients or groups of patients. In this way each patient can

access different documents. While allowing the patients to access medical information proves to be useful, as reminded in the introduction, the patients encounter big difficulties in understanding that information. For this, TELEASIS is using an interpretation engine that allows the patient to get the medical information "adapted" to regular language, which is easier for them to understand. The process of user getting a document containing medical information adapted to lay language from TELEASIS database is shown the sequence diagram illustrated in figure 1. The interpretation engine is described in more details bellow.

3. Interpretation Engine

Existing solutions: There are several language and text processing tools available online, but we couldn't identify some that are dedicated to specialized language interpretation and text adaptation. A step forward solving this kind of accessibility issue is given by research and tools analyzing the level of accessibility of specialized language. One of these research applied in medical area has delivered a framework for classification of specialized medical language by the level of accessing difficulty [6]. The final results of this research mentioned "We found that only 4% of pages were classified at a layperson level, regardless of the Flesch reading ease scores, while the remaining pages were at the level of medical professionals. This indicates that consumer health web pages are not using appropriate language for their target audience". Other research [7] proposed a framework to inform the design of an "interpretive layer" to "mediate" between lay (illness model) and professional (disease model) perspectives. The classic solution for this area is language interpretation done by human interpreters. The presence of the interpreter makes it possible for the patient and provider to achieve the goals of their encounter as if they were communicating directly with each other. There are several international institutions like IMIA (International Medical Interpreters Association) [8] that are providing standards and frameworks for medical interpreters.

<u>Proposed Solution</u>: The area of software applications focused on terminology is increasing, and it also is into the process of standardization. ISO organization has already released standards like ISO/TC 37/SC 3 which "defines standards and best practices for using computers to manage terminology and other language resources." [9] In order to develop qualitative software solutions, some research on these standards are in plan. Also in order to assure the quality of text interpretation the project partially tries to simulate the interpretation done by human simulators. For this, the standards [10] given by the IMIA association has been used as a set of guidelines for this research considering issues like: interpretation, cultural interface, ethical behavior. This was the area specific framework description that is used as guidelines for this research. To perform interpretation of specialized language this research proposes a simple design for an interpreting tool, having two main modules, a text parser (TP) and a terminology dictionary (TD). The text parser will process all the row text, word by word, checking each word against the terminology dictionary. Whenever a word is found it means it's a specialized term. The methodology described here is implemented into a functional prototype developed in Java.

<u>Text parser</u>. The text parser is working on raw or tagged text (like HTML) in this phase, performing the basic operation of iterating through all the words and checking whether the word is contained by the dictionary or not. If positive, the meaning of the term is

appended to the word in parenthesis. It is able to tag words and offer output as XML, or several HTML compliant formatted text.

<u>Terminology Dictionary.</u> (TD) The problem with linguistic data, especially natural language processing, is that it is dealing with uncertain information. A method of dealing with this kind of data is using error-tolerant methods like fuzzy string matching. In many cases when dealing with text, the back-end data storage solutions are databases. Fuzzy usage in database information manipulation is being worked on for a while, FSQL (FuzzySQL) or SQLf getting closer to standardization [11]. Not the same thing is true when coming to in memory fuzzy data structures. This project uses a fuzzy data structure that was designed especially for this terminology interpretation. A detailed presentation of this novel data structure named FuzzyHashMap (FHM) can be found in article [12], and the data structure project is available as open source at [13].

Fuzzy Medical Dictionary. We want to identify, in plain text, medical specific terms. The terms have to be identified even though they are not in the canonical form. For this we will use a FHM to build a medical specific terminology dictionary. We will use that terminology dictionary to recognize specialized law terms in the given text.

So we consider we are parsing the following phrase:

"... in diabetic diet recommendations ... "

Each word is checked against the dictionary. When arriving to "diabetic" term, as presented in Fig. 2, the dictionary will search by firstly pre-hashing the term. The hash code for the resulted string "diab" is computed, and it points to the "diabet" entry. The Levenshtein distance [14] (which is the default approximate matching algorithm in FHM) between "diabet" and "diabetic" is 2, which is default threshold value in FHM. So the word diabetic has been associated to the term diabet from the dictionary. In conclusion, the FHM enables finding terms that are not in their canonical form, in a very efficient way. To make this possible, this is error tolerant, so it may do mistakes, but a good threshold and algorithm tuning improves the performance of the FHM.

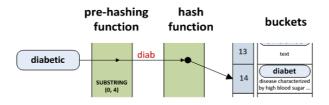


Fig. 2. Fuzzy searching for word "diabetic"

4. Discussion

Medical language is known for its specificity and specialized terminology. Given the fact that human health security may be affected by information understanding lack, the accessibility to this kind of information has attracted some interest in last years. If the foreign people interact with specialized language the accessibility problems are even bigger. In some countries there are laws dedicated to this kind of accessibility. Some research investigating language accessibility and related legislation mentions that "For twenty-three million Americans who speak English less than "very well," language barriers lead to lower quality of and worse access to health care. ... the lack of comprehensive implementation and enforcement leaves millions of patients with

limited English proficiency forced to accept a lower quality of care than English speakers receive." [15]. In our project we preferred to limit the text adaptation only to terminology labeling, rather than a complete "translation" to lay language. An interesting research [16] concluded that a translation to lay language may decrease the confidence level of the message for patients. The described service has only been tested by student testers. We're looking forward to perform real scenarios tests with patients.

5. Conclusions

Patient empowerment is important in order to increase the quality of life of the patients. The personalized information available for the assisted persons and the communication channels established in the system increase the possibility of the patients to be better informed about their health problems. They can better understand their own health status and problems, by this contributing to patient empowerment.

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