Design and implementation considerations for a personalized patient education system in burn care

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Summary Patient education is a significant factor in the provision of health care services, contributing to improved disease management and health care outcomes. Personalization has been suggested as a means for increasing patient education effectiveness and computer-based approaches have been explored as a possible means of achieving this goal. The success and capabilities of the resulting applications have been restricted by the absence of a direct link to patient data and the reliance on locally produced written material, which is expensive to produce, update and tailor. In our research project STructured Evaluated Personalized Patient Support (STEPPS), we are investigating the potential of a novel strategy for personalized or tailored patient education, based on the integration of electronic patient record data and material derived from online health information resources. In this paper we present an overview of the pertinent technical issues and the way we have addressed them in the context of our development work in the domain of burn care. Further, we discuss how the choices made in the design of the system interrelate with the considerations for its implementation in health care practice settings.

1. Introduction

Patient education has been acknowledged as an important factor in the process of health care, with beneficial effects ranging from the adoption of health-promoting behaviors to improved management of chronic diseases and increased level of users' satisfaction with health care services [1–4]. It has been suggested that in order to be most effective, patient education should be personalized, i.e. adapted to characteristics of the individual recipient, such as age, gender, language, educational level [5]. In actual health care
settings, however, the ideal of patient education tailored to the needs of each individual is rarely achieved [6].

Computer-based approaches to patient education have been explored as a possible solution [7]. The success and capabilities of the resulting applications have been restricted by two factors: the absence of a direct link to patient data and the reliance on locally produced paper-based material, which is expensive to produce, update and tailor [8,9]. Recent developments, however, have opened up new possibilities to address the challenges of personalized patient education: on the one hand, the continuously expanding presence of electronic patient record systems and, on the other hand, the availability and popularity of a wide range of health information resources on the Internet.

In our research project STructured Evaluated Personalized Patient Support (STEPS), we are investigating the potential of a novel strategy for personalized or tailored patient education based on the integration of electronic patient record data and material derived from online information and knowledge resources. The current application area of STEPS is the post-hospitalization support of burn care patients in the Netherlands.

The design of a personalized patient education system that is based on utilizing online content poses considerable challenges from a technological perspective. In this paper we present an overview of the main technical issues and the way we have addressed them in our development work in the domain of burn care. In addition, we discuss how the considerations for the system’s implementation in actual practice settings interrelate with and largely determine the choices made in the design phase.

2. Background

2.1. Patient education in burn care

Due to a number of characteristics inherent or commonly observed in burn injury cases, patient education is both an important, as well as a challenging task in the context of burn care.

Each patient, depending on the type of injury, age, gender, functionality level before the accident, personality characteristics as well as other factors will have a very personal journey through recovery. This strong individual differentiation must also be taken into account in information provision strategies.

Burn care is a highly specialized, interdisciplinary field bringing together experts from emergency care, intensive care, general and plastic surgery, nursing, physiotherapy, nutrition, occupation therapy, psychology and psychiatry. The field’s multidisciplinary nature is also reflected in the information needs of patients and their families during the healing and rehabilitation phase.

Burn injuries bring abrupt, critical changes in the health and functional status of the affected individual and family. Often these changes are combined with psycho-social problems, either pre-existing and exacerbated by the injury or developing as a result of the traumatic experience [10]. In addition, ethnic, cultural and language background issues can impact on the ability to understand, accept and implement advice [11].

Changes and trends in the organization of healthcare services also impact on the tasks of patient education. Severe burns, often a life-threatening injury, require a period of hospitalization in the intensive care unit, eventually followed by discharge to rehabilitation clinics or, quite frequently, to home. Care for burn patients, however, should not stop at the moment they exit the burn care unit. Research indicates that after discharge from the hospital patients face considerable problems and are mostly in need of support [12-14]. The growing trend towards earlier discharge and home or ambulatory care increases even further the need for informing, educating and supporting burn patients and their families [15].

Traditionally, the place and time to educate burn patients has been during hospitalization or outpatient visits. In the Netherlands, support after discharge is available in the form of information booklets, outpatient visits, contacts with patient organizations and, since recently, a dedicated phone service [16]. The need for individualized education has been recognized, but efficient solutions are still lacking: paper-based education, although useful, has limitations. Further, professional expertise is located in the three specialized units, but since patients come from all parts of the country they often need to rely on the services of general practitioners and home care personnel. Lack of the necessary skills and knowledge required in caring for burn injuries—a recognized problem on the primary care level—can lead to sub-optimal treatment results, as research in minor burns has indicated [17,18]. Therefore, solutions that could make information sources available to both professionals and patients at the time and place where they need them would be more than welcome.
3. Design objectives

The main objective of STEPPS from the perspective of technology is to support personalized information retrieval by establishing a link between electronic patient record data and health related content available online. When designing such an application, researchers and developers face a central choice: who will be the users of the system? Should the system be designed for use by health care professionals, by the patients themselves or both?

The centerpiece of STEPPS is the patient’s record, which healthcare professionals create and update as part of their routine documentation practices. In our system, that same record also acts as the starting point for tailoring education material to the characteristics of the specific patient. The focus therefore has been on creating a system that facilitates the integration of patient education with other tasks of clinicians’ everyday work.

We will first describe the system development of STEPPS and then proceed to discuss the interplay of design choices and implementation considerations, from two perspectives in particular: the use of electronic patient record (EPR) data and the use of Web content in the context of patient education.

4. System development

The architecture of STEPPS combines the electronic patient record with standard international terminologies and software that indexes and matches online content to the clinical profile of a specific patient (Fig. 1). A more detailed description is available at [19].

4.1. Creating a standardized and user-friendly data collection system

The capability of an EPR system to provide structured and coded patient data is a valuable asset in the process of integration with online resources and subsequent retrieval. If data is not acquired in a coded form, additional effort is required to identify and extract the relevant patient characteristics (also referred to as the ‘patient profile’) through free-text processing of medical records [20]. Equally important, though, is a data collection system that does not act as an extra burden to clinicians, particularly in the strenuous and time-pressured environment of a burn care unit [21].

STEPPS uses the Structured Data Entry (SDE) module developed by van Ginneken et al. [22,23], which aims at providing a balance between acquisition of structured data and flexibility of data entry [24].

4.2. Promoting standardization—incorporating terminological systems

The process of matching between documents requires the use of a shared (preferably controlled) vocabulary [25]. The Unified Medical Language System (UMLS) tools have been created to facilitate the conceptual connections between information needs and various digital resources [26]. In STEPPS, we utilize the UMLS Metathesaurus (2001 version) as the bridge between the data entry interface and the retrieval software, which matches patient specific data to (relevant) online material.

STEPPS: Graphical Overview

Fig. 1. Graphical representation of the STEPPS prototype architecture.
During the modelling phase, a subset of the terms present in the SDE interface were assigned corresponding UMLS codes. As a result, patient data entered in the system is also UMLS-coded, without additional effort required on the side of the clinicians.

The same UMLS Metathesaurus is also used as the indexing vocabulary for the Web pages we have assembled in our test collection.

4.3. Locating pertinent online material

Investigating the potential of Web-derived content as patient education material presents many new challenges. The objective of integration with the electronic patient record forces us to give priority to conceptual and vocabulary-related aspects; as indicated by the scarcity or lack of meta-data and the inconsistency of indexing, these features are poorly developed in health-related Web pages [27].

To by-pass issues such as volatility of content, connection problems and performance times, we created an offline database of Web-derived content, which permits experimentation during the project. The creation of this database took place in two phases. First, we combined a variety of resources to single out topics which constitute recurrent, common problems facing burn patients. Then we used a commercially available meta-search tool, Copernic-Pro®, to retrieve and store pertinent Web pages.

4.4. Indexing and matching

In order to index the assembled Web material we employed the Collexis® tools. Collexis® supports indexing and cataloguing of large collections of documents (in STEPPS, the Web pages in our collection) using the vocabulary of choice (in this case, the UMLS Metathesaurus). Subsequently, it assists retrieval against the profile of a desired document (the patient data subset extracted from the electronic patient record). Communication between the SDE interface and Collexis® is realized in the form of an XML message. For a more detailed description of the Collexis® architecture see [28].

5. Discussion

5.1. Use of EPR data in patient education

The importance of the electronic patient record and the role it could play in computerized patient education programs have been suggested by prior research in the field [9,29]. Nevertheless, patient education tasks are not regularly incorporated as standard functions of EPR systems, while the availability of computerized patient education systems for direct use by health care professionals remains scarce [30]. As a result, personalization depends either on elaborate extraction techniques applied on free-text records or on the provision of data by the patient, through a questionnaire or survey. In both cases, the requirement of prior processing has meant that education material cannot be retrieved and made readily available at the point of care, i.e. at the time and place where the interaction between professional—educator and patient occurs. In STEPPS, as a result of the integration with structured and coded EPR data, retrieval of tailored information is a direct sequence of regular clinician documentation activities.

The use of EPR data for patient education purposes, besides its advantages, also raises considerations regarding the patients’ rights to privacy and confidentiality, as well as aspects of medical data ownership and use. A system design assuming the use of EPR data beyond the local environment of care would place security requirements too demanding and costly to implement at the level of a single application. The choice of embedding the STEPPS patient education system in the clinical setting has the advantage of enabling implementation within existing structures and frameworks, thus minimizing the need for additional measures. Security aspects were not addressed in STEPPS. In a separate research project, however, the Dutch Burns Foundation is exploring the use of Privacy Enhancing Technologies as a solution to the pertinent security issues [31].

With regard to medical data ownership and use, the prototype version of STEPPS is again addressed to the primary users of clinical data, i.e. physicians and the other members of the clinical team. Since patient education is part of standard clinical duties, data is therefore not employed for purposes other than the original goal for which it was collected, i.e. patient care. Moreover, as part of their work, health care professionals are bound to specific obligations and moral duties; among them, respect for patient confidentiality.

Other implementation configurations would also be possible, as shown in Table 1, but then different issues would arise. A most interesting option would be entrusting the record and system to patients themselves, but that scenario would require on the one hand, different perceptions regarding the actual patient record (moving beyond the current approach of the EPR being primarily or
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Table 1 Implementation options for STEPPS.

<table>
<thead>
<tr>
<th>User group</th>
<th>Setting of use</th>
<th>Implementation issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialized doctorsa</td>
<td>Burn unit—outpatient department</td>
<td>Vocabulary—interface design</td>
</tr>
<tr>
<td>Nurses</td>
<td></td>
<td>Fitness to workflow</td>
</tr>
<tr>
<td>Paramedical personnel</td>
<td></td>
<td>Acceptance by personnel</td>
</tr>
<tr>
<td>(physiotherapists, nutritionists, psychologists, etc.)</td>
<td></td>
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<tr>
<td>General practitionersa</td>
<td>Primary care</td>
<td>Access to specialist EPR or discharge summary</td>
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<tr>
<td>Nurses</td>
<td></td>
<td>Communication protocols</td>
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<tr>
<td>Patients—caregiversa</td>
<td>Patient’s home</td>
<td>Specialist—GP record integration</td>
</tr>
<tr>
<td></td>
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<td>Security infrastructure (public networks)</td>
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<tr>
<td></td>
<td></td>
<td>Access to EPR</td>
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<td></td>
<td></td>
<td>Ability to add-update data</td>
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<td></td>
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<td>Language—interface design</td>
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<td></td>
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<td>IT skills</td>
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<td>Security infrastructure (public networks)</td>
</tr>
</tbody>
</table>

The prototype version has assumed the scenario presented in the first row of the table.

a Primary user group.

exclusively a 'tool for physicians') and on the other hand, a different level of security and operative legal framework (for a more detailed analysis see [32]).

National level developments in the Netherlands and elsewhere are gradually shaping the infrastructure needed for the advancement of ventures such as these in the near future [33,34].

5.2. Use of Web content as a patient education source

Research on tailored or personalized patient education has thus far assumed the use of locally produced, often paper-based material. In STEPPS we are investigating the requirements and limitations of utilizing health-related Web material as a patient education resource. The multiple health information sources available online, combined with the growing number of people familiar with the use of such technologies warrant this exploration. Moreover, the additional advantages are considerable, particularly from the viewpoint of meeting the needs of burn patient education. Online material could offer a solution to the problems of storage, access, easiness of reproduction, update and adaptation of content (with regard to language, cultural content, etc.). Further, the use of the Web as an education tool facilitates access to auxiliary, educational resources and enables the use of new learning methods based on multimedia techniques [35].

The technical challenges of creating a conceptual link between EPR data and Web resources are one of the aspects we are exploring in STEPPS. Another critical factor for the success and reliability of a patient education system that draws on online health content is the quality of the available information and, more particularly, the verification of its accuracy [36].

Healthcare professionals and institutions need to ensure that the information provided in the context of patient education is not harmful, inaccurate or misleading, a problem that affects also burn-related information online [37]. Therefore, the design of STEPPS has assumed the use of Web material appraised by healthcare professionals prior to its delivery to the patient.

Resource review by clinicians or information specialists is an approach that has been adopted in several projects concerned with quality assurance of Internet health information [38–40]. In addition, it is in accordance with patients’ preferences for their caregivers to act as knowledgeable intermediaries when utilizing Web-derived material [41]. The sustainability of such solutions however—particularly in terms of time and cost demands, as well as acceptance by healthcare professionals themselves—remains to be seen [42].

6. Future prospects

In the prototype version of STEPPS we have chosen to follow the lines of traditional patient education models. Health care professionals are assigned the role and responsibilities of educators; they monitor and adjust the flow of the system’s output, according to their assessment of patients’ evolving needs.
Subsequently, the tailored material can be delivered through a variety of mediums, ranging from printouts to CD-ROMs and online access to tailored Web pages. The participation of patients and their carers is not excluded in the current system design though; they can communicate specific information needs during consultation or take the initiative to explore the provided material in more detail by directly accessing the original, as well as additional resources online.

As presented earlier, there are several possible alternatives in designing a system such as STEPPS. Our choices are not aimed at perpetuating a paternalistic model of healthcare delivery. They simply reflect the limitations of the presently available legal and operational frameworks of healthcare practice, as well as the maturity level of the employed technologies. Still, the insight and results we expect to gain through our research can inform the ongoing efforts on advancing computerized patient education methods and applications.

The availability of numerous and diverse health information resources and services on the Internet is enabling the emergence of new patterns of interaction between professionals and patients [43,44]. The ideal of clinician–patient partnerships has been promoted, suggesting that health care professionals should seize the opportunity to work together with their patients in order to use the latest available knowledge and expertise in the best possible way [45].

Personalized patient education systems could be employed to assist the evolution of the co-operative model of health care practice. Now and in the future, designers and developers of patient education systems should acknowledge and be prepared to address the demands of a more active patient role in healthcare [47].

Acknowledgements

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