User modeling of disabled persons for generating instructions to medical first responders

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Abstract. To provide personalized health recommendations concerning disabled persons, an adaptive system needs a detailed user model that can account for the peculiar aspects of the many existing disabilities. This paper describes how we built such a user model and illustrates the Web-based system that allows all interested stakeholders to access and provide user model data.

Keywords: personalized health services, user model, disabled patients, adaptive instructions, first responders

1 Introduction

Emergency medical services (EMS) rely on well established procedures that apply to the most frequent cases a first responder encounters in her practice, but often do not include special cases concerning (sensory, motor or cognitive) disabled persons. In these cases, first responders may end up applying suboptimal or possibly wrong procedures or lose precious time trying to adapt on-the-fly to the special case. Adaptive systems could thus be employed to generate personalized instructions for medical first responders, taking into account a model of the disabled person involved. For example, an adaptive system could consider the presence of chronic pain or paralysis in specific parts of the body to instruct first responders – while they are traveling in the ambulance to the patient location – about changes to the standard procedures, e.g. the question “Do you feel pain here?” could have to be substituted with “Do you feel more pain than usual here?”, and manual procedures to immobilize the patient and to transfer her to a stretcher should treat paralyzed body parts with extra care (e.g., loads and tractions).

In general, to provide personalized health recommendations concerning disabled persons, an adaptive system needs a detailed user model that can account for the peculiar aspects of the many existing disabilities. This paper describes how we built such a user model and illustrates the Web-based system that enables all the identified stakeholders (disabled users, their families, clinicians, and medical first responders) to contribute and receive personalized data and knowledge.

2 Related Work

Adaptive systems have been applied successfully in medicine to inform patients about their conditions, enable them to take decisions, persuade them to be compliant with care plans. Different diseases, such as diabetes [9], cardiovascular disease [1], cancer [2], and asthma [3], have been addressed. The PULSE project [1] combines patient data acquired from paper-based medical records with adaptive Web-based presentation techniques to provide personalized education materials about cardiovascular risk. The personalized materials address medical and psychosocial aspects together with clinical guidelines to motivate people to take care of their health. The PIGLIT [9,2] system also focuses on health education materials, aiming at providing users with personalized hypertext explanations of their conditions, exploiting information from the patient's health record, a medical knowledge base and a natural language generator.

Many Computer Decision Support Systems (CDSS) have been proposed to support physicians in their activities (for a survey, see [4]), and share with adaptive systems the need for integrating medical knowledge bases, electronic medical records and computer-interpretable clinical guidelines. Relevant patient data can be acquired from Electronic Health Records (EHR), which unfortunately still have usage and adoption issues as discussed in [4]. While EHRs are typically managed by clinicians and staff of health care institutions, the idea of Personal Health Record (PHR) - i.e. an health record that conforms to recognized standards and is managed by the individual – is becoming popular, also thanks to Web-based applications such as Google Health [6] and Microsoft Health Vault [7]. Web-based PHRs are particularly interesting from a personalization point of view, since they offer: (i) standards upon which to build user models and health personalization applications, (ii) more access and control on what personal information is contained in and shared by the PHR, thus contributing to address some of the crucial privacy and trust issues highlighted in [9].

3 Modeling disabled users

Identifying and modeling all the impairments of each disabled patient to personalize EMS operations is a challenging task because severely disabled patients can be affected by many different and unrelated conditions which are not taken into account by generic disability stereotypes (e.g., blind, deaf, …). Moreover, current EHR and PHR standards do not support the detailed specification of disabilities. However, starting from scratch without relying on any standard makes it much more difficult to propose a medical user profile as well as having it adopted by clinicians.

3.1 The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) [10] is an initiative that is particularly relevant for our project, because it focuses specifically on disabilities. The ICF is the World Health Organization (WHO) international standard for measuring health and disability at both individual and population levels, and is endorsed by all WHO member states since 2001. The ICF organizes information in two parts. Part 1 concerns Functioning and Disability, and is structured into two components:

- *Body Functions and Structures*, to classify functions of body systems (e.g., Mental Functions, Sensory Functions, and Pain) and body structures (e.g., the Nervous System, The Eye, Ear and Related Structures);
- *Activities and Participation*, to cover functioning from both an individual (e.g., Communication, Mobility) and a societal (e.g., Interpersonal Interactions and Relationships) perspective.

Part 2 covers Contextual Factors, and is structured into two components:

- *Environmental Factors*, organized from the individual's most immediate environment (e.g., Products and Technology) to the general environment (e.g. Services, Systems and Policies);
- *Personal Factors*: they include gender, age, race, fitness, lifestyle, habits, coping styles, and other such factors.

Each of the above components consists of various *domains* (e.g. Sensory Functions and Pain is a domain of Body Functions and Structures). Within each domain, *categories* are the units of classification and are arranged hierarchically (e.g. for the domain of Sensory Functions and Pain, examples of nested categories are: Seeing Functions, Quality of Vision, Light Sensitivity). Health and health-related states of an individual are recorded by selecting the appropriate category code and then adding *qualifiers*, which are numeric codes that specify the extent or the magnitude of the functioning or disability in that category, or the extent to which an environmental factor is a facilitator or barrier. For instance, the code b210.4 indicates a complete impairment of seeing functions: the "b" prefix identifies the ICF component of Body Functions, the "210" code identifies the Seeing Functions category of the Sensory Functions and Pain domain, and the ".4" identifies the "complete impairment" value of the impairment category qualifier.

Since the ICF contains over 1400 categories, efforts to facilitate its use in clinical practice are underway. In particular, the ICF Checklist [11] consists of a selection of 125 ICF categories of more frequent use in clinical practice, and provides a questionnaire that can be filled out by a health professional to generate a disability profile of a patient.

3.2 Disabled user profile (DUP)

In our first meetings with medical experts (3 clinicians working with disabled patients and 1 emergency medicine doctor), the ICF Checklist was identified as a starting point to develop a Disabled User Profile (DUP) that describes the disabilities of an individual which are most relevant in the context of EMS. We asked domain experts to carefully analyze each category of the ICF Checklist and evaluate its appropriateness for the EMS context. The analysis pointed out that the DUP could be built by making some changes and extensions to the ICF Checklist. Our DUP contains:

- Twenty categories[1] of the ICF Checklist, selected by the domain experts based on relevance in the context of EMS.
- Some PHR fields (allergies, medications, diagnoses) to capture medical data not strictly related to disabilities, but relevant in EMS operations for any individual.
- For some specific diagnosis (e.g., autism), additional associated fields (e.g., self injurious or aggressive behavior) recommended by experts.
- Personal data (e.g. social security number, name and surname, address), to identify the disabled person.
- Contact information of relatives and/or representatives to be called or who may call in case of emergency, and a free text field where particular notes about the patient's needs can be stored.

With respect to ICF categories and qualifiers, we made the following changes:

- Since some ICF categories (e.g., b280-Pain, b710-Mobility of joints, b730-Muscle power, b735-Muscle tone, b765-Involuntary movements) do not include the precise identification of the body parts affected by impairments, which is needed for our purposes, we extended them using a 27-parts anatomical representation.
- The qualifiers used to specify the magnitude of an impairment in the different categories have been simplified, by including only 4 of the 7 ICF values: we kept the values *No impairment*, *Moderate impairment*, *Complete impairment* and *Not specified*, while we discarded the values *Mild impairment* and *Severe impairment* to reduce subjectivity in the assignment and interpretation of impairment, and *Not applicable*, since it is useless in our considered categories.
- For the qualifiers of some categories, domain experts identified the need of using specific terms (e.g. Hypoventilation, Normal, Hyperventilation for the category b440 Respiration) to make the values more precise for physicians and first responders, in particular where the above ICF values could lead to ambiguous interpretations (e.g. a Moderate impairment of Blood pressure could mean Hypotension as well as Hypertension).

4 Building and Using DUPs

PRESYDIUM is a Web application that provides a Web Portal allowing disabled users, their relatives and physicians to access DUPs through a user interface that adapts to user category and user disabilities, by exploiting stereotypes. The system also includes a Web Service, which is accessed by EMS center phone operators

[1] MENTAL FUNCTIONS: Consciousness, Orientation (time, place, person), Intellectual (incl. Retardation, Dementia), Language; SENSORY FUNCTIONS AND PAIN: Seeing, Hearing, Vestibular (incl. Balance functions), Pain; FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS: Heart, Blood pressure, Respiration (breathing); GENITOURINARY AND REPRODUCTIVE FUNCTIONS: Urination functions; NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS: Mobility of joint, Muscle power, Muscle tone, Involuntary movements; COMMUNICATION: Communicating with - receiving - spoken messages, Communicating with - receiving - non-verbal messages, Speaking, Producing non-verbal messages; MOBILITY: Walking, Moving around using equipment (wheelchair, skates, etc.)

through a desktop client and by first responders through a mobile client to retrieve tailored instructions for specific patients, EMS personnel (e.g. professional nurses, volunteers) and operational contexts.

PRESYDIUM has been built using the opensource JBoss Web application framework (jboss.org), which includes Drools (jboss.org/drools), a Rule Management System which is used as the personalization engine.

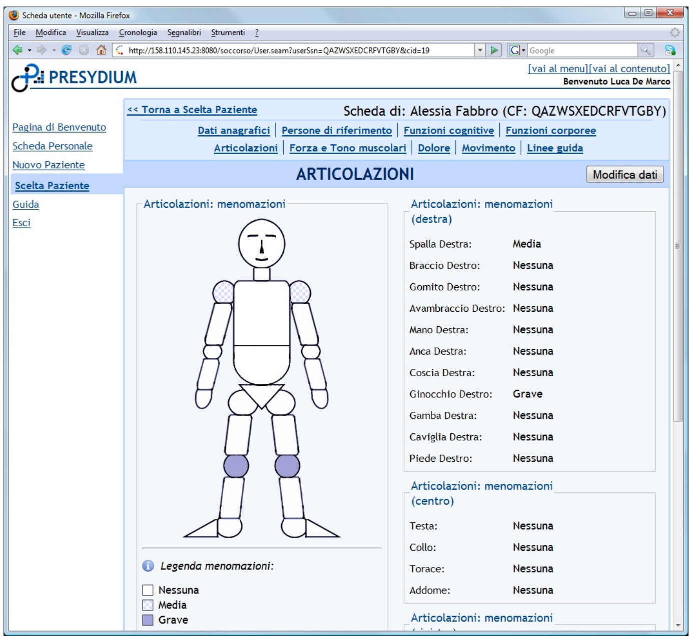

Fig. 1. User interface of the PRESYDIUM Web portal: inspecting a DUP section

The Web portal allows managing DUPs through a shared initiative between physicians, who contribute typical EHR data, and the disabled (or their relatives), who contribute personal information more typical of PHRs. Moreover, disabled users can access their own full DUP so that they can inspect all the data the system stores about them (also to address trust issues). The Web portal adapts the interface of the system (illustrated by the screenshot in Figure 1) by changing the presentation of elements of the user interface (e.g. bigger font size and inverted contrast for users with low vision), and by form adaptations during data entry of a DUP, to show or hide parts of the form (e.g. fields, schematic representations of human body), based on the values entered for specific fields.

Besides usual password-based access, the Web portal supports user identification based on the European Health Insurance Card (the most recent version of which includes a memory that contains identification data and can be read by a PC card reader which in our region is freely distributed to all households).

5 Conclusions

The PRESYDIUM system is currently going through a process of clinical validation. In particular, the present stage of validation is focusing on DUP data entry. A set of reference disabled patients has been selected and each member of a pool of clinicians (with different backgrounds) is separately entering DUPs for all cases. This will allow us both to detect possible misunderstandings in the DUP forms and to analyze consistency among clinicians in filling the DUP of a same patients.

Acknowledgements

We are particularly indebted to dr. Elio Carchietti (118 Emergency Medical Services, Udine Hospital, Italy), dr. Agostino Zampa and dr. Emanuele Biasutti (Istituto di Medicina Fisica e Riabilitazione "Gervasutta", Udine, Italy) for sharing their experience with us. Our research is partially supported by the Friuli Venezia Giulia region under the project "Servizi avanzati per il soccorso sanitario al disabile basati su tecnologie ICT innovative" ("Advanced emergency medical services for the disabled based on innovative ICT technologies").

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