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Design Considerations for a Personalised Patient Education System

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Abstract

Patient education is a significant factor in the provision of health care services, contributing to improved disease management and health care outcomes. In order to be most effective, patient education should be adapted to the characteristics of the individual recipient. 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 and knowledge 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.

Keywords:
Patient education, Electronic patient record, Internet, Personalization, Consumer Health Informatics

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 behaviours 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 adapted or tailored to the characteristics of the individual recipient [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 written material, which is expensive to produce, update and tailor [8,9]. New possibilities to address both of these limitations have opened up as a result of recent developments: on the one hand, the continuously expanding presence of electronic patient record systems in various health care settings 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 (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 information and knowledge resources. The current application area of STEPPS is the post-hospitalisation 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 pertinent technical issues and the way we have addressed them in our development work in the domain of burn care. Further, we discuss how the choices made in designing the system interrelate with the considerations for its implementation in health care practice settings.

2. Background

2.1. Patient education in burn care

Burn injuries are among the most traumatic experiences a human being can endure. After a long and painful period of hospitalisation in the intensive care unit, patients are discharged to rehabilitation clinics or, most often, home. Research indicates that after discharge patients face considerable problems and are mostly in need of support [10, 11].

In the Netherlands, support after discharge is currently available in the form of information booklets, outpatient visits and contacts with patient organizations. 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 patients come from all parts of the country. Therefore, solutions that could make information sources available to patients at the time and place where they need them would be more than welcome.

3. Design Objectives

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

In STEPPS we have decided to follow the lines of traditional patient education models, where health care professionals are assigned the role and responsibilities of educators. The focus, therefore, has been on facilitating the integration of patient education with other tasks of clinicians' everyday work.

Health care professionals create the patient record as part of their routine documentation practices. In STEPPS, that same record also acts as the starting point of tailoring education material to the specific patient. The clinician monitors and adjusts the flow of the system's output, according to his or her assessment of patients' evolving needs. Subsequent patient access to the tailored material could be accomplished through a variety of mediums, ranging from printouts to CD-ROMs and online access to tailored Web pages.

We will first describe the system development of STEPPS and then proceed to discuss the effect design choices have on 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. A more detailed description is available at [12].

4.1. Creating a standardized and adequately 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 pertinent patient characteristics (usually referred to as the 'patient profile') through free-text processing of medical records [13]. STEPPS uses the Structured Data Entry (SDE) module developed by van Ginneken et al [14, 15], which provides a balance between acquisition of structured data and flexibility of data entry.

4.2. Promoting standardisation – Incorporating terminological systems

The process of matching between documents requires the use of a shared (preferably controlled) vocabulary [16]. The Unified Medical Language System (UMLS) tools have been created to facilitate the conceptual connections between information needs and various digital resources [17]. 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.

Patient data entered in the system is automatically accompanied by the corresponding UMLS code, without additional effort required on the side of the clinicians. The same UMLS Metathesaurus is also used as the indexing vocabulary for the online material we have collected as educational material.

4.3. Locating pertinent online material

Investigating the potential of Web derived content as patient education material presents many new challenges. The need to integrate 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 [18].

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 (here, 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 [19].

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 programmes have been suggested by prior research in the field [9, 20].

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 [21]. As a result, tailoring 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 education material is a direct sequence of regular clinician documentation activities. Additionally, this integrated approach enables implementation within existing security and confidentiality structures. In that context, considerations regarding the patients' rights to privacy and confidentiality, as well as aspects of medical data ownership and use have largely been addressed, minimizing the need for additional measures.

With regard to medical data ownership and use, STEPPS is 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 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.

Although security issues were not explicitly addressed in STEPPS, the pertinent aspects have already been explored in the context of the NBIS project, and solutions have been sought through the use of a combination of Privacy Enhancing Technologies [22]. In case of other implementation approaches, however, most interesting of which would be entrusting the record and system to patients themselves, different issues arise [23]. National level developments in the Netherlands are shaping the legal and societal framework needed to enable the advancement of ventures such as these in the near future [24].

5.2. Use of Web content as a patient education source

Research on tailored patient education has thus far assumed the use of locally produced, often paper-based educational 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 resources available online, combined with the growing numbers of people familiar with the use of such technologies warrant this exploration. Moreover, the additional advantages are considerable. Online education material could offer a solution to the problems of storage, access, easiness of reproduction, update and adaptation of content. 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.

The technical challenges of creating a conceptual link between EPR data and Web material 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 [25].

We believe that any solution to the problem of information accuracy assessment will eventually need to draw upon the basic knowledge and training of health care professionals as a resource. As dictated by the non-maleficence principle, health care professionals and institutions have a duty to ensure that the information provided in the context of patient education is not harmful to their patients. Moreover, patients seem to

prefer and support the prospect of their caregivers as knowledgeable intermediaries in utilizing Web-derived material [26].

The design of STEPPS assumes the use of Web material already appraised by health care professionals. We intend to study how such a strategy might work in practice, particularly from the viewpoint of clinicians' role in this new approach to patient education.

The proposed assignment of information quality assurance on the side of professionals is by no means aimed at perpetuating the traditional paternalistic model of delivering health care. The availability of numerous and diverse health information resources and services on the Internet has enabled the emergence of new patterns of interaction between professionals and patients [27]. 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 interest of each individual [28, 29].

Tailored patient education systems could be employed to promote and assist the evolution of a new, cooperative model of health care practice. The insight and results we expect to gain through STEPPS can inform the ongoing efforts targeted both at computerized patient education and at broader applications of information retrieval in health care. The potential implementation scenarios and uses of such applications can have profound organizational and societal consequences that warrant careful consideration [30].

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References

[1] Mechanic D. Issues in promoting health. Soc Sci Med 1999; 711-718.

[2] Silva J.S., Zawilski A.J. The health care professional's workstation: Its functional components and user impact. In: Ball M.J., Collen M.F. (eds.), Aspects of the computer-based patient record, New York: Springer, 1992: 103-123.

[3] Contento I, Balch GI, Bronner YL, et al. The effectiveness of nutrition education and implications for nutrition education policy, programs and research: a review of research. J Nutr Educ 1995; 27:277-422.

[4] Hammond A, Lincoln N. The effect of joint protection education programme for people with rheumatoid arthritis. Clin Rehabil 1999;13 (5):392-400.

[5] Tang PC, Newcomb C. Informing patients: a guide for providing patient health information. J Am Med Inform Assoc. 1998;5:563-570.

[6] Deccache A, Aujoulat I. A European perspective: common developments, differences and challenges in patient education. Patient Educ Couns 2001;44:7-14.

[7] Lewis D. Computer-based approaches to patient education. J Am Med Inform Assoc. 1999;6:272-282.

[8] Osman LM, Abdalla MI, Beattie JAG, Ross SJ, et al. Reducing hospital admission through computer supported education for asthma patients, BMJ 1994; 308: 568-571

[9] Jones R, Pearson J, Mc Gregor S, Cawsey AJ et al. Randomised trial of personalized computer based information for cancer patients. BMJ 1999;319:1241-1247

[10]Gordon MD, (Editor), *Discharge Planning and Teaching Programs,* JBCR, Vol 9, No 4, July August 1988, p.414-421

[11]Dattolo J, Trout S, Connoly ML, Home Health Care and Burn Care: An Educational and Economical Program, JBCR, Vol 17, March/April 1996, No 2, p. 182-187.

[12]Doupi P, van der Lei J, Towards personalized Internet health information: the STEPPS architecture. Med Inform Internet Med. 2002 Sep;27(3):139-51.

[13] Hatzivassiloglou V., Merport O., McKeown K.R., Jordan D.A., 1999, ExtractingPatient Profiles from Patient Records and Online Literature. *Proc AMIA Symp,* Washington DC, November 1999, p.1073.

[14]van Ginneken AM, Stam H, van Mulligen EM, et al. ORCA: The Versatile CPR. Method Inform Med

1999; 38:332-8.

[15]Doupi P, van Ginneken AM. Structured Physical Examination Data: A Modeling Challenge. In Patel VL, Rogers R, Haux R. (editors), Medinfo 2001, Proceedings of the 10th World Congress on Medical Informatics, Sep 2-5, London UK. London: UK; 2001 p. 614 – 619.

[16]Geissbuhler A, Miller RA. Clinical application of the UMLS in a computerized order entry and decision-support system. Proc AMIA Symp 1998, pp.320-324.

[17]Humphreys BL. Electronic health record meets digital library: a new environment for achieving an old goal. J Am Med Inform Assoc 2000;7:444-452.

[18]Shon J, Musen MA, The Low Availability of Metadata Elements for evaluating the quality of Medical Information on the WWW. Proc AMIA Symp. 1999;:945-9.

[19]van Mullingen E, Mons B, Schmidt M, Diwersy M et al. Architecture for Information Mediation, In: Patel VL, Rogers R, Haux R. (editors), Medinfo 2001, Proceedings of the 10th World Congress on Medical Informatics, p. 301-2

[20]Bental DS, Cawsey A, Jones R. Patient information systems that tailor to the individual. Pat Edu Couns 1999;36:171-180.

[21] de Vries H, Brug J. Computer-tailored interventions motivating people to adopt health promoting behaviours: Introduction to a new approach. Pat Edu Couns 1999;36:99-105

[22]Taal L, Oen I.M.M.H., den Daas F, Mulder-Tollenaar J, Beirlaen P., 2001, The Dutch Burns Information System, (in Dutch). *Zorg Administratie en Informatie,* 104, 12-15.

[23]Doupi P, van der Lei J. Aspects of Privacy and Responsibility in Personalizing Internet Health Information. In: van der Lei J, (editor): Proceedings of the EMD 2001 Symposium. Huisarts, Specialist en het Elektronische Medisch Dossier

[24]Meijer W. Standards for information security in health care (in Dutch). In: van der Lei J, (editor): Proceedings of the EMD 2001 Symposium. Huisarts, Specialist en het Elektronische Medisch Dossier

[25]Doupi P, van der Lei J., 1999, Rx medication information for the public and the WWW: quality issues. *Med Inform Internet Med.* 24(3): 171-179.

[26]Patient and the Internet , Report by RVZ, April 2000. Available at:http//www.rvz.net/internet/engels.htm

[27]Goldberg HS, Morales A, Gottlieb L, Meador L et al. Re-inventing patient-centered computing for the twenty-first century. In: Patel VL, Rogers R, Haux R. (editors): Medinfo 2001, Proceedings of the 10th World Congress on Medical Informatics, p.

[28]Jadad AR. Promoting partnerships: challenges for the internet age. BMJ 1999; 319:761-4

[29]Brennan PF, Kuang YS, Volrathongchai K. Patient-centered Information Systems, Yearbook of Medical Informatics 2000, p.79-86.

[30]Robert Wood Johnson Foundation Report on eHealth: The eHealth landscape (June 2001). Available at: http://www.rwjf.org/app/rw_publications_and_links/publicationsPdfs/eHealth.pdf

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