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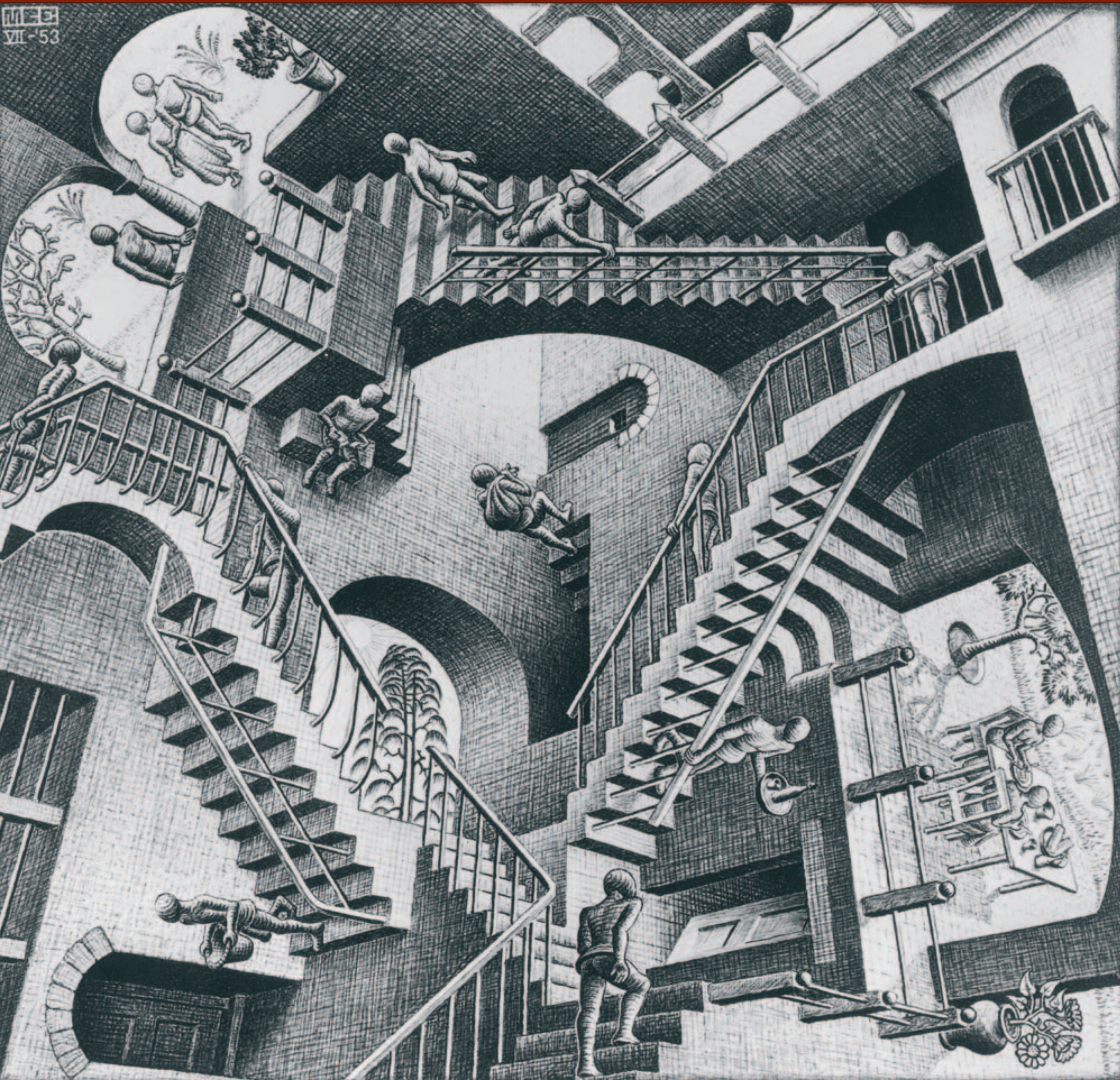
Persephone Doupi

Personalized Patient Education and the Internet

STEPPS in burn care



Persephone Doupi

Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record

STEPPS in burn care

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Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record

STEPPS in burn care

Geindividualiseerde patiëntenvoorlichting en het internet:
Gezondheidsinformatie gebaseerd op gegevens in het Elektronisch Patiënten Dossier

STEPPS in brandwondenzorg

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To my parents Xenia and Vasilis and my sister Dimitra

To Kristian

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General Introduction

General Introduction

Background

For patients and their carers, information seeking and processing is an integral part of managing disease or coping with a health condition. The nature and content of that information may vary widely; from general medical knowledge, to practical details on diagnosis and treatment options and to very specific questions addressing own concerns. Healthcare professionals have been perceived and expected to function as the main information resource for patients, as well as for their families and caregivers. More formally, the process of information provision by healthcare professionals has become known as health or patient education [1]. The term *health education* however, has been most often connected with interventions that target a particular behavior change, for the purposes of preventing the onset or the complications of a disease or condition. *Patient education* on the other hand, has been primarily concerned with providing patients and their caregivers with the necessary information and skills to better manage an existing disease or condition. It is this latter type of information provision activities that are the focus of this thesis.

Research on the effects of patient education has provided evidence of its beneficial impact on disease management and treatment outcomes, quality of health-related decision making and patient satisfaction with healthcare services and providers [2–6]. These effects are particularly relevant in the context of chronic diseases, the incidence of which is constantly rising. The role of information provision to patients and their families has gained further attention due to changes in healthcare service delivery models, such as earlier discharge and increasing emphasis on outpatient care and self-management [7]. In some countries, patient education is even a legal requirement [8–10].

In spite of the acknowledgement of its importance, patient education has encountered a number of obstacles such as time- and resource-constrained healthcare practice settings, inadequate communication between patients and healthcare professionals and lack of suitable materials. As a result, patient information needs often remain unmet; the information provided is perceived as insufficient or difficult to understand, it is sometimes contradictory and often hard to remember [11–13].

The magnitude of the gap between the information that patients and the general public *do* receive through formal healthcare channels and the information they would *like* or *need to have* regarding health- and medicine-related matters came strongly to the foreground through the rise of the Internet and the World Wide Web.

From the very beginning of widespread Internet use, health and medicine related web sites have consistently been among the most frequently visited [14,15].

The importance of the public's use of online health resources has been acknowledged but the Internet has been regarded primarily as a communication and dissemination channel [16,17]. The possibility of utilizing the abundance of health information content available online has not as yet been explored in depth and certainly not beyond the provision of a list of predefined links to online quality-controlled resources such as MEDLINE [18,19]. The online health information landscape, however, contains a much wider variety of resources than scientific literature that thus remains less accessible to the interested end users, professionals or patients.

In addition, online health information has qualities that would render it a suitable candidate for inclusion in patient education strategies. One such quality is the opportunity for personalization. Personalization or tailoring of content has been one of the desiderata of patient education strategies, as an effective response to the fact that individual patients have differing information needs [20]. The use of medical record data has been identified as a potential method of achieving personalization of patient education material [21,22], but the means for realizing it have rarely been tested in practice due to the limited availability and use of electronic patient record systems.

The aim of this thesis is to study the feasibility of using structured and coded electronic patient record [EPR] data as the representation of the patient's clinical profile, in order to personalize the selection of patient education material derived from online health resources. The domain where we will test the feasibility of this approach to personalized patient education is the provision of information material to burn patients and their families at the point of discharge from specialized burn care units.

Burn injuries are among the most traumatic incidents a human being can experience [23]. Severe burns require a long and painful period of hospitalization in the intensive care unit, after which patients are discharged to rehabilitation clinics or, most often, home. During the recovery period both the affected individuals and their families need to manage with a changed health and functional status, as well as psychosocial problems, either pre-existing or developed as a result of the injury [24]. Research indicates that particularly in the period after discharge patients face considerable problems and are mostly in need of support [25].

The integration of the EPR with online health-related content facilitates the generation of education material for patients and their families as a direct by-product of regular clinician documentation activities. Prior research on the use of the EPR in the context of information retrieval tasks has concentrated on supporting the needs of scientists or health professionals rather than patients [26, 27]. Our approach, on the other hand, as demonstrated with the STEPPS system for burn care, can provide a solution to one of the obstacles hindering the success of patient education activities: the lack of suitable tools and materials for availability of information at the place and time of patient-clinician interaction. In addition to enabling patient-physician communication, the use of such a system ensures the availability of information at the point in time when patients and caregivers will need to cope without the immediate support of specialized personnel, in our example at the time of discharge from the "protective" environment of a burn care centre.

Outline of the thesis

The thesis is divided into two parts. In Part I, comprising Chapters 1 to 3, we discuss aspects related to the issue of online health information quality and to the challenges of knowledge representation for supporting the collection of structured and coded EPR data. In Part II, comprising Chapters 4–6 we explore various aspects of the problem of integrating EPR data and Internet health information for personalized retrieval of patient education material, as represented in the design, development and evaluation of the prototype STEPPS system for the domain of burn care. The concluding chapter of General Discussion reviews our findings and suggests target areas for future research.

Chapter 1: Quality of online health information

Do the proposed quality criteria and codes of conduct have an impact on the quality of online health resources?

The Internet opened a completely new path to health and medical information and knowledge for the general public. From the early years, the public's response was strong and enthusiastic. Along with this development came also concerns [28]. Until that point, most sources of information on health and medicine were supported by a peer-review and editorial system, meant to also act as a method of quality assurance and accountability. In the online environment, the process of assessing the validity of claims and the reliability of the content could not be taken for granted since no such mechanisms were in place. The scientific community – motivated by the principle of ensuring public safety and well being – responded to the threat of misinformation and potential harm by compiling and introducing quality criteria and codes of conduct for health information made available through the Internet [29,30].

The introduction of quality initiatives was greeted as a positive and much needed step [31]. It remained, however, unclear how transferable to the pragmatics of the Internet the proposed criteria were and whether they lend themselves to implementation in the online environment.

In the study reported in this chapter, we used information on prescription medications – a domain where information provision has a critical role in avoiding treatment failures and adverse events [32] – as a focus area to explore the extent that the proposed quality criteria were reflected in web sites providing such information to the general public.

Chapter 2: Exploring the relationship between quality and trust

How is quality constructed through the proposed criteria for online health information?

Do quality initiatives for online health information promote and facilitate trust building online?

For a number of years, considerable efforts were placed in developing and refining criteria and other methods meant to ensure the quality of health information on the Internet [33,34]. Still, the degree of their adoption by online health information providers remained limited and the evidence of how the quality assurance efforts were affecting end users' behaviour was conflicting [35].

In spite the substantial amount of work on Internet health information quality issues, a systematic and comprehensive analysis of the concept of quality in the online environment had not been undertaken. We attempted therefore to clarify the origins, nature and interrelations of the quality dimensions underlying the proposed quality criteria, in order to assist further progress in the area.

We also identified that an important aspect had been overlooked by the initiatives promoting quality of health-related web sites. Information is indeed an important element in a decision making process and in choosing a course of action, also with regard to health-related decision making and behavior. However, for acquired information to become incorporated and significant in determining one's actual actions, an additional requirement must be fulfilled. The recipient needs to trust the information.

The element of trust had thus far not been addressed in the context of online health-related information. In the work reported in this chapter we aim to clarify the relationship between quality of online health information and trust and determine whether the proposed initiatives are actually contributing to the development of trust or whether further adjustments are necessary.

Chapter 3: Modeling medical knowledge to support collection of structured and coded EPR data

What are the challenges of enabling flexible data entry while ensuring reliable retrieval?

The advent of Electronic Patient Records brought the promise of improving the quality of data available for delivering and monitoring patient care [36]. An essential and crucial step in order to achieve these aims is to ensure the accuracy and completeness of the data at the point and time of its collection. Entering EPR data in a structured form, or *structured data entry* can enhance data quality, but it also requires a change in long-standing documentation traditions in the health professions and the re-arrangement of daily processes and practices.

As speed and time are of the essence in busy healthcare settings, ensuring the flexibility of the data entry system is a prerequisite for its acceptance by potential users. A model for domain knowledge representation and corresponding software tools – the Open Record for CAre (ORCA) and Structured Data Entry (SDE) modules – have been developed by van Ginneken et al. with the purpose of supporting predictive, user-friendly interfaces for collection of structured data [37].

Prior research experiences with ORCA and SDE had primarily concentrated on creating interfaces for entry of examination results [38,39]. Although by no means an easy task, the advantages of working with examination reports were their relatively structured nature and the clearly circumscribed knowledge domain. Scaling up the modeling process to clinical narrative traditionally available as free text brings forward new problems to address. We explored these problems and potential solutions in an exercise in modeling physical examination – a common component of a patient-physician interaction in any clinical setting. The lessons learned in this experiment were later on utilized further in developing the SDE interface of a prototype system, STEPPS (STructured Evaluated Personalized Patient Support), adapted to the documentation needs of burn care professionals in The Netherlands.

Chapter 4: Creating a system for personalized retrieval of health information – The architecture of STEPPS

How can we link online health information to the EPR?

Personalization in information retrieval systems is about taking into account specific features of an individual recipient and adapting system output to these features. The underlying assumption is that when the information addresses the recipient on a more personal level there is better fitness to the specific individual's information needs; therefore it is more likely for the information to be perceived as interesting and relevant and, possibly, to be acted upon.

Implementing personalization of patient education material on the basis of a patient's clinical data is essentially a problem of integrating the EPR with health information. In our research, an additional level of complexity is introduced by using not standardized, quality controlled, locally produced material but information available on health-related web sites.

What are the components of such a system for personalized patient education, how should they be interconnected to each other and what are the challenges to be dealt with in the system development process? Chapter 4 provides an insight as to how these questions were answered in building STEPPS for application in burn care after patient discharge. Further details and insight into both the development and the actual functionality of the system are provided in Appendices I and II, respectively.

Chapter 5: Design considerations in STEPPS

How do the requirements of implementation in health care practice settings affect design choices?

Patient education should be part of daily health care practices. Several obstacles are standing in the way of realizing this objective – primarily lack of time and lack of suitable materials and tools that would support and facilitate the patient education process. The needs of professionals must be accounted for, as well as the rights and needs of patients and the way both of the above are reflected and defined in the corresponding legal framework. Any system designer and developer who aspire to create an application likely to be adopted by its targeted end users must take the result of these considerations into account. What are the requirements that healthcare practice settings realities enforce on a personalized patient education system and what do they mean for the system design process? In Chapter 5 we present how the considerations for implementation in the clinical setting interrelated with and eventually defined the development of the STEPPS prototype for burn care.

Chapter 6: Pilot evaluation of STEPPS

Assessing system performance in personalizing the selection of online health information material for burn patient education

One of the hallmarks in the development of a novel health information system is the proof that the system achieves its stated objectives. In STEPPS the objective was to achieve retrieval of health information material collected from online resources in a personalized manner, i.e. fit to the profile of each individual patient as contained in his/her EPR. In Chapter 6 of this thesis we outline how we performed the evaluation of the prototype STEPPS system for burn care, we present the findings of the evaluation and discuss their implications for the current status and future improvement of STEPPS and for automated personalized patient education systems at large.

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PART I

Chapter 1

Rx medication information for the public & the WWW: Quality issues

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Abstract

Misuse of prescription medications is a serious problem, largely due to lack of information. Lay users are making use of resources available on the World Wide Web in order to bridge this information gap. It has already been noted though that health and medicine oriented sites present serious shortcomings with regard to quality and reliability of their content. In this review, checklists were used to determine to which extend the criteria suggested for quality evaluation of on-line health information are observed by sites offering information on Rx medications to the public. We also evaluated the sites' comprehensiveness in coverage of important subject specific topics. The reviewed sites met inadequately the proposed quality criteria and presented significant variations in their coverage of the subject. Evaluation of information accuracy remains an unresolved problem in quality assessment, while techniques for automated review and retrieval are urgently needed. In the meantime, though, quality guidelines could prove more useful in getting valuable feedback from information providers and lay users alike, improving quality of information at its point of production.

Keywords: Internet; Medication; Information; Quality Evaluation; Consumers

Introduction

Medication misuse is a major source of morbidity and mortality, both in hospital and in ambulatory settings [1,2]. It is also a considerable burden to health expenditures. In the US alone, the annual costs of improper prescription medication use have been estimated to approach the sum of $100 billion. It is notable though that in 30–50% of the cases, medication misuse is attributed to nothing else than lack of information [3].

To bridge this information gap, patients and consumers are increasingly making use of the capabilities offered by information technology and especially the World Wide Web (WWW) [4–7]. Health oriented sites attract close to 40% of Internet users, with almost half of them demonstrating a specific interest in information on prescription medications [8].

Prior research has indicated that on-line medical information targeting the general public leaves much to be desired with respect to quality and reliability [9–11]. In response, several national and international groups, as well as individual researchers proceeded to propose sets of guidelines or criteria to assure the quality of health information available on the WWW [12,13].

There is considerable agreement among authors as far as the essential criteria for quality assessment are concerned [14]. On the other hand, studies applying these criteria in an in-depth evaluation of domain-specific sites are scarce. Sites addressing the topic of prescription medications are of special interest, given the need for such information [15,16] and its potential to ameliorate the problem of medication misuse. Therefore, our study aimed to determine the extent to which Internet sites offering information on prescription medication to the public abide to quality criteria and to assess their comprehensiveness in coverage of the subject. This overview of the present situation is a first necessary step in the effort of making medication information available on the Web more useful and reliable for the end user, patient or consumer.

Methods

Checklist compilation

We performed an evaluation of sites offering information on Rx medications to the public, on two distinct, but interrelated levels: their adherence to the general quality guidelines proposed for health and medical sites and their comprehensive coverage of the specific subject. This evaluation was conducted by means of two respective checklists (see Appendices A and B).

As far as general quality criteria are concerned, we reviewed the suggestions published by several groups and investigators, focusing on the aspects pertaining to, or influencing information content, rather than presentation [12,13,17–20]. Thus we identified and selected the criteria less susceptible to subjective interpretation, i.e. authorship, objectivity, disclosure and currency, which were consequently included in the first checklist.

Adequate topic coverage is usually featured as one of the general quality criteria. We chose, however, to treat it as a separate item since it requires further, subject-specific refinement and clarification to be applicable in practice. It is also an important factor in determining the usefulness of a site to the end user. In other words: "The answers to which questions are available on the site"?

The checklist we compiled for coverage assessment brings together the guidelines of EU [21] and US [22] regulatory authorities for the provision of necessary information on Rx medications to the general public. Again, we selected the items more relevant to content of information, rather than presentation or aspects that are more technical.

Site inclusion criteria

Sites were considered eligible for review if they fulfilled the following criteria:

- Free access: We felt that users faced with the choice between a site offering free access and another charging a fee for its services would opt for the former – at least as a starting point.
- Comprehensive collection of information on Rx medications: We aimed to identify sites which could act as one-stop-shopping places for a large spectrum of different users; preferably, sites providing a relevant database or on-line medication guide. Consequently, sites devoted to medications employed in the treatment of a specific ailment or group of diseases were not considered. The same applies to sites maintained by pharmaceutical companies, where one finds information exclusively about the manufacturers' own products. Mailing lists, bulletin boards, discussion and news groups were also excluded.
- Lay users as/among the site's target audience: Sites explicitly stating health care professionals as their target audience were not included in the review (although, naturally, some lay users will choose to view the information available on such sites).

Site identification and review

We used information clearinghouses and indexing sites as a starting point and main source in identifying sites eligible for review [23]. Some sites were located through references in literature addressing the issue of quality evaluation of health information on the Web, while others were identified by following links found on sites already considered and/or reviewed.

The identification and review phase of our study took place between February and June 1998. The Web pages of the sites fulfilling the inclusion criteria were revisited and double-checked in November 1998 (see Table 1, p. 24).

We reviewed the information available on each site for the top six best-selling drugs in the US, in 1997 [24] to assess the site's coverage of necessary topics. These six medications are representative of therapeutic categories extensively used in everyday medical practice worldwide; namely: antibiotics (Trimox), hormones (Synthroid and Premarin), analgesics (Hydrocodone w/APAP), antidepressants (Prozac) and heart medication (Lanoxin). We used generic and/or brand name to search for the information.

TABLE 1. Sites included in the study, offering R_x medication information to the public.

Name of site		URL
1.	Chesire-med.com	http://www.cheshire-med.com/services/pharm/medindex.html
2.	DrugInfoNet	http://www.druginfonet.com/generic.htm
3.	HealthPhillynews	http://health.phillynews.com/pharmacy/search.asp
4.	Healthtouch	http://www.healthtouch.com/levell/p_dri.htm
5.	Infomed	http://infomed.org/100drugs/index.html
6.	Intelihealth	http://intelihealth.com/IH
7.	Mayohealth	http://mayohealth.org/usp/html
8.	Medicinenet	http://www.medicinenet.com
9.	Mediconsult	http://www.mediconsult.com
10.	Medscape	http://www.medscapte.com/misc)formdrugs.html
11.	On-Health	http://www.onhealth.com/chl/resource/pharmacy
12.	PharmInfoNet	http://www.pharminfo.com
13.	Rx-Advisor	http://e-pharmacy.com/HTML/health_info/rx_advisor.html
14.	Rx-List	http://www.rxlist.com

Results

Fourteen sites in total fulfilled the inclusion criteria and thus were eligible for review; none, however, observed all of the suggested quality evaluation criteria (Table 2). In more detail:

- *Authority:* The name of an individual author(s) was given only in 3 out of 14 sites, while adequate information about his/her qualifications, affiliation and contact address were present only in 1 site.
- *Attribution/objectivity:* Ownership of sites providing Rx medication information to the public is mainly commercial (10 out of 14 sites), with 2 more sites being a joint commercial/educational venture. Sponsorship of the sites could be determined only in 6 out of 14 sites, while some indication as to the funding source was available in 2 more. References to original sources of information were scarcely present (2 out of 14) sites, with on-line links to them available only in one case. Copyright statements or logos were present on all sites; the primary source of information though remained unknown. Advertising – mostly in the form of banners – was present in 9 out of the 14 sites, being in the majority of cases (8 out of 9) clearly distinct from the information

section. A policy statement regarding the site's advertising policy was available only in 4 of these sites and in 1 more, explicitly refusing to advertise. All sites featured disclaimers, alerting visitors to the need of consulting a health care professional.

- *Currency:* The production date of the available information can –at best- be only approximated by the starting date of the copyright time span offered by web site owners. None of the 14 sites declared the date the information was first posted on the web. As for revision dates, they were available in 5 out of the 14 sites.

Subject coverage

The sites included in the study were extensively reviewed on their coverage of a multitude of topics relevant to Rx medications. Tables with the results for each site and its information completeness on each of the six drugs are available on request, their detailed analysis and presentation though was considered beyond the scope of this paper.

Here we focus on a subsection of the checklist used in the reviewing process; namely, that pertaining to proper medication use. The information included in this section is the most relevant to the commonest misuses of prescription medication: taking incorrect doses, taking doses at wrong times, forgetting to take doses and stopping medication too soon. Thus, the extent to which these issues are addressed by each site will largely determine its usefulness for the user.

TABLE 2. Overview of evaluation results on general quality criteria

	AUTHORITY				ATTRIBUTION			DISCLOSURE/OBJECTIVITY						CURRENCY (DATES)		
NAME OF SITE	Name of author	Qualifications	Affiliations	Contact Address	References	Links to references	Copyright	Ownership	Sponsorship	Policy statement	Advertising Present/ Absent	Distinction	Disclaimer	Written	Posted on the Web	Revised
1. Cheshire-med	Pharmacy staff	YES	YES	NO	NO	NA	NO	Edu/Com	YES/NO	NO	Absent	NA	YES	NO	NO	YES
2. Drug Info-Net	Manufacturers	NO	YES	YES	YES/NO	NO	YES	Commercial	NO	NO	Absent	NA	YES	YES/NO	NO	YES/NO
3. Health Phillynews	USP DI	YES	YES	YES	NO	NA	YES	Commercial	YES	NO	Present	YES	YES	YES/NO	NO	YES
4. Healthtouch	Medi-Span Inc.	NO	NO	e-mail	NO	NA	YES	Commercial	NO	NO	Absent	NA	YES	YES/NO	NO	NO
5. Infomed	NO	YES/NO	YES/NO	YES	YES	NO	YES	Educational	NO	YES	Absent	NA	YES	YES/NO	NO	NO
6. Intelihealth	USP DI	YES	YES	YES	NO	NA	YES	Edu/Com	YES	YES	Present	YES	YES	YES/NO	NO	NO
7. Mayohealth	USP DI	YES	YES	YES	NO	NA	YES	Educational	YES	YES	Present	YES	YES	YES/NO	NO	NO
8. Medicinenet	YES	YES/NO	YES/NO	NO	NO	NA	YES	Commercial	NO	NO	Present	NO	YES	YES/NO	NO	NO
9. Mediconsult	USP DI	YES	YES	e-mail	NO	NA	YES	Commercial	YES/NO	NO	Present	YES	YES	YES/NO	NO	YES
10. Medscape	First Data Bank	YES/NO	YES/NO	YES	YES/NO	NO	YES	Commercial	YES	YES/NO	Present	YES	YES	YES/NO	NO	NO
11. On-Health	USP DI	YES	YES	e-mail	NO	NA	YES	Commercial	NO	YES	Present	YES	YES	YES/NO	NO	YES
12. PharmInfoNet	YES	YES	YES	YES	YES	YES	YES	Commercial	YES	YES	Present	YES	YES	YES/NO	NO	YES
13. Rx-Advisor	Medi-Span Inc.	NO	NO	NO	NO	NA	YES	Commercial	YES	NO	Absent	NA	YES	YES/NO	NO	NO
14. Rx List	Mosby	YES	YES	YES	YES/NO	NO	YES	Commercial	NO	NO	Present	YES	YES	YES/NO	NO	NO

Table key: YES: Relevant information was present; NO: Absence of relevant information; YES/NO: Relevant information was present, but inadequate; NA: Specific category not applicable for the site.

There were no sites with full coverage of relevant topics for Trimox and Premarin, only one such site was found for Synthroid and Lanoxin, while 4 out of the 14 sites addressed those issues for Prozac and Hydrocodone w/APAP (Table 3 presents the results of the review for Trimox).

TABLE 3. Results of subject coverage evaluation of sites for the drug Trimox (amoxicillin). Section with instructions on proper use (see also Appendix B and key of Table 2)

Name of Site	General Information	Dosage	Method/Frequency of administration	Duration	Missed dose	O.D.
1. Chesire-med.com	YES	NO	YES/NO	YES/NO	YES	NO
2. DrugInfoNet	NO	YES	YES	YES	NO	YES
3. HealthPhillynews	YES	YES	YES	YES	YES	NO
4. Healthtouch	YES	YES/NO	YES	YES	YES	YES
5. Infomed	NO	YES	YES	NO	NO	NO
6. Intelihealth	YES	YES	YES	YES	YES	NO
7. Mayohealth	YES	YES	YES	YES	YES	NO
8. Medicinenet	NO	NO	YES/NO	NO	NO	NO
9. Mediconsult	YES	YES	YES	NO	YES	NO
10. Medscape	YES	NO	YES/NO	YES/NO	YES	NO
11. On-Health	YES	YES	YES	YES/NO	YES	NO
12. PharmInfoNet	NO	NO	NO	NO	NO	NO
13. Rx-Advisor	YES	NO	YES/NO	YES/NO	YES	YES
14. Rx-List	NO	YES	YES	YES	NO	NO

Discussion

Internet sites offering to the public information on prescription medications meet inadequately the quality criteria suggested for health-oriented resources. Features considered as elementary requirements for print publications, like author identity and references to supporting evidence, are often absent. Even the currency and timeliness of information – claimed to be among the strongest advantages of web publishing – are hard to determine (see Table 2).

On the aspect of subject coverage, there is variability between, as well as within sites, although a considerable amount of information is available (see Table 3). It remains scattered, however, thus underscoring the difficulties and frustration of locating sources of interest, a problem familiar to most Internet users [25].

Should these observations be perceived as indications of low quality information or could there be problems with the evaluation tools? There is no straightforward answer to this question. The pitfalls and weaknesses involved in evaluating information on the Internet are many; it has even been suggested that an attempt to do so may prove futile [26].

The findings of our study provide further evidence that health-related information available on-line presents considerable deviations from the traditional print literature paradigm. This questions the assumption underlying the development of quality criteria for on-line resources; namely, that standards used in the evaluation of print scientific literature could be adapted to electronic publishing [27].

In practice, a crucial determinant of quality is quite often impossible to assess. This is none other than information accuracy. Although a standard commonly included in quality evaluation lists, there is yet no solution for its effective assessment in the massive and ever increasing amount of information available on the Web. This is certainly the case when the topic of interest is an area so broad and complex as that of medications.

Consequently, the rest of the proposed quality criteria are limited to the role of “proxy indicators”, as the best available alternative [17]. Even then, the evaluation process remains cumbersome and unacceptably time consuming if performed manually. A minimal requirement for efficiency, if we are to keep up with the dynamic nature of Web information, is an automated review process. Work to this end is under way, aspiring to address simultaneously the issues of quality review and identification of relevant sources [28]. It remains to be seen whether such solutions will achieve their goals.

In the meantime, though, the proposed quality criteria can be put to use in a different manner. Alongside the efforts for improved evaluation of already available information, more attention should be shifted to its point of production. It is important to determine the beliefs and attitudes information providers foster with respect to quality and to increase their awareness concerning electronic publishing guidelines. Manufacturers of pharmaceuticals, physicians, pharmacists and other health care professionals are target groups eligible for further research in the area of medication information.

Equally important is the exploration of lay users’ perceptions on the usability and usefulness of the suggested criteria. Innovative approaches to this end have been suggested [29] and they are expected to provide us with valuable insight and feedback regarding end users’ needs, as well as information demands.

Both the scientific community and the public face the problem of finding information of interest on the Web and verifying its high quality. We should build bridges of communication and work in unison to realize the potential of the Internet to complement successfully and effectively the existing information sources.

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http://www.pharmacy.org.wwwdbs.html
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Appendix A: Checklist for Quality Evaluation

1. AUTHORITY

- Is the name of the author available?
- What are his/her qualifications and affiliations?
- Is a contact address given? (regular mail/e-mail/both)

2. ATTRIBUTION

- Are references given to original sources of evidence?
- Are there links available to these references?
- Is there a copyright statement?

3. DISCLOSURE

- Is ownership of the site clear? (commercial, educational, government, other)
- Is sponsorship of the site clear?
- Is advertising present on the site?
- Is it clearly distinguished from information content?
- Is there a statement available about the advertising policy of the site?
- Is there a disclaimer present on the site?

4. CURRENCY

Are there dates available as to when the information was:

- Written?
- First posted on the Web?
- Revised?

Appendix B: Checklist for Coverage Assessment

(Necessary Information on Rx drugs)

1. General information on proper medication use (information applicable to any type of medication or to a specific therapeutic category in order to be used properly).

2. Identification data/Therapeutic indications

- What is the generic and/or brand name of the drug?
- What therapeutic category does it belong to?
- What are its ingredients/active substance(s)?
- How is its action manifested?
- What are the indications for usage? Is there special mention made to unapproved ones?
- What are the available forms?
- Information on cost of therapy.

3. Information necessary *before* use

- Contraindications
- Appropriate precautions/possible interactions with:
    - Other drugs/nutrition supplements
    - Alcohol
    - Food
    - Smoking
    - Laboratory tests
    - Exposure to sunlight
    - Sleep/Alertness/Other activities
- Special warnings:
    - Pregnancy
    - Labor
    - Breast feeding
    - Pediatric population
    - Geriatric population
    - Especially sensitive groups (e.g. diabetics, liver/kidney problems, etc.).

4. Instructions for proper use of the *specific* drug

- Dosage
- Method/frequency of administration
- Duration of treatment
- Actions in case of missed dose
- Symptoms/actions in case of overdose (o.d.)

5. Possible undesirable effects (under ordinary use)
- How to recognize an adverse drug reaction (ADR)
- What to do in case of ADR
- Instructions to seek professional health in case of unlisted symptoms
- Risk of tolerance/symptoms of withdrawal.

6. Storage instructions
- Temperature/exposure to light
- Humidity
- Signs of decay

Chapter 2

Internet health resources: from quality to trust

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Abstract

Objectives

Quality of online health resources remains a much debated topic, despite considerable international efforts. The lack of a systematic and comprehensive conceptual analysis is hindering further progress. Therefore we aim at clarifying the origins, nature and interrelations of pertinent concepts. Further, we claim that quality is neither a necessary nor a sufficient condition for Internet health resources to produce an effect offline. As users' trust is also required, we examine the relation of quality aspects to trust building online.

Methods

We reviewed and analysed the key documentation and deliverables of quality initiatives, as well as relevant scientific publications. Using the insights of philosophy, we identified the elementary dimensions which underlie the key concepts and theories presented so far in the context of online health information quality. We examined the interrelations of various perspectives and explored how trust as a phenomenon relates to these dimensions of quality.

Results

Various aspects associated with the quality of online health resources originate from four conceptual dimensions: epistemic, ethical, economic and technological. We propose a conceptual framework that incorporates all these perspectives. We argue that total quality exists only if all four dimensions have been addressed adequately and that high total quality is conducive to warranted trust.

Conclusions

Quality and trust are intertwined, but distinct concepts, and their relation is not always straightforward. Ideally, trust should track quality. Apprehending the composition of these concepts will help to understand and guide the behavior of both users and providers of online information, as well as to foster warranted trust in online resources. The framework we propose provides a conceptual starting point for further deliberations and empirical work.

Keywords: Internet, World Wide Web, Quality of Information, Ethics, Trust

Introduction

The World Wide Web emerged within the scientific community as a tool to support research and information exchange. Despite its highly specialized origin though, the Web has in less than a decade established its prominent position as a global communication medium beyond the realm of science [1,2].

In the domain of medicine and health, the expanding online content has found avid users among patients and citizens interested in their well being and desiring a more active role in their care [3,4]. At the same time, health professionals – whether clinicians or scientists – are discovering in the Internet an unparalleled tool to access, distribute and exchange information and services [5,6].

Reliance on online resources, both as indispensable components of multidisciplinary research and as a medium for communicating the findings and results of science to society, is a trend expected to be further consolidated in the future [7]. As a result, the boundaries traditionally demarcating geographical areas, scientific disciplines, academic elites and the general public are gradually becoming blurred.

Despite the considerable positive potential of these developments every Internet user is inevitably faced with a major question: is the information reliable? This problem may manifest itself in a variety of ways, depending on the characteristics of the information and its user, but the underlying dilemma is always the same: how to *determine* the quality of the information and how to *decide* whether to trust it.

The significance of these questions has been reflected in the growing attention placed on the topic of quality of online health information in the course of the last six years [8–16]. However, despite the considerable efforts by several initiatives, issues of quality still lack a conclusive and effective answer, as a recent review of the field has brought to the foreground [17–19].

We believe that the causes of this impasse stem from two shortcomings in the thus far adopted course of action. First, the various quality initiatives have suggested or implied numerous criteria without taking into account the various dimensions of quality. As a result, considerable misconceptions and misunderstandings have arisen with regard to what constitutes quality and how it can or should be assessed, hindering both the operationalization of quality criteria and their wider adoption.

Second, quality initiatives' initiators have largely operated under the assumption that web sites of high quality are safer and more beneficial to their users, addressing only in passing an otherwise crucial fact; no matter how high a claim to quality an online resource makes, the impact of that resource on users' lives is likely to be trivial if they do not *trust* it. And, in day-to-day practice, quality – as perceived by current quality initiatives – appears to be neither a necessary nor a sufficient condition for people to place their trust in a website [20,21].

In this paper, we will explore the issues of quality of health information and trust building in the online environment. A close look will reveal this topic as a complex ensemble of interrelated ideas. We approach the issue of quality from a conceptual viewpoint and analyze its different dimensions, distinguishing between epistemic, ethical, economic and technological perspectives. We bring these perspectives into a common framework and argue that true quality (to which we refer as "total quality") can only be exemplified where all of these aspects and their interrelations have been adequately addressed and taken into account. We then use the proposed framework to indicate how the different dimensions of quality relate to building trust online.

Since the Internet is a faceless technology, making the origins of any information or service provided difficult to verify, trust does not flourish easily in the online environment. The ideal is of course to move to a situation where online sources of high quality will be trusted and sources of low quality will be distrusted [22]. Trust should track quality. It is therefore important to examine how and whether quality assurance efforts also advance the creation of the circumstances necessary to promote trust in the online context.

Perspectives on quality of information

The strength and potential of the several quality initiatives in the health domain can be seen in their ability to bring together people and organizations representing a wide spectrum of actors, in order to discuss quality issues. This has meant the participation, although to a varying degree, of traditional information providers (publishers), health service providers, Internet users (both laymen and professionals), the scientific community, governmental and policy agency representatives, as well as financiers of health web sites (sponsors, advertisers). Presumably, quality is the common objective of all. However, the motivations, interests, values and processes within each initiative, as well as the launching period have had a substantial effect on the form and content of their respective deliverables [23,24]. Table 1 (p. 40) provides an overview of the initiatives and summarizes some of their key features.

It is important to realize that, besides providing practical guidance in the form of guidelines and checklists, the initiatives also have a steering role in the development of Internet content. Intentionally or unintentionally, consciously or unconsciously, the initiatives define our conception of quality, i.e. determine what quality means in the context of online health information and services. We emphasize that the empirical, "bottom-up" manner of identifying quality by means of criteria lists derived through expert consensus (as has been the practice adopted thus far) is neither the only, nor the ideal way of defining this crucial and much debated concept. Quality can also be defined by employing a conceptual approach.

TABLE 1. Overview of Internet quality initiatives

	Year launched	Initiative	Object of review	Primary audience	Purpose	Criteria set	Ethical code	Guide-line	Quality-symbol, logo	Rating or Certification procedure	Tools and Techno-logies
1	1996	Medical Matrix http://www.medmatrix.org	Clinical medical resources	US health professionals	Utility of material	✓				✓	
2	1996	OMNI http://omni.ac.uk	Biomedical Internet information	Students, researchers, academics, practicioners	Gateway to high quality resources	✓				✓	
3	1996	BHIA http://www.bhia.org	Medical Web publishing	Professionals, patients	Statement on quality	✓					
4	1996	DISCERN http://www.discern.org.uk	Consumer health information	Consumers, professionals, providers	Quality assessment tool	✓					✓
5	1996	HON http://www.hon.ch	Health and medical web sites	Site developers, users	Self regulation, quick identifier/reliability – credibility		✓		✓		✓
6	1997	Silberg et al. JAMA 1997;277:1244-5	Medical information on the Internet	Professionals	Proposal for key quality criteria	✓					
7	1997	HSWG http://www.mitretek/hiti	Health information on the Internet	General public, consumers	Criteria for quality assessment	✓					✓
8	1997	IHC (eHealth Code of Ethics) http://www. ihealthcoalition.org	Health information, products and services	Consumers, professionals, educators, marketers, media, policy makers	Education of Internet users, self-regulation, online community		✓	✓			
9	2000	HiEthics http://www.hiethics.org	Internet health services for consumers	US based companies	Individual consumer benefit		✓	✓			
10	2000	AMA http://www.ama-assn.org	Health information and services (e-commerce)	AMA web sites	Promote transformation of patient-physician relationship			✓			
11	2000	TNO QMIC® http://www.health.tno.nl	Information, communication, transactions (e-commerce)	Organisations and government bodies interested in public trust	Promote reliability, trustworthiness, public trust				✓	✓	✓
12	2000	MedCERTAIN http://www.medcertain.org	Health web sites	Information providers and users	Safer and more beneficial use of Internet				✓	✓	✓
13	2001	EU http://europa.eu.int/ information_society/ eeurope	Web sites (information and services)	EU Member States, information providers and users	Guide quality assurance implementation, supplier and user education	✓		✓			
14	2001	URAC http://www.urac.org	Web sites	Information providers and consumers	Compliance with ethical standards, consumer benefit	✓	✓	✓		✓	

In this “top-down” manner, the main conceptual frameworks that contain relevant aspects of quality are identified first, and then their interrelations are analyzed.

Through such an analysis we will show that the concepts represented in the various quality instruments (quality criteria sets, ethical codes, guidelines, quality seals, logos, trust marks, certification procedures etc.) stem from distinct conceptual frameworks and value orientations. The associated conceptions of quality are thus derived from different discourses, each shedding light upon part of the topic and all suffering from some shortcomings. We distinguish the epistemic, the ethical, the economic and the technological dimensions of quality [25]. Only when integrated and considered as a whole can they result in qualitatively adequate online health resources.

Epistemology

Epistemology studies the nature of knowledge and the justification of knowledge claims. It can provide a valuable perspective on considering the properties of a medium such as the Internet, aimed at serving the needs of dissemination and acquisition of information and knowledge.

In traditional epistemology, knowledge is defined as true justified belief. For a belief to count as genuine knowledge, justification has always been considered a necessary condition. This makes the quality of the justification all-important. Many epistemological theories require that for a belief to count as knowledge the person him or herself should be in direct causal relation (conceptual or observational) to the evidence supporting the belief and should also have the cognitive competence to articulate that evidence him or herself [26].

Only very recently epistemologists have started to apply theories and accounts of knowledge and belief to *collective* knowledge practices and modern information technology. Our discussion of epistemic norms and standards cannot do justice to the sophistication and abundance of ideas and theories in this field, but an obvious place to start is research in epistemology that has explicitly focused on the subject of technologically supported collective knowledge practices.

Alvin Goldman has tried to formulate criteria to evaluate how well social practices do as knowledge practices, i.e. how well they contribute to attaining true beliefs [27]. The criteria proposed by Goldman can be used to assess the success of epistemic practices (such as going to a classical library, studying books in the reading room, making notes and Xerox copies, or asking your doctor for information on your condition).

The first standard to evaluate epistemic success of a practice is *power*, i.e. its ability to help people find true (for those among you who dislike “true”, you may think of “helpful”) answers to the questions that interest them.

Fecundity of a practice is its ability to lead to large numbers of true beliefs for many people.

Speed of a practice is determined by how quickly it leads to true answers.

Efficiency of a practice is how well it limits the cost of getting true answers.

The last and perhaps most important standard is *reliability*, which is defined by Goldman in terms of the ratio of truths to the total number of beliefs fostered by the practice. Both Goldman and Paul Thagard [28] have further shown that the Internet in general does well by these standards. The exception is reliability, which seems to be one of the problems with the WWW and the Internet at present [29]. The rubbish, the availability of outdated and inaccurate information, and the propagation of disinformation on the Net constitute commonly cited problems [30,31]. They actually served as the primary motivation for the emergence of several quality initiatives; faithful to the non-maleficence principle of medical practice, patients and laypersons ought to be protected from harmful information online.

Reliable epistemic practices that enhance human intellectual functioning by means of computers and electronic networks may be said to 'epistemically empower' users and researchers, i.e. upgrade their capacity to reason and make decisions by means of computational devices and communication networks. The limits of epistemic empowerment converge with the limits of our scientific imagination in cognitive psychology, artificial intelligence, mathematics, software engineering and micro-electronics: intelligent filters, autonomous agents, data-mines, data-distilleries and knowledge refineries are becoming part of reality.

From an epistemic point of view, the reliability of on-line health information provision needs to be specified in a way which accommodates the essential social nature of both the networked nature of our modern communication networks and our elaborate systems of division of cognitive labor. The study of knowledge and information along these lines focuses on knowledge dependence, testimony and collaboration in knowledge acquisition; in short: the social and technological context of knowledge production, utilization and dissemination.

Ethics

While epistemology focuses on knowledge and information, as well as on their production and justification, ethics in this context is concerned with moral constraints on the acquisition, processing and dissemination of knowledge and information. Information providers and users – whether individuals or organizations – are construed as moral agents whose actions are based on and guided by moral values on the one hand, and legal requirements and restrictions on the other. Their behavior should be evaluated in moral terms. Privacy and the protection of personal information, respect for the autonomy of patients and disclosure or transparency requirements are examples of moral values. Other moral values that are relevant in the case of providing medical information on-line are responsibility, that is the moral obligation to provide adequate information, and the acknowledgement of intellectual property rights [32].

The awareness of the ethical aspects of quality has so far taken the form of several "Codes of ethics" for health information on the Internet. Ethics and moral reflection however, should not be perceived as identical to the adoption of a code of conduct. Quite to the contrary, the code may start to function as a replacement for genuine moral reflection. Further, it is often difficult to find the appropriate level of abstraction in the formulation of a code, in the sense of achieving the right balance between statements that are either too generic or too detailed. "Respect privacy" is a too vague guideline to be helpful in practice; on the other hand, exhaustively detailed instructions of what should be done with which data, could effectively govern one's behavior, but would make verification of compliance by outsiders extremely impractical.

The magnitude of this problem is more clearly exemplified in the process of translating ethical principles or values to corresponding legislation, a process that has faced considerable and still unresolved challenges in the global context of the online environment [33].

Economics

The role of economics with respect to quality is twofold. On the one hand, economic theories may provide valuable insight in understanding the production, dissemination and consumption of health information online [34,35]. Examples are the application of Malthus' law to the Internet, signaling theory and theories of transaction cost. On the other hand the economic perspective draws our attention to considerations of the financial sustainability which is required in initiating and maintaining any information provision undertaking, as well as in assessing and assuring its quality [36].

Technology

Technological efforts have come to support the needs of information providers and users. As a result several standards and tools have emerged which provide solutions to a variety of issues (Table 2, p. 44). Technology stands at the crossroads of the other three dimensions of quality, since in code, protocols, systems and devices the epistemic, ethical and economic perspectives are materialized. And conversely, the technological artifacts affect our experiences, values, perceptions and actions.

TABLE 2. Examples of quality-related technologies

Purpose	Technologies	Sources for more information
Content selection, metadata, filtering	PICS (Platform for Internet Content Selection)	http://www.w3.org/PICS/
	RDF (Resource Description Framework)	http://www.w3.org/RDF/
	Semantic Web	http://www.w3.org/2001/sw/
	HIDDEL (Health Information Disclosure, Description and Evaluation Language)	http://www.medcertain.org/english/metadata/model.htm
	Agent technology	http://www.dstc.monash.edu.au/agents
	Information filtering	http://www.sciam.com/0397issue/0397resnick.html Eysenbach & Diepgen, BMJ1998;317:1496-1502
	Portals and search engines	http://www.hon.ch http://omni.ac.uk
Accessibility	WAI (Web Accessibility Initiative)	http://www.w3.org/WAI/
Quality assessment and indication	Tools for third-party rating/certification	http://www.medcertain.org
	Kitemarks	http://www.hon.ch/HONcode/audience.html http://www.medcertain.org/english/consumer/explanation.htm
Privacy & Security	DSig (Digital Signature Initiative)	http://www.w3.org/DSig/
	P3P (Platform for Privacy Preferences)	http://www.w3.org/P3P/
	Digital watermarking	http://www.watermarkingworld.org

It is noteworthy that quality initiatives in the health domain have by and large focused on content and policies, while refraining from addressing technological matters. Moreover, there appears to be a confusion as to what constitutes technological or technical aspects, since elements essentially epistemological or ethical in nature (such as 'accuracy' and 'transparency') have been recently classified as 'technical' [37], an interpretation which is bound to hinder further progress in compliance to standard technological specifications.

Framework for building warranted trust

Building on prior work [26], we propose a framework of total quality of online health resources, which comprises the four aforementioned dimensions, defying the belief that quality is either an exclusively epistemic, ethical, economical or technical property (see Figure 1). Rather, this framework places the aspects of quality in context, clarifies their interrelations and facilitates a better understanding of how quality relates to trust building online. We shall proceed to discuss the composition and dynamics of the framework in further detail by analyzing the principal ways in which the various dimensions interface with each other.

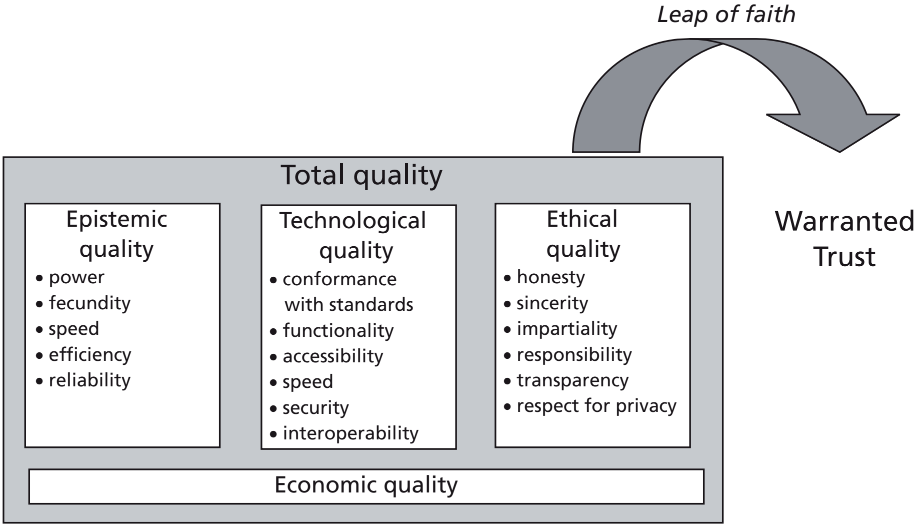

FIGURE 1. Framework for building warranted trust

This framework incorporates all of the described dimensions of quality, eventually composing 'total quality' which, in turn, warrants trust. The interrelations and interactions among the dimensions are not depicted in this diagram. The economic dimension is distinct in the sense that it provides the foundation for sustainability of the other three dimensions.

Interrelations between quality dimensions

a. Epistemology and Ethics

The modern knowledge enterprise is an intricate but delicate web of trust: cooperation, not intellectual self-reliance, is the key virtue in any (scientific or other) community [38]. Epistemology is thereby construed as requiring ethics insofar as knowledge is based on certain kinds of moral relations between people. So it seems that the use of electronic media in collaborative research and health service provision gives the information providers an explicit responsibility for seeing to it that the users of their resources can assess the extent to which it is reasonable for them to assume that the sources are worthy of trust. On the other hand, the users of information sources are themselves embedded in the web of trust (either by applying the information to themselves or their near ones, by passing the beliefs to others, or by refusing to do any of the aforementioned), and thus they also bear the responsibility for contemplating the reasons of their trust or distrust.

In some cases, moral values or principles further epistemic values. For example, clear indications of commercial interest could serve as a warning to consumers for possible bias and deception and thus keep them from drawing false conclusions. However, there are also cases where epistemic criteria are satisfied by morally objectionable information practices. For instance, there may be sites that do well by Goldman's criteria for epistemic success, but which violate privacy norms.

b. Epistemology and Economics

The application of Malthus' law to the Internet provides an interesting vantage point for analyzing what is more commonly known as the problem of information overload: now it is information (and not the population) that grows exponentially, while the scare resource is no longer food, but the time and attention of people as information users. This fact has profound repercussions in the way the online landscape is evolving.

The rapid growth of health related content has made it more difficult and therefore more costly for resources to reach their target audience (and thus their source of revenue). Conversely, locating the information users need or are interested in is becoming increasingly challenging. The situation is complicated further by the fact that "good" information is driven out by "bad" information in the long run, since the latter is cheaper and easier to produce [39]. As previously discussed, it seems that economics and epistemics may be on collision course, resulting in poor information sites outnumbering the good ones.

c. Epistemology and Technology

Omitting to incorporate technical requirements in proposed quality criteria and guidelines may render ethical and epistemic ambitions fruitless. As an example, although readability requirements have been made explicit, calling for information to be presented in a way easily understandable by the intended audience, no requirements have been placed regarding compliance to technological specifications. Failing to require compliance to technological standards, such as HTML (hypertext mark up language) or CSS (cascading style sheets), a clear and consistent representation of any information to the end user cannot be guaranteed.

The rapid development of intelligent search technologies has been suggested as a possible solution to the problem of sifting efficiently through vast amounts of available information [34]. But this begs a central question, since more intelligent technology will not help solve the central epistemic problem in online medicine and health care: How do we know whether we are dealing with reliable information, information that can be safely acted upon?

d. Technology and Ethics

Technological solutions to epistemological problems -such as the information overload- are sometimes faced with ethical constraints, particularly with regard to the consequences of their implementation. These problems may manifest themselves in a variety of ways, for example as difficulties in allocating responsibilities in the context of using modern decision support systems or databases. Some issues may call for a broader societal discussion, such as the use of filtering with respect to freedom of speech, and cookies and data mining with respect to privacy and security.

On the other hand, technology may also be called to the assistance of ethical goals, for example to automatically trace the claims of adherence to ethical codes (e.g. by identifying sites that display kitemarks or logos). Further, technological solutions might even be used to verify and assist the actual implementation of some ethical principles (e.g. so-called Privacy Enhancing Technologies, or active logos that link to evaluative data in third-party databases).

e. Technology and Economics

A strong financial basis, which will allow the development of sites and services according to the latest available technologies and at the same time guarantee their consistent presence, is an indispensable factor (and quite often a delimiting one) for the survival of sites. Similar problems and shortcomings have also been noted with respect to current quality efforts [36]. In general, technological systems that implement epistemic and ethical desiderata need to be evaluated from a point of view of economic feasibility. If they cannot be sustained, their contribution to quality improvement is bound to remain theoretical and illusory.

f. Ethics and Economics

Thus far, financial aspects have been framed in a rather negative light by quality initiatives, as a very likely source of bias, affecting content reliability. The resulting requirements, inspired by ethical principles such as honesty and impartiality, raise often irreconcilable tensions with respect to attaining financial/economic sustainability.

Further, according to the economic theory of negative externalities, those who produce low quality health information shift the cost (negative externality) associated with acting upon it to others. If these costs would be taken into account and construed as cost for the producer, providers would have a powerful incentive to refrain from producing low quality information. The problem with such an approach though lies in the ability to develop and even more so, enforce pertinent regulation and legal frameworks.

Trust and the dimensions of quality

Recent studies indicate that trust should be distinguished from confidence. Confidence refers to a system or institution where roles, responsibilities and sanctions can be identified and effectively assigned. Trust is what we need when we do not and cannot have confidence [40]. Confidence is what we have when we know what to expect in a situation, trust is what we need to maintain interaction in the face of uncertainty. As Seligman argues, trust arises at system limits, “the limits of knowledge, the limits of our ability to predict the behavior of the other” [40]. The Internet, and new ways of depending on it for important or vital health information take place at system limits. Trust as a moral phenomenon, is the assumption or belief that relevant others will act from the moral point of view towards us [22].

Ideally, total quality contributes to building trust, which in turn is required for online health resources to have an impact beyond cyberspace. By examining the extent to which the respective conditions are fulfilled, we can come to a conclusion as to whether trust is warranted or not. There will be, however, trust exemplified beyond the presence or absence of quality and that remains a very intriguing phenomenon (Table 3).

Efforts in promoting quality of online health information and services have been primarily focused in supporting the distinction between ‘high-’ and ‘low-quality’ sources. By using this quality framework (translated and adapted to the realities and objectives of specific contexts of information use) as a guide in our analysis, we can also improve our insights in identifying and understanding the reasons for which reliable sources fail to acquire the trust of users or, vice versa, sources which do not conform to proposed standards of quality seem to satisfy users’ information seeking needs (Table 4).

TABLE 3. Relation of high total quality to trust

	Trust present	Trust absent
High total quality present	Warranted trust	Unwarranted distrust
High total quality absent	Unwarranted trust	Warranted distrust

TABLE 4. Justification of trusting/distrusting web sites

	Trust present	Trust absent
Action* warranted	High-quality sites trusted	Low-quality sites distrusted
Action* unwarranted	Low-quality sites trusted	High-quality sites distrusted

* ‘Action’ refers to trust or distrust, as seen in Table 3.

Trust and epistemology

In an early modern conception of knowledge we find a perfect alignment of epistemic and moral responsibility. The knower is by definition also the one who can be held personally accountable if anything goes wrong in acting upon that knowledge. Today the responsibility for *knowing* and the responsibility for *doing* seem to have come apart [26]. Often, the knower can give no other account of his claims to knowledge and the ensuing actions than in terms of the structure of the epistemic network in which he is embedded, i.e. by pointing to trustworthy nodes in the epistemic value chain, such as authorities or results of original studies. Most people would, for example, claim to know that smoking causes lung cancer, although they could not possibly present – let alone reproduce – the biochemical, histological and epidemiological evidence themselves. Knowledge-dependent functioning in the modern information society relies on a delicate web of trust [38]. We operate based on trust relations between people, i.e. on assumptions and beliefs about the moral motivation of other agents.

Trust grounds the rationality of our epistemic enquiries nowadays. This calls into question and sets limits to individual control and autonomy in the domain of knowledge acquisition, since trust implies a leap of faith, a reaching outside our cognitive grasp.

Trust is required by both scholars and laypersons using the Internet as a health information resource. However, persons with a scientific background are more familiar, aware and at ease with this model of interaction and formation of belief, as compared to the general public. Furthermore, they have the skills (both general and domain-specific) to perform a more rigorous assessment of reliability, even if left unaided. The same cannot be taken for granted for lay people; an equally pertinent observation, however, is that their assessment criteria and strategies may be different, something that needs to taken into account in anticipating future developments.

There are two basic points of view with respect to the acceptability of testimony (that is, information reports) from on-line sources: reductionism and non-reductionism. According to the former, one is justified in accepting a statement only if one believes that the source is reliable and sincere and this belief is not based on the testimony itself but on independent sources. The opposing position implies that one is always justified in believing reports from sources, for which there is no obvious defeating information available [41].

Goldman argues [42] that it is quite natural for people to look for independent evidence to assess the credibility of a source, whether that is a human being or a website. They could, they sometimes do and perhaps they always should look at the reasons the sources are themselves providing for their epistemic authority. They should also look whether other putative experts in the field side with them, or whether there is meta-expertise available that provides clues as to whether the source is reliable. And finally they could look at the past track record of the source in answering the question one is interested in.

Although the Internet provides us with interesting possibilities to present the user with a reductionist cast of mind with the means to assist him in evaluating the epistemic trustworthiness of a health website, existing evidence regarding the stance of end users towards the issue of reliability is truly intriguing. The results indicate that people tend to behave more like 'non-reductionists', often accepting online information 'at face value' and disregarding (independent) evidence for the credibility and reliability of the source [20,21,43].

Nevertheless, both reductionist and non-reductionist users would be greatly helped by a perspicuous representation of the bases of epistemic authority of sources, justification of knowledge claims and of the logical interrelations between them, in establishing whether sources can be trusted.

Trust and ethics

Trust, as we have stated above, is a moral relationship between moral agents. It differs from confidence in performance, reliance on predictable behavior. Trust is an attitude, belief or assumption that others will act towards us conscientiously, responsibly and carefully from the moral point of view. Moreover, if we assume that others have sincerely and carefully deliberated about their actions towards us, while taking our perspective into consideration, trust relations are not easily damaged, even if it turns out that the outcomes are not always to our advantage.

The problem that arises when using the Internet to communicate, interact and build relationships lies in the risk of creating a false sense of community, relying on assumptions which eventually may turn not to be equally valid or beneficial for both parties. The explicit definition and understanding of what constitutes responsible and moral behavior for each of the actors involved is a crucial step. In the context of health and related domains, where ethics have traditionally played a central role in regulating the behavior of actors, this issue requires particular attention.

Trust and economics

One approach to the problem of quality of online health information that could be imported from economics is signaling theory [44]. According to the theory, buyers who do not have a way of distinguishing high from low quality goods pay attention to the 'signals' the sellers give. This economic theory has been broadly applied in the offline world where warranties or advertisements are employed as such signals. It is unclear, however, what the prospects of this strategy are in the online environment, since the cost of establishing a fancy web site may no longer be discriminatory, so as to provide consumers with quality indicators.

Unless there is a further guarantee that the warranties offered by Internet resources are any good, looking for warranties is not very helpful. Secondly, technology levels out what used to be distinguishing features, such as sophisticated corporate image. A health business with a skillfully made web site may operate on a minimal budget from a garage.

The theory of economic efficiency, when applied to health information, predicts that if consumers are unable to tell whether the information is of high or low quality - and if they realize this as well - they are not willing to invest as much in getting high quality information as they would, if they had tools and means to determine the quality. This is partly the assumption behind promoting certification or accreditation of web sites. The ability to use 'trust marks' or other proposed 'quality indicators' to promote trust building, is seen as providing a competitive advantage in gaining the attention and loyalty of online resource users.

Trust and technology

Any attempt to share knowledge, i.e. to communicate true beliefs over the Internet suffers from an inherent shortcoming. Traditional cues and triggers of trust, such as a person's identity or characteristics, may be obscured, forged or simply beyond verification [22]. Similar obstacles arise with respect to maintaining assumptions deriving from role allocation in real life settings to the vague context of online transactions. It is difficult to gauge someone's moral motivation towards us in an on-line situation.

Technological artifacts change, distort or completely obscure certain elements which are strategic in the process of trust building. At the same time, however, various new technologies have emerged, aiming at making the trust gap narrower: digital signatures, real-life communication (e.g. through video-conferencing), third-party certificates and trust marks are such examples. Despite their novelty though, they suffer from the same inherent problem as the artifacts they aim to verify. The future will show how trust as a phenomenon will evolve when facing the online challenges.

Discussion

In this paper we have provided a conceptual exploration of the issues of quality and trust in the online health environment. We believe that the proposed comprehensive ideal of ‘total quality’ provides a fruitful starting point for quality initiatives to have an effect beyond their original idea of preventing potential immediate harm. Quality is not only oriented towards the prevention of harm, it can also be construed in a more positive way, as facilitating scientific collaboration and rapid distribution of research results; as promoting the beneficial effects of online information as concerned with the long-term, cumulative effects of internet information or misinformation on health-related behavior on the population level; as oriented towards enhancing privacy of those searching for medical information; and as dealing with ways to encourage people to become actively involved in and take responsibility for their own health.

Internet-based technologies have a central role in the progress towards the vision of synergistic biomedical research, on the one hand and of individualized healthcare on the other. Providing answers to some of the central questions facing contemporary research is close to impossible without the use of distributed, networked resources, both in terms of available knowledge and information, as well as computing power and applications required. Similar technologies are needed to achieve rapid transfer and adoption of beneficial findings into clinical practice and to support informed self-care. Hence, issues of quality and trust, as discussed in this paper, are of fundamental importance to all actors involved: scientists, clinicians, decision-makers and citizens at large.

We emphasize that quality and trust, although intertwined, are disparate concepts. Trust is a determining factor for the impact of online health resources on their users. We argue that total quality as construed above is conducive to warranted trust. Future research should indicate how the epistemic, ethical, economic and technical aspects of online health information and services provision should be configured, and how we may reconcile tensions between the values within each of these perspectives, e.g. how we should in particular cases balance the ethical requirement of privacy with epistemic requirements of power and fecundity, or how the ethical requirement of respect for privacy translates into security technology, or again how economic incentive structures may induce consumers to waive their privacy rights.

The framework we propose serves as a tool to guide further deliberations and work on quality and trust. Apprehending the composition of these concepts will help to understand and guide the behavior of both users and providers of online information, as well as to foster warranted trust in online resources. Furthermore, the framework provides a point of reference for the design and implementation of much needed empirical studies on the impact of quality initiatives concerned with online health resources and the consequent effects of those resources on people's health.

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Conflicts of interest

K. Lampe is project manager for MedCERTAIN Finland.

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Chapter 3

Modeling challenges for Structured Data Entry

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Abstract

The success of systems facilitating collection of structured data by clinicians is largely dependent on the flexibility of the interface. The Open Record for CAre (ORCA) makes use of a generic model to support knowledge-based structured data entry for a variety of medical domains. An endeavor undertaken recently aimed to cover the broader area of Physical Examination by expanding the contents of the knowledge base. The model was found to be adequately expressive for supporting this task. Maintaining the balance between flexibility of the interface and constraints dictated by reliable retrieval, however, proved to be a considerable challenge. In this paper we illustrate through specific examples the effect of this trade-off on the modeling process, together with the rationale for the chosen solutions and suggestions for future research focus.

Keywords: Medical Records, Data Collection, Knowledge Representation, Terminology

Introduction

The collection of data in a structured form performed directly by health care practitioners has been among the central challenges in the development of electronic patient record systems [1–3]. Several groups have targeted their efforts to this end and have explored various approaches. Often though, the resulting applications have been criticized for being too rigid in their ordering and scope of recorded data. The Open Record for CAre (ORCA) is a system developed at Erasmus University Rotterdam to facilitate knowledge-based data collection (and subsequently data management) by specialists [4]. To date, the ORCA knowledge base covered highly specific domains. Yet, specialists regularly encounter relevant data outside their field of expertise, which they should be able to record. To serve this goal of enhanced recording capabilities, an expansion of the knowledge base content of ORCA was deemed necessary. Our first task was comprehensive coverage of data pertaining to the physical examination of patients, at least to a level of descriptive detail suitable for the needs of primary care. In this process we aimed to explore whether addressing a broader scope of knowledge would pose new demands on the expressiveness of our model and, if so, to identify limitations and shortcomings to be resolved. In this paper we provide examples describing the modeling challenges we encountered, we discuss the rationale of the chosen solutions and put forward suggestions for future research focus.

Materials and Methods

In our endeavor to broaden the content coverage of the ORCA knowledge base we used both as a starting point and as point of reference accredited medical textbooks (in English), covering the topics of history taking and physical examination [5,6]. Additionally, the medical background of both authors served also as a source of increased perception on the data collection needs arising during physician-patient interaction.

An overview of ORCA-SDE tools

The ORCA structured data entry (SDE) tools have been developed with the goal of maximizing expressiveness and flexibility for the clinician end-user. The interface functionality required to achieve this task is primarily supported by the system's knowledge base. The knowledge base (KB) is comprised of a list of available terms and a tree-like generic model, defining how terms can be combined into (meaningful) medical descriptions. In this model, all medical context is represented by the *ordering* of concepts, in the sense that every 'parent' concept is followed by 'children' which are context-dependent and hence relevant descriptors. A limited number of predetermined relationship types are available for creating links between concepts. These relationships, however, convey only the information required for guiding interface behavior and thus are hidden from users during data entry. Further, each node in the tree has properties placing valid restrictions on the descriptive options available in the interface, based on various concept-specific aspects (such as the possibility to indicate absence or presence of a concept, to enter a quantitative value, or to specify cardinality) [7].

An expansion of the ORCA knowledge base, either by modeling new knowledge or by making adjustments to pre-existing content consists of the following steps:

a) choice of terms to be used and subsequent ordering of the relevant concepts in the knowledge base 'tree'
b) choice of the relationships linking the concepts
c) assignment of properties to the tree nodes.

At the initial stage of concept choice, we used a simple word processor to create a rough overview of the 'knowledge tree' for Physical Examination. Consequently, we proceeded to use the dedicated ORCA software tools for knowledge engineering; the Knowledge Editor for the modeling, and the SDE interface to check the effect of the populated knowledge base on interface behavior.

The knowledge base offers the support necessary to facilitate predictive or 'intelligent' structured data entry. The physician enters data by selecting with a pointing device the concepts pertinent to his observations. Employing the context created by prior selections, coupled with the information contained in the knowledge base, the interface responds by providing the descriptive options most likely to be relevant. Finally, the selected concepts form a tree which represents patient-specific data. A path (or sequence of instances) in this tree reflects the ordering of the concepts in the knowledge base model and corresponds, essentially, to an elementary clinical statement, e.g. *heart-auscultation-murmur* [8].

The Modeling strategy

We employed a stepwise, iterative approach in our work. The representation of a finding involved exploring several modeling options, assessing them and arriving to final choices for the order of concepts in the knowledge base. All through the modeling process, we carefully documented the encountered problems and the alternative solutions we considered.

The aspects we examined and, consequently, our assessment criteria when considering each modeling option were the following:

Intuitiveness

Our aim was to create a knowledge base which would ensure a behavior of the interface as compatible as possible with physicians' recording practices (in order to minimize potential disruptions of clinical work processes). As a result, the simplicity and straightforwardness of a representation was often the determining factor in selecting between alternative options.

Granularity

The knowledge base should not simply contain the concepts and descriptors most likely to be relevant in each context, but also present them in sufficient granularity, so that clinicians' expressive needs can be met. Even though the option of entering free text notes is always present, we hope to maximize the richness of record content available in a structured form by offering adequate, but not overwhelming descriptive detail through the SDE interface.

Interpretation

ORCA's philosophy relies explicitly on the distinction between description and interpretation (or reasoning) in the process of medical work. The aim was to separate to the maximum degree possible (ideally, completely) the interpretation from the observation elements in the recording of data, but without compromising the directness of the interface.

Retrieval-related issues

So far, modeling work in ORCA had primarily evolved around the demands of data entry. Still, the evident next step in the process of data use is retrieval. Exploring the possible consequences of modeling flexibility from the viewpoint of data retrieval emerged as a central issue in our work.

The way the aforementioned criteria translate in practice will be demonstrated through several examples which illustrate in a more concrete manner the type of considerations a modeler is confronted with.

Results

In terms of flexibility and expressiveness, the ORCA knowledge representation model proved suitable for covering a general knowledge domain such as Physical Examination. What also became apparent though, were the limitations of our approach with respect to information retrieval requirements. In this context, the challenges we encountered through the modeling process could be perceived as touching upon two ‘generic’ categories of relevance:

a) the *ordering* of concepts in the knowledge tree
b) the presence of *semantically equivalent* expressions.

Partitioning Physical Examination

Basic structure

Actions performed during physical examination often assess simultaneously more than one functionality or anatomic entity. While examining the mobility of a patient’s shoulder, for instance, the physician assesses features of both the musculoskeletal and the peripheral nervous system. This practice reflects both existing anatomical and physiological ‘combinations’, as well as clinicians’ desire for economizing time. Medical textbooks simply acknowledge the overlap between physical examination of different systems through cross-referencing of the respective chapters. Such a solution though is not equally suitable for formal representation, where clear distinctions are required. Organizing Physical Examination in sections pertaining to body systems seems to be generally well accepted by physicians, and so we adopted it in the basic structure of the knowledge base [9]. Nevertheless, we tried to incorporate and facilitate the more pragmatic aspects of the ‘natural’ sequence of a physical examination through additional capabilities of the interface.

Anatomy vs. functionality

The choice of focus point in the process of organizing context-relevant concepts is not always straightforward, and certainly not a matter of simply following usual medical practices. We shall demonstrate the difficulties involved by using the examination of the central nervous system, and more specifically cranial nerves, as an example. Medical textbooks typically organize this section of the physical examination on the basis of anatomy, i.e. using the cranial nerves as the ordering principle. The limitations of this approach in a formal representation soon become evident, though. It is well known that more than one cranial nerve collaborate to provide several forms of functionality. The attempt to represent formally this otherwise simple fact leads to redundancy and possible inconsistency of entered data or forces the introduction of ‘hybrid’ terms created by an artificial combination of concepts; for example, cranial nerve III/cranial nerve IV/cranial nerve V, as regulators of extra-ocular movements (conjugate movements, convergence, nystagmus).

This kind of “compound” concepts though, is best avoided from the viewpoint of efficient retrieval. Thus, we organized the examination of cranial nerves using their functions – which are distinct concepts – as the starting point; in other words, we substituted the anatomical terms of cranial nerves (grayed out in the right column of Table 1) with their provided functionality. This alternative approach preserves the knowledge needed, without violating retrieval requirements.

TABLE 1. Neurological examination

Approach with focus on anatomy	**Approach with focus on function**
Examination of cranial nerves	Examination of cranial nerves
……	Examination of function
Examination of CNII	……
Visual acuity	Examination of vision
……	(CNII)
Examination of CNIII/IV/VI	Examination of extra-ocular movements
Extra-ocular movements	(CNIII, CNIV, CNVI)
Conjugate movements	Conjugate movements
Convergence	Convergence
Nystagmus	Nystagmus

Finer structure

Ordering-related issues also appear in a more fundamental layer, namely in the ordering of concepts in a "path" of the model, which essentially corresponds to an elementary clinical statement. The main components or building blocks of such a statement regarding Physical Examination could be identified as:

1. Technique of examination, (inspection, auscultation, palpation or percussion)
2. Findings observed or discovered through the use of this technique as, for example, a deformity, a swelling, a mass, a murmur, etc.
3. Location, in the sense of anatomic localization of the finding, which may be represented in varying degrees of granularity, e.g. thorax, sternum, costal interspace, etc.

In terms of possible combinations between these components, six alternatives would be theoretically available:

1. TECHNIQUE – LOCATION – FINDING
   e.g. inspection – knee – swelling
2. TECHNIQUE – FINDING – LOCATION
   e.g. inspection – swelling – knee
3. LOCATION – TECHNIQUE – FINDING
   e.g. knee – inspection – swelling
4. FINDING – LOCATION – TECHNIQUE
   e.g. swelling – knee – inspection
5. LOCATION – FINDING – TECHNIQUE
   e.g. knee – swelling – inspection
6. FINDING – TECHNIQUE – LOCATION
   e.g. swelling – inspection – knee

All of these orderings can lead to meaningful sentences, at least from the point of view of natural language. It is also possible to represent these sequences in the ORCA model. In terms of clinical intuitiveness, though, the last three orderings are not quite satisfactory; the examination method is presented last (#4 & #5) or the abnormality is placed on a higher level in the tree (#6), while the anatomical structure to which it applies is presented much later. As a result, the first three options – where Technique precedes Finding – appear to be simpler and more straightforward. But even among them, alternative #3 presents the added advantage of allowing the grouping of findings around the anatomic entity under examination (in this example, the knee). Use of an anatomical concept as the point of reference is closer to the way physicians organize and also look for information, thus more intuitive. Consequently, we adopted the ordering of alternative #3 as the preferred option in our modeling work.

Representing laterality

Representation of laterality often poses an interesting challenge in modeling medical knowledge. To a large extent this stems from the fact that laterality appears in several diverse contexts and, consequently, can be modeled in various alternative ways, as the following examples demonstrate:

1. face → side → right
   ↳ left
   ↳ both
2. pupil dilatation → laterality → unilateral → right
   ↳ bilateral ↳ left
3. nystagmus → direction → right/left
4. reaction to light → direct → side → right
   ↳ consensual ↳ left

(There is no need to provide further specializations of 'consensual' since it can be deduced that it refers to the side complementary to the one specified for the direct reaction to light). Apparently, laterality can be represented in various ways, some of them interchangeable, resulting in semantically equivalent statements. Given our main goal to preserve physicians' usual way of expression by providing them with intuitive selections of concepts, at present we have incorporated all of these variations in different sections of the knowledge base. Thus, the representation judged as most appropriate in a specific context has been employed. Still, we are aware of the problems this choice might present in the context of information retrieval.

Descriptive knowledge vs. Interpretation

In medical practice in general, as well as in its reflection in medical textbooks, there is often no clear distinction made between descriptive observations and their interpretation. On the other hand, the formal representation of medical knowledge in ORCA aims explicitly at achieving this distinction [10]. This is clearly demonstrated in the example of modeling extra sounds which may be discovered during heart auscultation. As can be seen in Table 2 (p. 64), there are several options from which the modeler may choose, covering the whole spectrum between complete intertwining of descriptive knowledge and reasoning (textbook structure) to complete exclusion of reasoning from the model. In the last case, the need to express the clinician's interpretation of the findings has been

TABLE 2. Alternative modeling options of findings on heart auscultation

Textbook structure	Interpretation Absent	Clear Distinction
Auscultation	Auscultation	Auscultation
heart	heart	heart
Extra sounds	Extra sounds	Extra sounds
Systolic	Phase	Phase
Ejection Sound	Systolic	Systolic
Click	Diastolic	Diastolic
Diastolic	Timing	Intensity
Opening snap	Early	**Type**
S3, S4	Mid(dle)	**Ejection sound**
Summation gallop	Late	Click
	Location	Opening snap
	Intensity	S3, S4
		Summation gallop

accommodated by modeling interpretation-related concepts (in this example, the type of the extra sound) as a separate entity besides observations. It is interesting to note that the separation of description and reasoning allows for non-valid (albeit explicit) combinations of entered data. Still, the possibility of expressing medically incorrect concepts could also be perceived as an indicator of physician competency and thus is not altogether unwelcome.

Discussion

The ORCA knowledge model and engineering tools were developed with the specific aim of facilitating structured data collection - a target closely connected to accommodating physicians' habits and thus increasing the potential acceptability of the system. As a result, ensuring flexibility had been given a clear priority so far. Characteristics of the model such as intuitiveness, variable granularity and ability to clearly distinguish between observation and interpretation reflect this emphasis on expressiveness and were also confirmed in this work. These are significant advantages, especially since they allow clinicians to get hands-on experience with modeling and tailor the application to fit their needs.

Naturally, the present state of the knowledge model largely reflects the outlook of its developers. It still needs to be tested and evaluated by clinicians themselves, in a real practice setting where valuable feedback could be gathered [11]. In addition, several modeling issues remain unresolved, such as the representation of comparative aspects (e.g. the intensity of a murmur is louder when the patient leans forward) and the use of substitute terms (e.g. 'tachypnea' for breathing which has ‘rhythm – rapid’ and ‘depth – shallow’, or ‘breathing Cheyne-Stokes’ for the alternating presence of ‘hyperpnea’ and ‘apnea’). Since these are aspects which must be accounted for in order to make the system suitable for clinical practice, we are already in the process of studying possible solutions.

It is important to keep in mind, however, that one can never model case-dependent descriptors. Hence, the best achievable modeling is limited to description of conceptual entities, one of more of which may apply to a particular patient. At present, the need to express patient or setting-specific detail is catered partly through the concepts as incorporated in the model and partly by the possibility to specify user-defined views on the model.

Another, even more important limitation of modeling flexibility is the great demand it poses on developing innovative, more efficient strategies of reliable data retrieval. The importance of retrieval-required consistency was also underscored through our experiences in expanding the content of the ORCA knowledge base.

As we demonstrated with our examples, it is often the case that modeling alternatives are semantically equivalent, while respecting the formal framework of the model. Although this is again proof of the model’s representational strength, problems may arise with respect to retrieval. At present, the only way of retrieving semantically equivalent data recorded with a different ordering is the ‘membership of path’ strategy [12]. This strategy would produce reliable results with any alternative, provided that semantic equivalence is restricted to different ordering of the same concepts. If synonymous concepts are used in a semantically equivalent representation, the ability to retrieve the recorded findings depends on whether the modeler has incorporated these synonyms in the systems list of terms. Further, if an altogether different approach is adopted in the representation, only someone thoroughly familiar with the knowledge base structure and contents can retrieve the corresponding findings. Clearly, this is not a satisfactory or adequately pragmatic approach. It seems apparent that freedom of expression should be somehow limited. Still, we need to explore what would be the best way of achieving that goal and also, whether the possible gain in retrieval efficiency justifies the sacrifice in data entry capabilities. Currently, and while further work is continuing in several specialized domains, the ORCA list of terms has reached a substantial size and adequate scope of coverage. Thus we believe that the possibilities to make use of international terminology systems should be explored. When it comes to structured data entry support, terminological approaches to medical knowledge representation have faced the reverse problem with respect to flexibility vs. consistent retrieval. Since they define what is sensible to say and represent this meta-knowledge in a formal structure, inference-based retrieval becomes possible, thus overcoming the problem of semantic equivalence [13]. However, because terminology-based systems do not explicitly model which of these numerous sensible options would be relevant in a specific context, they overwhelm the end user with an excessive amount of choices which is almost impossible to navigate. The complementarity of the two approaches clearly warrants further exploration.

Modeling of medical knowledge is a complex process. When its ultimate goal is to support the collection of structured unambiguous data, it gives a new dimension to familiar challenges in knowledge representation, such as the trade-off between flexibility, on one hand and consistency requirements for reliable retrieval on the other. The synergy between structured data entry and terminological approaches may hold the solution for achieving standardization in the collection and exchange of medical record data [14].

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PART II

Chapter 4

Towards personalized Internet health information: the STEPPS architecture

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Abstract

Primary objective

STEPPS (STructured Evaluated Personalized Patient Support) proposes a strategy for the integration of the electronic patient record with Internet health-related content and its consequent use in personalized information retrieval for patient education. The application domain is the post-discharge support of burn patients in The Netherlands.

Materials and Methods

We developed an electronic patient record interface for structured data collection in burn care. The system's thesaurus was projected to UMLS terms and the corresponding codes were incorporated in our software. A list of topics central to burn patient education was identified and a collection of related Web pages, was compiled using meta-search software (Copernic2001Pro®). The HTML pages were filed into catalogues by the Collexis® indexing-matching software, using the UMLS Meta-thesaurus as indexing vocabulary.

Results

The bilingual (English and Dutch) structured data interface is currently used to create a database of retrospective patient data. Each patient's profile, i.e. set of characteristics employed to personalize information retrieval, can be automatically extracted. We have assembled a collection of more than 2,500 Internet pages containing relevant information for burn patients. When patient data is available, the Collexis® matching engine will accept the patient's profile as input and retrieve the most relevant HTML documents available in the catalogues.

Discussion

We have addressed some basic issues around the technical feasibility of linking electronic patient record data to online content. Although the functionality of STEPPS is not yet optimal, it contributes to the efforts towards improved relevance of information retrieval. Electronic patient record applications in conjunction to Internet resources can give a significant boost to the availability of tailored health education material. In this context, quality assurance of online health information is an indispensable element.

Keywords: Internet, World Wide Web, Information Retrieval, Personalization, Electronic Patient Record, Patient Education

Introduction

Personalization or tailoring of health-related content according to individual characteristics is a much desired goal for information retrieval research in the field of medical informatics [1,2]. The use of medical record data has been identified as a potential method to achieve this goal. Several approaches aiming at linking online information resources with electronic patient record systems have been explored, but their primary focus was that of supporting scientific or health professional information needs [3–5]. Personalization, however, has also proven to be an important factor in the success of patient education programs [6–10]. It has been shown to increase patients' satisfaction with provided education material, improve understanding of their condition or disease, and enhance people's ability for disease management. Moreover, several benefits of combining patient education applications with electronic patient records have been well documented [9]. Still, solutions that fully integrate patient education functions to the standard features of electronic patient record systems are not yet available. Further, the strategies explored so far have been based on the use of locally produced education material, often paper-based originally and then transferred to a computer-based version [9,10]. In the years since 1996 and onwards, however, the Internet has posed as a much promising channel for health information dissemination and has been widely used as such by the general public [11,12]. Besides its popularity, the Web also presents traits which – when fully exploited – make it a good candidate for patient education purposes, such as currency of material and easiness of update, adaptation to variable audiences, ability to access the information at the time and place it is needed, opportunity to access supplementary information resources, etc. [13,14]. Taking into account these developments, our project STEPPS – which stands for STructured Evaluated Personalized Patient Support – studies the possibilities of personalization of Internet health-related content, based on an individual's electronic patient record. The current application domain is the support of severely burned patients at the period after discharge from the burn care unit. In this paper we present and analyze the components of the STEPPS architecture, discuss the rationale of the design choices and present the results of the progress achieved thus far in the project.

Materials and methods

Background

The architecture proposed by STEPPS is based on the following reasoning: in the process of caring for an individual patient, information needs both arise and are defined by the health problems at hand. This observation has been corroborated by studies regarding information seeking behavior and demands of both professionals, as well as patients [6,15]. Further, for any given health problem of a patient, it is the specifics of the clinical case or of a certain event of care which largely act as determinants of information relevance. The corresponding data are documented in detail in one's medical record, making it in turn an ideal starting point in the search for information and knowledge. One of the main problems to be resolved in this context has been the identification and extraction of the required patient data from large amounts of unprocessed patient-related documents, since a considerable amount of the information in electronic patient records has thus far been contained in the form of free text [16,17].

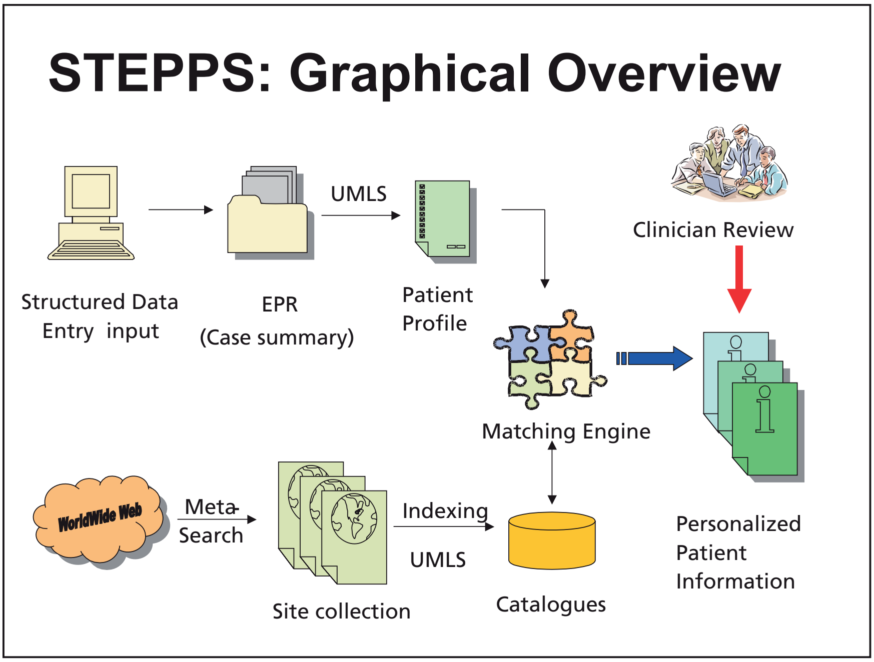


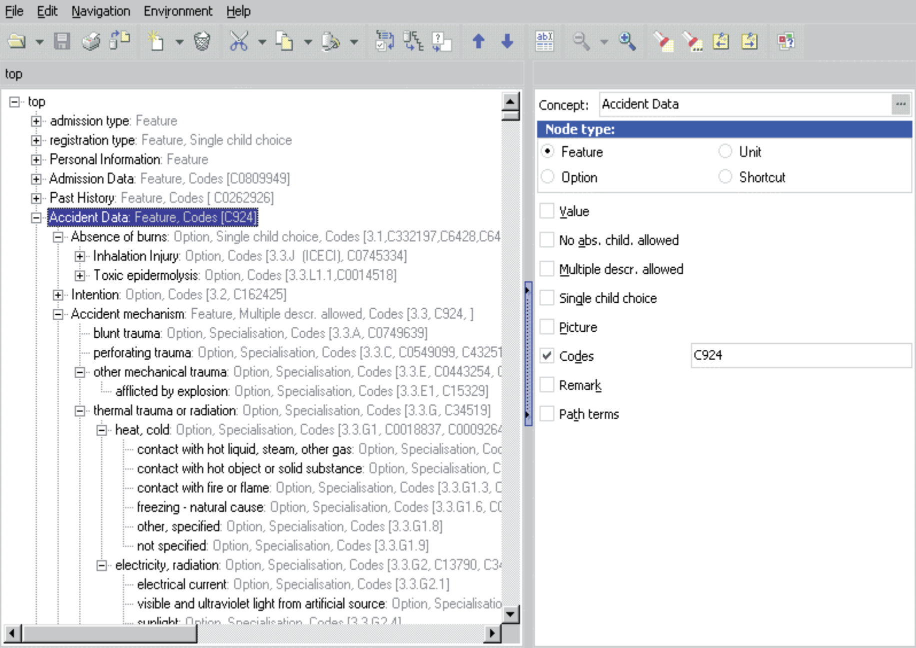
FIGURE 1. Graphical Overview of the STEPPS architecture
The case summary is created using the SDE interface, while the Collexis® tools perform the indexing of Internet pages and matching to patient profiles.

In STEPPS this process is made considerably simpler, through the use of an interface to the electronic patient record (EPR), which provides structured and coded clinical data at the point of care. This approach allows us to seamlessly connect data with health content available online, using international terminologies and indexing-matching software as the link. A graphical overview of the STEPPS architecture can be seen in Figure 1 (p. 71). In the following paragraphs we analyze the components of the STEPPS strategy and the way they have been configured to collaborate with each other.

Components of the STEPPS strategy

Domain specific interface for structured data entry

In the initial phase of STEPPS we used the knowledge engineering tools developed in the context of the Open Record for CAre (ORCA) electronic patient record system to create an EPR interface for structured data collection, tailored to the documentation needs of burn care. A more detailed description of the ORCA software is available elsewhere [18]. In the context of this work, most relevant is the component of the Knowledge Editor, where the structured data entry (SDE) generic knowledge model is used to represent terms used in the specific clinical application domain (See Figure 2). The resulting knowledge model defines and



```
top
  admission type: Feature
  registration type: Feature, Single child choice
  Personal Information: Feature
  Admission Data: Feature, Codes [C0809949]
  Past History: Feature, Codes [ C0262926]
  Accident Data: Feature, Codes [C924]
    Absence of burns: Option, Single child choice, Codes [3.1,C332197,C6428,C64
      Inhalation Injury: Option, Codes [3.3.J  (ICECI), C0745334]
      Toxic epidermolysis: Option, Codes [3.3.L1.1,C0014518]
    Intention: Option, Codes [3.2, C162425]
    Accident mechanism: Feature, Multiple descr. allowed, Codes [3.3, C924, ]
      blunt trauma: Option, Specialisation, Codes [3.3.A, C0749639]
      perforating trauma: Option, Specialisation, Codes [3.3.C, C0549099, C43251
      other mechanical trauma: Option, Specialisation, Codes [3.3.E, C0443254, (
        afflicted by explosion: Option, Specialisation, Codes [3.3.E1, C15329]
      thermal trauma or radiation: Option, Specialisation, Codes [3.3.G, C34519]
        heat, cold: Option, Specialisation, Codes [3.3.G1, C0018837, C000926
          contact with hot liquid, steam, other gas: Option, Specialisation, Coc
          contact with hot object or solid substance: Option, Specialisation, C
          contact with fire or flame: Option, Specialisation, Codes [3.3.G1.3, C
          freezing - natural cause: Option, Specialisation, Codes [3.3.G1.6, C(
          other, specified: Option, Specialisation, Codes [3.3.G1.8]
          not specified: Option, Specialisation, Codes [3.3.G1.9]
        electricity, radiation: Option, Specialisation, Codes [3.3.G2, C13790, C3
          electrical current: Option, Specialisation, Codes [3.3.G2.1]
          visible and ultraviolet light from artificial source: Option, Specialisatio
          sunlight: Option, Specialisation, Codes [3.3.G2.4]
```

Concept: Accident Data

Node type:

● Feature ○ Unit
○ Option ○ Shortcut

☐ Value
☐ No abs. child. allowed
☐ Multiple descr. allowed
☐ Single child choice
☐ Picture
☑ Codes C924
☐ Remark
☐ Path terms

FIGURE 2. Screen shot of the Knowledge Editor environment
Selected terms have been assigned with corresponding UMLS Metathesaurus codes.

supports the behavior of the data entry interface, which in turn presents to the clinician context-dependent, relevant options to select while documenting the data pertinent to a specific patient. Part of the Knowledge Editor is the Thesaurus or list of terms compiled for use in the particular application domain. The software offers the possibility to define synonyms per term, as well as to select which should be the preferred term in a specific context. Another feature is the possibility to translate the Thesaurus terms to other languages, in the environment of the Translator. Finally, codes from multiple coding systems can be assigned per term during the modeling stage.

We first created a pilot SDE version addressing the data entry needs for the first assessment of patients, based on the Emergency Management of Severe Burns handbook [19] and local data entry protocols. This step served as a means to test the feasibility of using the SDE software in the field of burn care. After the successful completion of this phase, an extended data entry system was developed (See Figure 3). For this purpose we used as reference a consensus data set, agreed upon by burn care specialists in The Netherlands. The consensus process took part within the framework of an ongoing project (Dutch Burns Information System project – Nederlandse Brandwonden Informatie Systeem or NBIS in Dutch), aiming at the creation of the infrastructure and tools for a longitudinal national research database for the field of burn care [20].

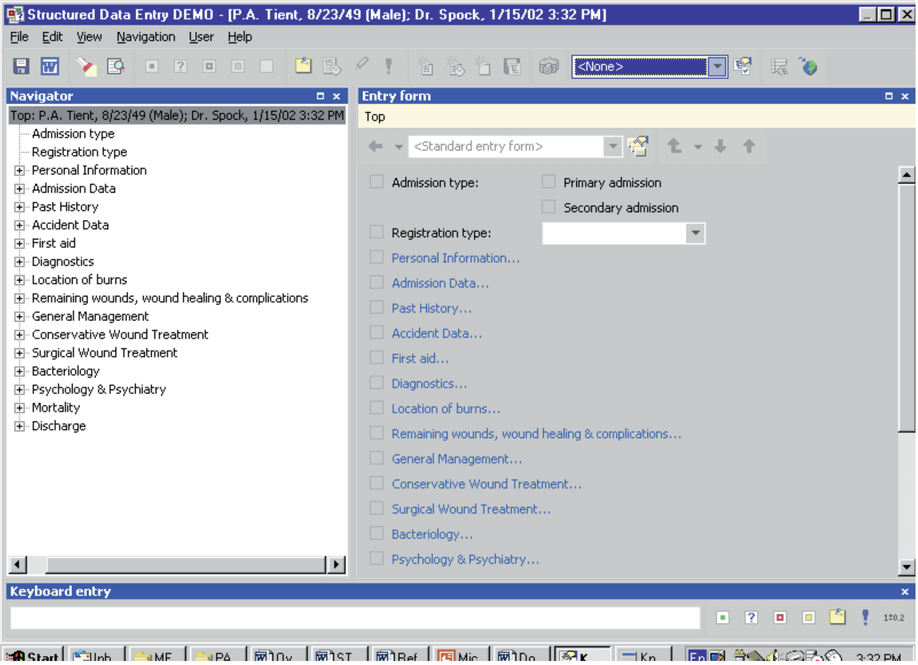


FIGURE 3. The opening screen of the structured data interface for burn care (English version)

Coded data (UMLS) – Patient profiles

The process of matching between documents requires the use of a shared (preferably controlled) vocabulary. In STEPPS, we employed the Unified Medical Language System (UMLS) Metathesaurus to act as the link between electronic patient record data and material retrieved from online resources.

A prerequisite for achieving this aim was the association of the terms used in the burn care version of the SDE (essentially, the terms preferred by clinicians for their documentation) to the more standardized UMLS Metathesaurus terms. This process of associating terms was accomplished in a semi-automated manner. First, we run the contents of the thesaurus through proprietary software which performed automated matching in a batch form [21]. Consequently, we manually reviewed the output and categorized the resulting terms to 'exact matches' (exact term present in the Metathesaurus), 'non-exact matches' (more specific or more general term found in the Metathesaurus) and 'failures to match' (no corresponding term found in the Metathesaurus), accordingly. Finally, we incorporated UMLS codes in the data entry software, by making use of the possibility to define codes per term in the SDE knowledge editor.

At this point it is important to note that not all of the data represented in the structured data interface have been provided with a UMLS code. Based on prior work on definition and extraction of patient profiles from electronic patient records [22,23], we have made a selection of patient characteristics (or attributes) with potential relevance for the personalization of information material. These characteristics fall in two categories: a) General, topic-independent: age, gender, past history, medications and allergies etc. b) Topic specific, i.e. mechanism of accident, type and location of burn, method of surgical treatment etc.

At the moment that information on any of these elements is entered in a person's medical record through the SDE interface, it is immediately 'tagged' with a UMLS code and thus included in the data comprising the patient's profile, which is eventually used in the matching and retrieval process.

The UMLS Metathesaurus is also used by the Collexis® tools as the indexing vocabulary for the material collected through online resources, to facilitate the process of matching to patient record data.

Meta-search tools – Selection of pertinent topics

A key element in designing the STEPPS architecture was the identification of topics on which information should be provided in the context of patient education. We have not attempted to ascertain the information needs of patients on an individual basis. Rather, we have adopted a more 'collective' approach. We have made use of published research on the issue of patient education in burn care, (particularly regarding the period around and after discharge) and singled out topics constituting recurrent, common problems facing burn patients [24,25]. The relevance of these topics was further confirmed through the experiences of local burn care teams in smaller scale research projects [26]. Accessing burn patient oriented sites and reviewing the subjects covered and posted in their pages, provided additional corroboration to the original selection [27–29]. Finally, further feedback was gained through a parallel project of the Dutch Burns Foundation in collaboration with the three specialized units in The Netherlands, for improvement of patient education during the hospitalisation period.

All the aforementioned sources seem to converge on the following areas:
1. wound management & related problems (sleep disturbances, itching, etc.)
2. scarring management (prevention with exercise and pressure garments, etc.)
3. pain relief
4. physiotherapy
5. psychological problems (such as post-traumatic stress disorder) and emotional support.

This subject group constitutes the set of topics on which we shall aim to provide relevant information, tailored to the needs of each individual.

Having identified the topics on which information was to be provided, we then needed a method and tool to create a collection of pertinent Web pages, in order to explore the technical feasibility of linking them to electronic patient record data. For the purpose of ensuring stability and control over the material, we decided to store and use the collection locally, rather than online.

Initially we considered the option of using a selection of popular search engines and specific, fine-tuned queries per topic. However, some already known limitations of general search engines made this approach less attractive [30,31]. Firstly, each search engine requires a different strategy in order to make best use of its capabilities. Secondly, even if engine-specific optimised queries are constructed and used per search engine, bringing together all the returned results and, even more so, tracing their evolution over time remains an impractically tedious task.

We thus concluded that the best means to serve our purposes would be the use of a meta-search tool. That approach would considerably simplify the whole process by allowing us to apply a simple search strategy simultaneously across a number of widely used search engines. We chose the Copernic Basic® and Copernic Pro 2001® software, since this tool offered certain features which were particularly suitable to our task and could effectively decrease the amount of time and effort required:
- ability to automatically download and store the URLs of the identified Web pages;
- automatic removal of duplicate results and non-functioning links;
- ability to automatically repeat the search periodically, in order to check for changes – updates of available pages.

The Professional version offers the additional possibility to search specifically among health related sites, which increases the specificity of the returned results. Another advantage is the ability to search bilingually, since our aim was to create both an English and a Dutch collection of Web pages. The main body of sites will be collected through this process, while further pages may be added through links found on other pages, references in publications etc. (Further information on the STEPPS collection of Web pages is provided in Appendix I).

Indexing & matching software – Web catalogues

The large volume of the collection would make manual indexing impractically time consuming and expensive. In STEPPS we used the Collexis® software which allowed indexing of the retrieved pages using UMLS Metathesaurus as the indexing vocabulary in matters of seconds per topic. In addition, Collexis® also generates more concepts or keywords per indexed page than manual indexers in general do and assigns a relevance score to each keyword. The indexed pages form thus catalogues, which are classified thematically, according to the search query by which they were identified.

The second function performed by the Collexis® tools is that of matching, i.e. finding documents within a collection which fit the 'profile' of the query document. In this case, the query document is the patient's profile, consisting of a subset of the data available in his or her electronic patient record, as discussed earlier. The patient's profile is communicated by the SDE interface to Collexis® as an XML message, a solution allowing for seamless integration of the two programmes. Once patient data is made available, the Collexis® search engine will accept the patient's profile as input and retrieve for review the URLs of the most relevant HTML documents present in the catalogues.

Results

The development of the 'first assessment' knowledge model and initial prototype version of the SDE interface required approximately two months of modeling work, while the subsequent expansion to the NBIS-adjusted version entailed an additional period of six months.

We are currently using the burn-care specific structured data entry interface to populate a research database with retrospective data. Our source material are files of patients who have been hospitalised in the specialized burn care units in The Netherlands during the course of the same year (2000–2001), to guarantee that uniform treatment standards would be applicable. Twenty records per centre were selected by the clinicians of each unit, with the aim of having adequate variability of types of cases included in our study. Data collection is in progress in two burn care centres (Beverwijk and Rotterdam). The ability to incorporate coding systems, so that codes are automatically assigned to data at the time of entry has proven especially valuable. This feature allowed both the inclusion of the UMLS codes needed for the matching, but also of other coding systems required for clinical purposes (such as ICD-10 and ICECI). Further, the bilinguality of the interface allows for simultaneous querying of both Dutch and English Internet resources without additional manipulation of the clinical data, but rather by simply selecting the language preferred by the user.

The projection of our system's thesaurus to the UMLS Meta-thesaurus terms yielded an initial 80% correspondence. Our purpose was two-fold; achieving the maximum possible degree of standardization in the vocabulary used in the medical record, as well as making use of the rich synonym content of the UMLS in the next phase of the project. Through further analysis of the results we also expect to gain better insight on two issues: the degree that burn-specific terms are represented in international terminological systems and the implicit semantic content of the SDE model.

In making use of Internet resources in STEPPS, we begun by anticipating that there would be a multitude of sites – besides the ones explicitly dedicated to the topic of burn injuries – providing information material pertinent to the concerns of burn care patients or of those around them. Thus far, we have created a collection of more than 2,500 Internet pages, which may contain relevant information for burn patients trying to cope with their condition. This collection will be further complemented with resources identified through links found on other pages, references in publications etc.), plus it will be updated during the project with a check for deletion of pages or appearance of new ones. Of course, the true value and reliability of this material can only be determined through an evaluation process. This final phase of STEPPS, focused on the review of online content by qualified clinicians, is scheduled to begin in the near future.

Discussion

Electronic patient record applications in conjunction to Internet resources can give a significant boost to the availability of tailored health education material, by making use of data that is extensively documented in every patient's file. Several projects are underway to achieve this goal, employing different starting points and methodologies, which range from natural language processing techniques to health geomatics [32–34].

The distinguishing feature of the STEPPS architecture is its use of an interface to the electronic patient record, which makes structured and coded data immediately available at the point of care, with no need of further processing. By incorporating access to patient education material as a standard feature of electronic patient record functionality, the production of information tailored to the needs of each individual can become an additional gain of routine medical record documentation [35]. In turn, this can promote the smooth integration of patient education with other main tasks of everyday clinical workflow.

The system we have developed at this phase of the project primarily reflects the data recording requirements of burn unit physicians and nurses, as well as of psychologists (although to a lesser extent). The fact that burn care is a multidisciplinary field means that eventually the needs of all professional groups involved (such as plastic surgeons, microbiologists, physiotherapists, nutritionists, etc) should be addressed. Expanding the record content to include issues pertinent to other disciplines does not pose considerable problems in terms of the modeling work required. Rather, the step that can prove more challenging and time consuming is achieving consensus among the eventual user groups, as to what data to include and how it should be recorded. Additionally, aspects of user interface acceptance and system usability in the conditions of the work floor need to be tested.

In prior research work where the concept of 'attribute-value' pairs has been used as an approach to health/clinical information retrieval, there was extra effort required to identify those pairs through free text processing of the medical record [23,36]. That is precisely where one of the main advantages of the STEPPS architecture lies; patient profile generation and subsequent information retrieval becomes a simple, effortless by-product of regular data recording. Through this 'shortcut', considerable gains in time, effort and accuracy can be achieved.

The approach we have chosen in defining a patient's profile is at the current development phase of STEPPS rather unrefined and comprehensive. We will have a better understanding of the capabilities and limitations of the technique as soon as we conclude testing with real patient data. A more fine-grained approach of partitioning the current patient profile to 'sub-profiles', further tailored to the specific information topics, could potentially be more effective. Although we have not made use of it yet, such a possibility exists at the level of the data entry interface. By using the template definition function of the SDE Knowledge Editor, we can create filters to already collected data and produce different profiles for retrieval in the context of each specific topic.

In the framework of STEPPS, we created an extensive collection of Web pages addressing issues of interest for burn patients and their families. The focus of the project is not on dynamic retrieval of online information, but rather on experimentation with Internet health-related *content*, to assess the potential of its use as patient education material. Therefore, aspects pertaining to navigation, web site performance and stability (although important factors in determining the interactive experience of an end user) have not been addressed so far.

The current static nature of the assembled Web material has the advantage of allowing for quality assurance and approval of the content, before it is actually employed in patient education. On the other hand, additional effort will be required in order to maintain currency of the collection in the longer term. Using truly dynamic, online content in the implementation of the STEPPS architecture might reduce the burden of maintenance, although not without difficulties, as prior experience has indicated [37]. It would, however, place even bigger demands in providing an efficient, fast and reliable manner for quality assessment.

The novel Collexis® tools [38], which evolved out of research in the AWARE (Automated Web-based Archive Retrieval and Exchange) system [39], are another asset of the STEPPS architecture. The abstraction engine has allowed for considerable time savings on the task of Web page indexing. Further, the possibility to use more than one indexing vocabularies is another important feature. On the one hand it makes the use of both Dutch and English resources feasible (since only a small subset of the UMLS Metathesaurus is available in Dutch), but it also allows for a comparison in indexing of Web material between the two vocabularies, i.e. the UMLS Metathesaurus vs. the SDE thesaurus (in essence the preferred terminology of clinicians in the field).

The use of the Collexis® matching engine is a key component in the process of achieving personalized retrieval of Web content. Earlier applications of this tool have been primarily in the realm of scientific publishing, with very promising results. Its use in the context of consumer-oriented health information and the combination with the electronic patient record are still in an experimental phase. The results and experience gained through the STEPPS project will provide important feedback to the ongoing development and improvement of this technology.

We have managed to address some of the basic issues around the technical feasibility of linking electronic patient record data to online content. Although the functionality of our system is not yet optimal, it contributes to the efforts towards improved relevance of information retrieval.

Proving the feasibility of this approach was our first, but not only task. Another crucial issue is the scientific and medical correctness of advice available on the Internet. Patients and the public at large are not always equipped with the necessary knowledge to evaluate the information they retrieve. Medical professionals, on the other hand, are qualified to perform this type of quality assessment. Moreover, patients expect or wish that their carers would provide them with that type of expert opinion [40]. We intend to make use of the personalized health information material produced by our system to study healthcare professionals' attitudes to this new approach to patient education.

With respect to retrieval of Internet information, the option of eliminating the human review element is not really available if one seeks for optimisation of content. Further, it may not even be desirable or feasible, having in mind the need for quality assurance [41,42]. Regarding the latter, we believe that promoting collaboration with health care professionals from various fields is an absolute necessity. The presence and support of umbrella organizations, bringing together researchers, patients and professionals (as, in our case, the Dutch Burns Foundation) is a significant aid in this effort. Activities of similar bodies, combined with projects and initiatives aiming at certification of health information quality [43] hold much promise for the future.

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Chapter 5

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

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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. 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.

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

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 etc.[1] [5]. In actual health care settings, however, the ideal of patient education tailored to the needs of each individual is rarely achieved [6].

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[1] In patient education literature the term 'tailoring' has been used to refer to what we describe as 'personalization', a term more commonly applied in the context of Web applications. Both terms are used interchangeably in the paper.

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 (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-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 system implementation in actual practice settings interrelate with and largely determine the choices made in the design phase.

Background

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.

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 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.

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].

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 pertinent patient characteristics (usually 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].

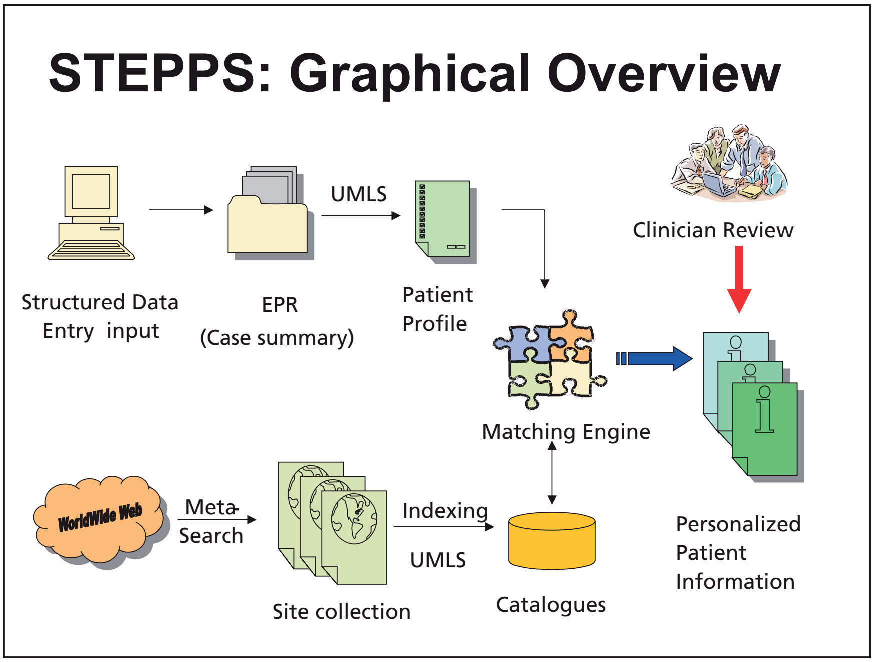

FIGURE 1. Graphical representation of the STEPPS prototype architecture

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.

During the modeling phase, a subset of the terms present in the SDE interface was assigned corresponding UMLS cods. 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.

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.

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].

Discussion

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 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].

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 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, particularly from the viewpoint of meeting the needs of burn patient education. Online education 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].

TABLE 1. STEPPS – Implementation Scenarios

User group	Setting of use	Implementation issues
Specialized doctors – nurses – paramedical personnel (physiotherapists, nutritionists, psychologists etc.)	Burn unit – Outpatient department	• Vocabulary - interface design • Fitness to workflow • Acceptance by personnel
General Practitioners [a] – nurses	Primary Care	• Access to specialist EPR or discharge summary • Communication protocols • Specialist – GP record integration • Security infrastructure (public networks)
Patients – Caregivers [a]	Patient's home	• Access to EPR • Ability to add-update data • Language – Interface design • IT skills • Security infrastructure(public networks)

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

[a] Primary user group.

Future Prospects

In the prototype version of STEPPS we have decided 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 health care 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 interest of each individual [45,46].

Personalized patient education systems could be employed to promote and 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].

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Chapter 6

Personalized patient education using Internet health resources and EPR data: a pilot evaluation of the STEPPS prototype system

Submitted as:
Doupi P, van Wijk M, van Wijk J, van der Lei J. Personalized Patient Education using Internet health resources and EPR data: a pilot evaluation of the STEPPS prototype system.

Abstract

Objective

Evaluation of the ability of the prototype STEPPS system (STructured Evaluated Personalized Patient Support) to personalize the retrieval of online health information material, on the basis of structured and coded electronic patient record (EPR) data, for the purpose of patient education in burn care after hospital discharge.

Design

Blinded clinician assessment of Web pages retrieved for 27 individual burn patient profiles through three different methods: the STEPPS system for personalized retrieval, random selection and online searches using Google. The reviewers graded the topic and content relevance of the five first Web pages retrieved through each method by assigning a score between 0 (totally irrelevant) and 9 (highly relevant).

Measurements

Mean of average relevance scores across the sets of Web pages identified by each retrieval method for the profiles of the study patients.

Results

A total of 405 Web pages was assessed, 135 pages for each retrieval method. The mean of the average relevance score for STEPPS was 3.50 (SD 2.59), for the chance selection of material 0.53 (SD 1.07) and for Google keyword-based searches 2.62 (SD 2.80). The use of the Mann-Whitney test indicated that the performance of STEPPS was significantly better than that of a random selection of material ($p < 0.001$, $N = 270$), thereby providing evidence of the ‘proof of concept’. STEPPS also performed better than the Google keyword searches for the specific patient test cases ($p = 0.010$, $N = 270$).

Conclusions

We have provided preliminary evidence of the feasibility of the STEPPS approach in achieving personalized retrieval of online health information on the basis of structured and coded EPR data, for the purpose of patient education in burn care.

Introduction

The Internet contains a substantial amount of health-related information that is widely accessed by patients and the general public. A central problem for Internet users is how to best locate among the vast amounts of online content the information that responds to their needs. Web site developers and providers have tried to cater to the need of effective information retrieval through personalization. Although no single definition of the term 'personalization' exists, a common theme in all approaches is the adaptation of content and its presentation to the user needs and context [1]. Web site personalization is based on the creation of user profiles through a combination of information voluntarily entered by users and information captured by their behavior while browsing or interacting with the site [2,3]. This approach, however, is not particularly suitable for applications related to health and medicine due to the sensitivity and privacy issues involved, as web site owners and developers themselves acknowledge [2].

Personalization in the healthcare domain has been explored in the context of patient education where it has been most commonly referred to as 'tailoring' [4]. The adaptation of patient education material to the characteristics of the recipient has been shown to improve patients' knowledge and ability to manage their disease, their decision making process and their satisfaction with health care services and providers [5,6]. Computer-based applications have played a central role in supporting the personalization of patient education material [7]. Even greater benefit could be realized by the ability to utilize electronic patient record (EPR) data as a direct source of the patient – information recipient profile; however, the existing experience on this topic is limited [8]. In addition, although the Internet has been perceived as an important tool for patient education activities, the possibility of using online health information as patient education material has not been explored [9].

Background

STEPPS is a system that personalizes the selection of patient education material collected from online health resources on the basis of structured and coded EPR data that constitute a patient's profile. By 'personalization' in STEPPS we mean that given specific information on a patient case as represented in EPR data, the system is able to identify information material that is more suitable for the particular individual and the problems he/she will be dealing with during the disease process. The prototype version of the system is developed for application in the domain of burn care, with the purpose of facilitating the provision of information to burn patients and their families at the point of discharge from a specialized intensive care unit.

The design and architecture of STEPPS are explained in more detail elsewhere [10]. Here we provide a brief overview of the main system components, which are the following:

a. A Structured Data Entry (SDE) interface that supports the collection of structured and coded EPR data for burn care.

   This module acts as the source of information about the patients and their specific health problems in the form of profiles represented in Unified Medical Language System (UMLS) codes.

b. A collection of over 90.000 Web pages, organized in six thematic sub-collections of topics of relevance for burn patients.

   This collection, which we compiled as a cross-sectional 'snapshot' of available health-related Web content, acts as the source of candidate patient education material.

c. The indexing and matching component, provided by Collexis®.

   The Collexis® software provides the indexing of the Web pages in the STEPPS collection on the basis of the UMLS Meta-thesaurus, generating profiles called 'fingerprints'. Subsequently the system's search engine matches the patient profile against those of the Web pages, to select the most relevant documents among the collection for each specific individual.

The material selected by STEPPS can be presented either in electronic or in print form, but there is no adaptation of content presentation to the user. The additional element that STEPPS assumes for its implementation in healthcare practice is the assessment of the material by clinician reviewers before it is provided to patients.

Aim of this study

This paper reports on a pilot evaluation of the STEPPS prototype system in the domain of burn care. The aim of the evaluation study was to verify that the system achieves its intended task of personalized selection of online health information content. This sort of 'proof of concept' evaluation is an essential step before proceeding to more resource-demanding methods of assessing system performance and its possible impact in healthcare practice settings. In addition, this process generates valuable information for further improvements of the system.

We assumed that the minimum requirement for proving the personalizing ability of STEPPS would be to demonstrate that the system achieves better personalization results than chance, i.e. a random selection of documents. For this purpose, the relevance of the Web pages retrieved by STEPPS from its test

TABLE 1. Study Population – Descriptive Information

Demographics									Information on Health Services Use								
Gender			Age Group*			Nationality			Initial Treatment**			Duration of Hospitalization			Destination Post-Discharge		
	n	%		n	%		n	%		n	%		n	%		n	%
Male	13	48,1	Infant	4	14,8	Dutch	15	55,6	Dutch Hospital	18	66,7	1 week	8	29,6	Home	20	74,1
Female	14	51,9	Child	6	22,2	Foreign	8	29,6	Hospital Abroad	2	7,4	1–2 weeks	5	18,5	Social care	2	7,4
			Adult	13	48,1	Unknown	4	14,8	BCU	5	18,5	2–3 weeks	9	33,3	Deceased	5	18,5
			Elderly	4	14,8				General Practice	2	7,4	> 3 weeks	5	18,5			

Information on Clinical Aspects																	
Etiology†			TBSA‡ (%)			Partial Thickness (%)			Full Thickness (%)			Surgical Procedures (during first hospitalization)			Psycho-social Problems		
	n	%		n	%		n	%		n	%		n	%		n	%
Flame/fire	11	40,7	< 10	14	51,9	< 10	17	63,0	< 10,0	23	85,2	none	13	48,5	Yes	9	33,3
Scald	6	22,2	10–19	6	22,2	10–19	7	25,9	40–49	1	3,7	1	10	37	No	16	59.3
Fat	3	11,1	20–39	2	7,4	20–29	1	3,7	70–79	1	3,7	2	2	7,4	Unknown	2	7,4
Chemical	2	7,4	40–79	3	11,1	30–39	1	3,7	80–89	1	3,7	> 3	2	7,4			
Contact	1	3,7	> 90	2	7,4	> 40	1	3,7	> 90	1	3,7						
Non-burn	3	11,1															
Unknown	1	3,7															

Key to Table 1:
* Infant: 1–23 months; Child: 2–12 years; Adult: 19–64 years; Elderly: 65 years and over.
** BCU: Burn Care Unit
† 'Non-burn' conditions include: inhalation injury without burns; toxic epidermic necrolysis.
‡ TBSA: Total Body Surface Area – the extent of burns as a percentage of the total skin surface area of the patient's body.

collection was compared against the relevance of pages retrieved randomly from the same collection. Further, for an indicative assessment of the system's 'added value' against the currently most commonly used method for online information retrieval, i.e. the use of a search engine with keyword search, we compared the performance of STEPPS with that of a popular search engine, Google. As measurement of personalization we used the averaged relevance score assigned by blinded clinician reviewers to the Web pages retrieved through each method against the corresponding patient profile.

Materials and Methods

Patient cases

A total of 35 case records of patients treated in two of the three specialized burn centers in the Netherlands (Beverwijk and Rotterdam) during the years 2000 and 2001 were selected by local physicians as representative of their centers' usual case mix. One of the authors (PD) extracted data from the original paper records and used the dedicated STEPPS-SDE interface for burn care to populate the system's patient database. Some patients – either because of new burn injury incidents or because of follow-up treatment of the original injury – had more than one admission to the burn centre and therefore more than one records of care. However, only the first record available for each patient was used for the evaluation study, making a total of 27 eligible records (see Table 1 for information on the study population).

Patient profiles

In STEPPS the patient profile is a UMLS-tagged subset of the data contained in the EPR at the time of discharge (see Table 2). The selection of the patient profile characteristics is based on the main elements of the NBIS (in Dutch, Nederlandse Brandwonden Informatie Systeem, i.e. Dutch Burns Information System) data set, excluding sections that are exclusively related to the in-hospital phase of treatment [11]. A similar selection has been used in the indicators of burn case complexity proposed by the British National Burn Care Review Committee [12].

For the purpose of searching with Google we took into account the left-to right assessment of entered keyword terms and re-ordered the characteristics of the patient profile in an order of importance more pertinent to the context of searching for information post-discharge, as follows: terms describing the "Etiology" are listed first, followed by terms describing the "Problems on discharge", then terms describing possible "Complications" and so forth (see also Table 2, p. 104).

TABLE 2. Overview of patient profile characteristics

STEPPS – UMLS Coding	British Burn Association	Patient profile Google search

• Gender
• Age
• Past History
• Accident Data
  • Absence of burns
  • Intention
  • Accident mechanism
  • Place of accident
  • Alcohol and drugs use
  • Violence
  • Etiology group
  • Escharotomy incisions
• Inhalation Injury investigations
• Location & extent of burns
• Conservative Wound Treatment
• Surgical Wound Treatment
• Bacteriology
• Psychology and Psychiatry
• Mortality
• Discharge
  • Advice
  • Problem list
	• Demographic data:
	  • gender
	  • age group
	• Past history (existing conditions at the time of accident)
	• Etiology & mechanism of injury or complex non-burn condition
	• Severity of injury:
	  • extent and location of burns
	  • inhalation injury
	  • complex non-burn
	• Conservative treatment
	• Surgical procedures
	• Complications
	• Problems on discharge
	• Psycho-social aspects:
	  • psychiatric problems
	  • suicide
	  • violence
	  • social problems
		• Etiology & mechanism of injury or complex non-burn condition (including intention)
		• Problems on discharge
		• Complications (during hospitalization)
		• Psycho-social aspects
		• Conservative treatment
		• Surgical procedures
		• Past history
		• Demographics

Review Material

For each of the 27 patient cases in the study we compiled a review binder with the following material:

a. A patient case summary

b. Candidate material for patient education tasks, derived from online resources. A total of fifteen Web pages were allocated to each patient profile, distributed as follows:
   - the first five Web pages retrieved by the STEPPS system, representing the personalized selection of material on the basis of the patient profile;
   - five Web pages randomly selected from the STEPPS collections;
   - the first five Web pages identified through a basic Google search, using keywords reflecting the patient's profile.

c. A review form where reviewers entered their relevance scores for each of the fifteen Web pages under assessment.

Generation of review material

Patient Case Summary

The SDE module of STEPPS has the ability to generate a basic textual overview of the patient record, comprised by a list of the patient attributes selected during data entry and their corresponding values, as well as potential accompanying comments in free text. On the basis of the record overviews, one of the authors (PD) produced the case summaries used in the evaluation study, so as to cover the information related to the patient profile.

STEPPS Web pages

For each patient case, we used STEPPS to match the patient profile against the Web pages in its collections and extracted the first five pages of the results for the evaluation. In cases where the results contained overlapping pages (because of a degree of redundancy among the STEPPS sub-collections), we ignored the duplicate pages and used the next unique page.

Random Web pages

All the Web pages in the STEPPS thematic collections have an identifying number, assigned to them during the downloading and storage process. Using the Random Numbers Generator Data Analysis tool of Excel we produced a list of random numbers that we distributed across the STEPPS sub-collections. We then looked in each sub-collection for the Web page bearing the corresponding number and assigned it to a patient case. If no page was found in the collection (e.g. pages in PowerPoint or .asp format, which were not stored during the downloading phase), we proceeded to the next sub-collection until all patient cases had five Web pages allocated to them.

Google Web pages

We searched through the basic search interface of Google and used as search terms key words corresponding to the patient profile categories. If no results were returned (due to the length of the query), we dropped terms sequentially from the search string in reverse order of their appearance, i.e. first the terms on “Demographics”, then on “Past History” etc. Every time we dropped a term, we ran the modified, shortened query and checked the results. If there were no or less than 5 results returned, we repeated the aforementioned procedure. We halted the search as soon as a query returned a minimum of five or more unique results, which we could then use in the STEPPS evaluation study.

Presentation of review material

To account for the effect of presentation order in the review process, we used the Random Numbers Generator Data Analysis tool of Excel and assigned random numbers to all fifteen Web pages retrieved per patient case. Subsequently we organized the Web pages in ascending order of the random numbers and re-named them as Document 1, Document 2 etc.

We chose to present the Web pages to the reviewers in print rather than on screen, since our primary target was to assess the content of the pages, rather than their presentation or interactivity features. In addition, offering the material in paper form allowed us to easily mask the origin of the page, as well as to account for the varying length of Web pages, by truncating each Web page print out to a length of ten A4 pages.

Review Task

The Web pages identified through the three different retrieval methods were assessed for their relevance by two of the authors who acted as reviewers (MvW, JvW). Both reviewers have a background in general practice and are working in medical informatics, but have not been involved in the design and development of STEPPS. The reviewing process was overseen by a moderator (JvdL). Both the reviewers and the moderator were blinded as to the source of the Web pages under review, the retrieval method by which each page was selected, as well as to the ranking order of the pages by each method (STEPPS and Google).

The reviewers were asked to first read carefully the summary of each patient case. Then they had to assess the corresponding fifteen Web pages as to their topic and content relevance for the given patient profile and assign a score between 0-9 (where 0 = totally irrelevant and 9 = highly relevant).

Each reviewer rated the pages independently and only in case the scores' difference was equal or larger than 3 points, the two reviewers discussed and 'reconciled' their ratings by one of them changing his originally given score.

Data analysis

We used the SPPS statistical package (version 12.5) for the data analysis. We first calculated the average of the scores the two reviewers had given to each Web page. Consequently, we calculated the mean of the average reviewer scores for the pages selected by each retrieval method across the patient cases in the study. Since the assumption of normal distribution was not fulfilled by the data, we used the nonparametric Mann-Whitney test to check the statistic significance of the differences between the mean average scores that each retrieval method had achieved.

Results

The review of the evaluation material took place in two rounds, each completed in approximately five hours, with an interval of two weeks. Fifteen cases were reviewed in the first round and twelve cases in the second round. In total, 405 Web pages were assessed, 135 pages for each retrieval method. The mean of the average relevance score for STEPPS material was 3.5 (SD 2.59), while the randomly selected material had a mean average relevance score of 0.53 (SD 1.07). The material identified through the Google keyword searches had a mean average relevance score of 2.62 (SD 2.80). The performance of both STEPPS and Google was significantly better than that of random selection, with both p-values < 0.001. STEPPS also performed better than Google keyword searches, but with a smaller statistical significance ($p = 0.01$).

Discussion

It is known that users of information resources – both healthcare professionals and laymen – often encounter difficulties mastering all the skills of information search and are thereby not able to fully utilize available resources [13,14]. Methods and applications to support users in information retrieval tasks has been a main research theme in medical informatics. However, much of the work in this area has concentrated on addressing exclusively or primarily the needs of healthcare professionals and as a result has focused on the use of scientific literature or professionally oriented online resources [15,16].

In STEPPS we have approached the problem from the viewpoint of patients and laypersons and have therefore worked with general, non-quality controlled health information resources available online. Other researchers in the area of consumer-oriented Internet health information retrieval have explored approaches based on Natural Language Processing techniques [17,18] and health geomatics [19] but have worked only with a restricted, predefined selection of Web sites and as a result have not tested the systems' ability to personalize selection among a large variety of resources.

The pilot evaluation study we report on in this paper has provided preliminary evidence of the feasibility of a novel approach to personalized patient education, utilizing online health information material selected on the basis of structured and coded EPR data. We have shown that STEPPS has the capacity to make the retrieval of online content more effective in terms of its topical relevance, compared to the experience that is currently available to end users, thereby offering a plausible alternative for health-related information seekers.

In STEPPS, the integration of the EPR with online health-related content facilitates the personalized selection of education material for patients and their families as a direct by-product of clinician documentation activities. By doing so, STEPPS provides a plausible solution to one of the obstacles hindering the success of patient education activities; the lack of suitable tools and materials for availability of information at the point and time of patient-clinician interaction.

Early work on tailored patient education has primarily explored the use of Artificial Intelligence techniques. The resulting systems have been based on the use of knowledge bases containing predefined text messages from which content was selected on the basis of provided rules [20–22]. There were two main problems identified: the complexity of the systems that made them inaccessible to healthcare professionals, and the difficulty of producing and maintaining the library of messages.

In addition, although the use of electronic patient record data had been assumed, it was not actually implemented in an automated fashion and personalization was not studied from the perspective of system performance [23].

STEPPS combines existing tools, either freely or commercially available, in order to produce the desirable personalization functionality, an approach which reduces the level of complexity for the end-user. The use of Web-based health information content as a source of patient education material can provide a plausible alternative to the option of predefined text for personalized messages, thereby reducing the demands on system maintenance. In spite the limitations of quality, online health information material has features that make it attractive for personalized patient education since it is easily updated and suitable for adaptation to the end recipient. In addition, using online content in patient education activities means that the application can be made available to end users beyond limitations of space and time. Enhanced availability is particularly important for conditions such as burn injuries, where expert information may be – and often is – missing locally, while it is central to the patient healing, rehabilitation and recuperation process.

Limitations of the study

An important limitation of this evaluation study is that the relevance assessments of the reviewed Web material were not performed by the intended recipients of system output, i.e. patients themselves. However, since we have used retrospective patient records such an option was not directly available, nor did we deem it necessary for the purposes of prototype evaluation. Moreover, the design of STEPPS has assumed that clinicians need to review the material before it is made available to patients. Through the evaluation study we have gained some initial understanding with regard to the practical demands of material review and we have collected data that can be utilized further in assessing the degree of concordance between professional and patient perceptions of relevance.

The small sample size of patient cases and the limited number of Web pages reviewed per patient case do not allow a more robust statistical analysis in order to examine how patient characteristics and their reflection in patient profiles interrelate with system performance. Further research with larger samples could provide information as to whether system results favor certain patient groups. However, the limiting factor in any such attempt will be the workload and time demands on the reviewers.

Future work

In this study we have assessed the performance of the STEPPS system as a whole. Further studies will be needed in order to clarify the role of each system component and optimize system performance. There is particularly the need to distinguish between the role of the EPR-based patient profile and the matching-indexing algorithm in terms of their contribution and impact on the personalization result.

In order to account for the impact of patient profile variability in the relevance of the selected material, experimentation with profiles of varying lengths and contents should be performed. Such testing would also provide further insight with regard to the desired, as well as achievable granularity of the patient profile for personalization purposes [4].

There is a need to clarify more concretely the role online health information material can play in patient education strategies, by analyzing in more depth its content and quality. A comparison with currently available paper-based patient education materials and their respective strengths and weaknesses in their ability to satisfy individual patient needs would be particularly informative. In the same context, a thorough analysis of the costs and benefits connected with each method of patient education material production should be performed, including the costs for maintenance and update.

Finally, STEPPS has addressed only the personalized selection of online health information content. Presentation of the material is an equally important aspect that should be the object of future research [24].

Conclusions

We have demonstrated the feasibility of the STEPPS approach for patient education in the domain of burn care. Further research will be necessary to optimize system performance, as well as to test its applicability and suitability for other clinical domains. The growing emphasis on disease management programs and self-care initiatives makes such investigations worthwhile.

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General Discussion

General Discussion

This thesis examined the feasibility of a novel strategy for personalized retrieval of patient education material derived from online health information resources, on the basis of structured and coded electronic patient record data. The prototype system we developed in order to demonstrate and test our approach - STEPPS (STructured Evaluated Personalized Patient Support) - addressed the needs of burn care, more specifically the support of patients and their families at the period after discharge from a specialized burn care centre.

In this chapter we discuss our findings and suggest areas where future research can provide further insight.

PART I

The Internet and WWW as a patient education resource

Erroneous information, be it a result of omission or commission, can lead to unwanted, sometimes even life-threatening effects on a person's health. For the purposes of quality assurance and patient safety, material to be used in patient education activities is usually subjected to accreditation procedures [1,2]. Health information available online appears to be problematic in that respect and concerns regarding the potential for public harm were raised from the very early days of health-oriented web sites. Quality criteria for online health information were developed with the aim of counteracting this shortcoming, but their effectiveness and practical impact were not known [3,4].

Our study on prescription medication information offered to the general public through Web resources revealed insufficient adherence to the proposed quality criteria. None of the fourteen web sites eligible for review fulfilled all of the quality requirements. Features considered elementary in print scientific publications, like author identity and references to supporting evidence, were often absent in the documents available online. Even the currency and timeliness of information – claimed to be among the strongest advantages of web publishing – were hard to determine.

An aspect of information quality that we investigated in more detail in this study was comprehensiveness of topic coverage. Although less frequently addressed by quality initiatives, comprehensiveness is important for the ability of a resource to provide answers to topic-specific information needs, as well as for the safety of the provided information. In order to perform the assessment of topic coverage, we defined specific criteria on the basis of the guidelines proposed by regulatory authorities in the European Union and the United States for the provision of necessary information on prescription medication. By applying these comprehensiveness criteria in the review of web site content we discovered that there is a considerable amount of information available online covering issues pertinent to prescription medications and their use. The information, however, is spread over a number of resources, which means that in order to discover it the end user needs to invest extra time and effort.

At the early days of the health Internet when this research was undertaken, search engines had not yet become the standard method for accessing information online. Rather, clearinghouses and directories acted as the starting point of a search, but even locating those suitable for one's area of interest was not an easy task. Navigational problems are still very much part of the Web today, although on a different level of complexity. Search engines are currently leading the area but although they have provided a more easily accessible starting point for the information seeker, they have not reduced the need of mastering information search skills, an area where many users suffer. STEPPS, the prototype system we have developed, proposes a possible method to address this problem.

Our study on prescription medication information was among the early works exploring in more detail the quality of online health information on a specific subject. A number of studies performed since then have covered a variety of medical domains and resulted in similar findings regarding the variable quality of Internet health resources [5]. These findings should not lead directly to the conclusion that online health information is of low quality and hence of no use.

We suggest that one of the possible explanations is the inadequate suitability of quality standards used for print scientific publications to the online environment. The differing scope and features of online vs. print publishing mean that the way these quality criteria have been applied thus far cannot be simply transferred to the online setting. Web publishing raises issues not encountered in print, such as the protection of privacy of information users or the accessibility of the technology used to deliver and present the information content. Overall, the need is emerging to re-assess our understanding and definition of online health information quality, a topic that was the subject of Chapter 2 of this thesis.

Dimensions of quality and trust-building online

Our analysis of the various instruments aimed at assuring online health information quality showed that they reflect notions which stem from distinct conceptual frameworks and value orientations. We distinguished four dimensions of health information quality online: the epistemic, the ethical, the economic and the technological dimension. Our proposal is that all of these dimensions need to be integrated and considered as a whole in order to achieve qualitatively adequate online health resources – an understanding that has thus far eluded health information quality actions and activities.

We also suggest that quality efforts should not focus exclusively on the prevention of harm in the medical sense (which to date has been limited, at least in terms of clearly documented cases) [6]. Rather, other aspects of quality should also be taken into account and effectively supported, for example: the promotion and facilitation of scientific collaboration and the rapid dissemination of research findings, the support of health promoting behaviour at the population level, the encouragement of self-responsibility for health matters and the protection of privacy and confidentiality.

Trust, a determining factor for the impact information has on recipients' beliefs and eventually on their behaviour, has not been explicitly addressed by quality initiatives. Trust and quality are distinct concepts, it is therefore important to clarify how they interrelate. By exploring quality and trust from various perspectives we have provided a framework for further analysis of the proposed quality criteria, in order to assess their ability to facilitate trust building among health web-site users.

As we are progressing towards the vision of synergistic biomedical research, on the one hand and of individualized healthcare on the other, Internet-based technologies are claiming a central role in our daily practices [7]. Information dissemination and exchange, as well as collaboration on the basis of information shared beyond traditionally existing boundaries are becoming more and more commonplace. Hence, issues of quality and trust, as discussed in Chapter 2, are of increasingly fundamental importance to all actors involved: scientists, clinicians, decision-makers, patients and citizens at large.

Structured and coded EPR data for personalized patient education

One of the assumptions underlying this research work was that the EPR (Electronic Patient Record) can be a valuable starting point in the context of personalizing patient education, since the data it contains describe the health issues a particular patient is confronted with. Generally, it is these health issues and problems that trigger a person's quest for information, independent of the means and channels through which one discovers answers to the corresponding questions. Other researchers exploring the possibility of linking EPR data to health information have drawn on Artificial Intelligence methods for user modelling and on natural language processing (NLP) techniques [8,9].

The approach we proposed for utilizing EPR data in the personalisation process and explored in the development of STEPPS was the use of data entered in a *structured and coded* fashion, as part of daily clinical documentation.

The ORCA-SDE knowledge modeling methodology and tools that we used have been developed with the primary goal of ensuring the flexible and intuitive collection of structured data. These features of the ORCA model were also confirmed in the process of modelling a traditionally narrative and free-text-dependent section of any medical record, i.e. the process and findings of physical examination. Transferring the experiences of our experimentation with physical examination modeling to the domain of burn care verified further our observations on model capabilities, but it also provided indications of remaining challenges.

One of the main shortcomings we identified in our work on physical examination was the inability of the modeling approach to account reliably for semantic equivalence. The solution we proposed to problems of semantic equivalence was the use of terminological systems. We proceeded to test this approach in the domain of burn care, using the minimum patient data set agreed upon among Dutch burn care specialists - known as the NBIS set [10].

We found that it is possible to map almost 80% of the minimum patient data set terms to concepts provided in the UMLS Metathesaurus (2001 edition). The granularity of representation, however, is not always optimal, resulting in mapping to broader or narrower terms. Although these are only preliminary results, the use of terminological systems in combination with structured data entry appears to be a promising approach in bridging the distance between clinicians' language of documentation and controlled vocabularies or terminologies. Achieving such a mapping is an important step on the road towards integration of EPR data and information resources [11].

From the viewpoint of personalization, though, it is important to keep in mind that it is not possible to model descriptors of all case-specific features. The best achievable modeling is limited to the description of conceptual entities, one or more of which may apply to a particular patient. At present, the need to express patient or setting-specific detail is served partly through the concepts incorporated in the model and partly by the possibility to specify user-defined views on the model (as we did with the patient profiles in STEPPS, discussed in Part II of the thesis).

PART II

Bringing the components together - the STEPPS Architecture

In developing the pilot version of the STEPPS system we aimed to test the feasibility of a solution to the challenge of personalized retrieval of patient education material. Our work was based on the idea of using existing, but disparate technological solutions, thereby placing the emphasis on discovering means to bring them together and producing a system that would support new functionality. In Chapter 4 we described in more detail the elements required for the STEPPS architecture and presented the issues that must be addressed in their development and integration. These components are the following:

- **Domain-specific SDE interface**
  Understanding the clinical documentation needs of the application domain is an essential starting point in system development. The consensus patient data set for Dutch burn care (NBIS data set) acted as the reference point for our work. We were able to produce a structured data entry model to support the data collection interface of NBIS, expanded only with the addition of a problem and advice list at the time of discharge. We found this expansion necessary in order to cover information present in sections of the record not covered by the minimum data set (such as the information provided by physiotherapists and social workers) but still important in the context of the period after hospital discharge.
- **Patient profiles in UMLS coding**
  In STEPPS the patient profile corresponds to a sub-set of the data present in the EPR, selected on the basis of their descriptive value regarding case severity and corresponding information needs. We mapped the terms that constitute the patient profile to UMLS Metathesaurus concepts, which we then incorporated in the domain model in order to enable the seamless matching between patient data and information material.
- **Knowledge of topics of interest and relevance for the specific targeted domain**
  The approach we used in our work for burn care was primarily based on literature review and experience gathered from local projects concerning the information needs of burn patients. In addition we demonstrated how the Internet in itself has offered us a channel for direct access to end user needs - through reviewing of topic-dedicated web sites, FAQ pages, discussion forums

etc. Currently ongoing research with burn patient focus groups will provide further insight on this subject [12].

- **Collections of online material**
  For the purposes of prototype system development, it is important to ensure control and stability of the Web content used. Therefore, we created an off-line test collection of Web pages aimed to function as a cross-sectional snapshot of a non-trained user's online experience. The identification of health information online that can cover the targeted information needs requires a method for broad searching of Web resources, plus a means for the retrieval, archiving and organization of the selected material. The process we used in STEPPS for the creation of the test collections also brought forward the requirements that tools meant to support these tasks should fulfil, e.g. ability for automated download and storage of identified Web pages, support for search in multiple languages, possibility for automatic update. At the time of development, we were not able to identify a single tool that would provide all these features and consequently we needed to combine the functionality of several tools (Copernic®, w-get, Collexis®).
- **A tool and method for indexing and matching**
  The Collexis® suite integrates both indexing and matching functionalities. By using the vocabulary of choice – in STEPPS the UMLS Metathesaurus (2001 version) Collexis® indexed the Web pages in our collection and subsequently matched their contents to the patient data.

  Earlier applications of the Collexis® tools have been primarily in the area of scientific publishing. Their use in STEPPS was the first experiment in the context of consumer-oriented health information and in combination with the electronic patient record. The advantages we gained were the reduced burden of indexing, as well as the ability for integration with the STEPPS SDE interface, allowing us to create a seamless experience for the end user (as explained in Appendix II).

Accounting for healthcare practice realities

Developing the architecture of STEPPS and identifying the necessary components was only one of the design phases of the system. In a parallel process, we needed to define the configuration of these components, taking specifically into account the realities of health care practice. At least three configuration scenarios were plausible from the viewpoint of system users: burn care personnel, general practitioners and patients. By contrasting the implications and requirements for the implementation of each option against the demands it placed on system development, we selected the approach were the targeted user group is the specialist burn care team. As a result we were able to minimize the burden of responding to security and privacy requirements resulting from the use of EPR data and aimed for a system that could be fitted in the reality of a burn care centre's workflow.

The selection of utilizing Web content as a potential resource for patient education activities also places restrictions in system design and implementation. Prior personalized patient education systems have used local material in print or hypertext form, thereby assuming adequate content quality. More recent attempts utilizing Web-based material have been limited to the provision of predefined links to a selection of accredited resources. STEPPS on the other hand explored the feasibility of using freely available Web material with no predefined selection of the source. We showed that it is possible to utilize a broad selection of online health material for patient education purposes. However, due to the responsibility of healthcare professionals and institutions to ensure the well-being of patients, the content of the provided information must be assessed for its accuracy. As a result, the architecture of STEPPS assumes the appraisal of online material by healthcare professionals, before it is disseminated to patients and their families.

Assessing system performance in personalized selection of health information material

The pilot evaluation study of STEPPS has provided preliminary evidence of the feasibility of our novel approach to personalized patient education, utilizing online health information material selected on the basis of structured and coded EPR data. We have shown that STEPPS achieves its stated goal of personalized retrieval by returning significantly better results than a random selection of Web pages from the system's test collection.

The integration of the EPR with online health-related content facilitates the personalized selection of education material for patients and their families as a direct by-product of regular clinical documentation tasks. By doing so, STEPPS provides a plausible solution to one of the obstacles hindering the success of patient education activities: the lack of suitable tools and materials for availability of information at the point and time of patient-clinician interaction.

It is known that users of information resources -both healthcare professionals and laymen- often encounter difficulties mastering the techniques of effective information search and are thereby not able to fully utilize available resources [13]. STEPPS addresses this problem, since it does not presuppose information search skills on the side of the user. We have also provided indicative evidence that STEPPS has the capacity of making the retrieval of online content more effective in terms of topical relevance compared to the experience that is currently available to end users through a search engine, thereby offering a plausible alternative for health-related information seekers.

Future research

Internet health information

The Internet and World Wide Web are a new medium for information production and dissemination, as well as communication and collaboration. Our knowledge about the best ways to utilize their powers, as well as of their effects (both positive and negative) is still new and in the making – a dynamic process evolving alongside the development of the medium itself.

It is important to determine the beliefs and attitudes that information providers foster on the topic of online health information quality and to increase their awareness concerning electronic publishing requirements. Equally important is the exploration of lay users' perceptions on the usability and usefulness of the suggested quality criteria for health information on the Web.

The framework we have proposed can serve as a tool to guide further deliberations and work both on health information quality and on related aspects of trust. Apprehending the composition of these concepts will help to understand and guide the behaviour of both users and providers of online information as well as to foster warranted trust in online resources. Furthermore, the framework provides a point of reference for the design and implementation of much needed empirical studies on the impact of quality initiatives concerned with online health resources and the consequent effects of those resources on people's health.

Future research will be required to clarify how the epistemic, ethical, economic and technical aspects of online health information and services provision should be configured, and how we may reconcile the tensions between the values within each of these perspectives.

Structured & coded EPR data

The present state of both the physical examination and the STEPPS SDE knowledge models largely reflects the perceptions of their developers. The resulting interfaces for structured data entry still need to be tested and evaluated by clinicians themselves, in real practice settings where valuable feedback can be gathered concerning necessary improvements [14]. The burn-care STEPPS model is currently based on a predominantly medical view of the patient's record. The fact that burn care is a multidisciplinary field means that eventually the needs and topics of interest of all professional groups involved (such as nurses, psychologists, physiotherapists, nutritionists, etc) should be addressed. Expanding the record content to include issues pertinent to other disciplines will necessitate a consensus process among the eventual user groups, as to what data should be included and how it should be recorded.

From the perspective of modeling, further research should provide more robust solutions to issues such as the representation of comparative aspects, the use of substitute terms, the representation of laterality and the indication of terms' context of use.

A more detailed analysis of the results of mapping the STEPPS thesaurus to UMLS could provide further insight into weaknesses and strengths of the model, by studying the semantic relationships now implicit in the model, as they are exemplified in terminological systems. Methods for improving the automation of the initial thesaurus mapping, as well as its future maintenance in view of the evolving terminology and corresponding systems should also be explored, in order to reduce the workload demands for the development and sustained use of a semantically interoperable system.

Although the SDE interface we developed for burn care is bilingual and able to support data collection in both English and Dutch, our mapping work of burn care terms was restricted to English as the working language. In the 2001 version of the UMLS Metathesaurus, the presence of medical terms in Dutch was limited. An exception were terms related to primary care (ICPC coding), but they would have been insufficient to cover the details of a highly specialized domain such as burn care. The 2004 Metathesaurus edition contains Dutch translations of MeSH, ICD-10 and the MedDRA vocabularies therefore it is perhaps possible to explore the mapping of burn care terms to Dutch source vocabularies of UMLS.

STEPPS architecture

Due to the limitations of indexing in Dutch, we were unable to test STEPPS with Dutch language Web resources. In order for the system to be applicable in the local context, experimentation with information in the patients' native language must also be undertaken.

Although we have proven the feasibility of the STEPPS approach, the issue of the scientific and medical correctness of advice available on the Internet remains open. Patients seem to prefer and support the prospect of their caregivers as knowledgeable intermediaries in utilising Web-derived content [15]. Still, the sustainability of the expert-reviewer approach to quality assurance, particularly in terms of time and cost demands, as well as acceptance by healthcare professionals themselves remains to be seen [16]. The personalized health information material produced by our system can be employed to study healthcare professionals' attitudes to this new approach to patient education and contrast them with the opinion of patients.

The architecture of the STEPPS prototype is based on the use of static Web content. Using truly dynamic online content instead might reduce the burden of maintenance, although not without difficulties, as prior experience has indicated [17]. It would, however, place even bigger demands in providing an efficient, fast and reliable method for quality assessment.

STEPPS design

Different implementation scenarios for the STEPPS approach are worth exploring in the future. Making the system available for use in primary care settings could enhance continuity of care and support the GP in patient education tasks that involve a highly specialised area such as burn injuries. The challenges in this approach lie in achieving the integration of specialist and primary care records of the same patient (in terms of structure and content), establishing communication protocols and ensuring the availability and security of the technological infrastructure.

An equally interesting prospect is entrusting the record and system to patients themselves. Offering the patient and his family or caregivers the opportunity to view and update the patient's record, as well as access information at the point and time that they need it would enable them to take a more active role in the care and healing process. On the other hand, such a solution assumes the availability of necessary skills and tools, access to the specialist record or discharge summary, as well as to the primary care record, and satisfactory public network security.

System performance optimization

In the evaluation study we have assessed the performance of the STEPPS system as a whole. Further research will be required for the purpose of clarifying the role of each system component and optimizing system performance. There is particularly the need to distinguish between the role of the EPR-based patient profile and the matching-indexing algorithm in terms of their contribution and impact on the personalization result.

In order to account for the impact of patient profile variability in the relevance of the selected material, experimentation with profiles of varying lengths and contents should be performed. Such testing would also provide further insight with regard to the desired, as well as achievable granularity of the patient profile for personalization purposes [18].

There is a need to clarify more concretely the role online health information material can play in patient education strategies, by analyzing in more depth its content and quality. Moreover, STEPPS has addressed only the personalized *selection* of online health information content. *Presentation* of the material is an equally important aspect that should be the object of future research [19].

A comparison with currently available paper-based patient education materials and their respective strengths and weaknesses in their ability to satisfy individual patient needs would be particularly informative. In the same context, a thorough analysis of the costs and benefits connected with each method of patient education material production should be performed, including the costs for maintenance and update.

Finally, studies exploring the applicability of this approach to other clinical domains would be worthwhile, particularly in the area of chronic diseases, where patient education is acknowledged as an integral part of high-quality care [20].

As information technology applications are becoming increasingly integrated with healthcare practices and Internet-based health information and services abound, new patterns of interaction between healthcare professionals and patients begin to emerge, based on the formation of partnerships [21,22]. Personalized patient education systems could be employed to promote and assist the evolution of this new, co-operative model of health care practice.

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Appendix I

Creating the STEPPS Web pages test collection

Aim of the test collection

After we had identified the main topics of interest for patient education in the domain of burn care (as explained in Chapter 4), we needed to create an offline test collection of Web pages, in order to study and analyze system behavior against controlled, stable material.

The aim was to create a 'snapshot' of the information available on the Internet regarding the corresponding topics, as it would be encountered by a "regular" user of online resources at a specific point in time.

Step 1: Creating Queries

- The starting point assumption was that there is a variety of information sources on the Internet, beyond those specifically targeted to burn patients, which may still contain information of relevance to burn patients and their families or caregivers.

  For example, post-traumatic-stress disorder is associated with a variety of severe physical or psychological traumas, therefore it is not a sequel particular to burn injuries (patients may draw from the experiences of other people facing the same problem, but from a different starting point and perhaps with different coping methods). As a result, we chose to make our searches for Web material rather broad in nature and not specifically limited to burn injuries.
- Results of several studies reporting on analysis of search engines log files indicate that most Internet users do not apply advanced search techniques, such as use of Boolean operators etc. Since we were trying to simulate the experience of a regular user, most of the queries we constructed were limited to one or two words related to the topic of interest.
  - Truncation, which is recommended in order to pick up both singular and plural versions, is not usually supported by all search engines covered by Copernic®, so whenever it was applied less search engines were included in the retrieval process.
  - Boolean operators are also not a default feature of searching with Copernic®. They can be used to *refine* a search, but that means that part of the URLs originally retrieved is then completely removed from the collection. Although that feature saves time for a regular user of Copernic®, in the context of research work it limits the insight into the process of creating the test collection and therefore we did not use it.

Step 2: Running the Queries

We used CopernicPro® to run queries over a variety of commonly used search engines. The list of the search engines and the search modes accepted by each one of them are provided in the list below.

LIST OF SEARCH ENGINES USED BY COPERNIC- PRO®
(Search domain: The Web)

SEARCH ENGINE	OPERATORS	SUPPORTED SEARCH MODES
AltaVista	AND, OR	Quotes, Exact phrase, Update
AOL.com search	AND, OR	Quotes, Exact phrase, Update
CompuServe	AND, OR	Quotes, Exact phrase, Update
FAST search (alltheweb.com)	AND, OR	Quotes, Exact phrase, Update
Google	AND, OR	Quotes, Exact phrase, Update
HotBot	AND, OR	Quotes, Exact phrase, Update
MSN Web Search	AND, OR	Quotes, Exact phrase, Update
Netscape Netcenter	AND, OR	Quotes, Exact phrase, Update
Open Directory Project	AND, OR	Quotes, Exact phrase, Update
Yahoo!	AND, OR	Quotes, Exact phrase, Update
Direct Hit	AND, OR	Update
FindWhat	AND, OR	Update
LookSmart	OR	

The following table provides an overview of the queries we used with Copernic Pro® in collecting candidate Web pages for STEPPS.

**OVERVIEW OF SEARCH QUERIES
USED FOR CREATING THE STEPPS TEST COLLECTIONS OF WEB PAGES**

BURNS (13,858 pages)	PAIN (8,581 pages)	PHYSIO (7,435 pages)	PSYCHO (15,561 pages)	SCAR (26,061 pages)	WOUND (21,630 pages)
• Burn extent: exact • Burn injury: all words, any word, exact • Burn severity: exact • Burn*: all words • Burn* prognosis: all words, exact • Chemical burns: exact • Electrical burns: exact • Heat inhalation: exact • Scald burns: exact • Thermal burns: exact • Thermal injury: all words, exact • Thermal trauma: any word, exact, all words	• Pain: all words • Pain control: all words • Pain relief: exact, all words • Pain management anesthetics: all words • "pain management" burns: all words • pain management burns: all words, exact • pain morphine: all words • burn* pain prevention: exact	• Burns rehabilitation: exact • Burns splinting: exact • Contractures: all words • Mobility regain burn injury: all words • Mobility regain maintain: all words • Occupational therapy: exact • Physiotherapy: all words • Range of motion: exact • ROM exercises: exact • Splinting positions: exact	• Anxiety: all words • Burn injury psychological effects: all words • Burns anxiety: exact • Burns psycho-social support: exact • Deformity: all words • Disfigurement psychological problems: all words, exact • Injury psychological adjustment: all words • Insomnia sleepless: all words, any word • Post-traumatic anxiety: exact • Pos-traumatic depression: any word, exact, all words • Post-traumatic dreams: exact • Post-traumatic insomnia: any word, exact, all words • Post-traumatic stress: exact • Psychological adjustment after injury: exact • Psycho-social support: exact • Sleep disturbances: exact, all words • Stress: all words	• Artificial skin: all words, exact • Burn scars: all words, exact • Burns cosmetic reconstruction: all words • Burns reconstruction: exact • Contractures: all words • Contractures release: all words • Cultivated skin: all words, exact • Cultured skin: all words, exact • Debilitating scars: all words, exact • Dermabrasion: all words • Dermabrasion burns: exact • Emollient creams: all words, exact • Hypertrophic scar: exact, all words • Itching: all words • Jobst: all words • Keloid scar: exact, all words • Laser treatment burns: exact • Plastic surgery burns: exact, all words • Pressure garment*: all words • Pressure garments: exact, all words • Pressure suits: all words • Scar formation: exact • Scar management: all words • Scar maturation: exact • Scar prevention: all words, exact • Scar*, itch*, sweat*: exact • Scarred skin: exact • Scars itching: exact • Scars sweat: exact • Silicone mask: all words, exact	• Burn lesion: all words, exact • Burn primary excision: all words • Burn wound: all words, exact • Burn wound healing: exact • Burn wound management: all words, exact • Burn wound therapy: all words, exact • Burn wound treatment: all words, exact • Burn wound washing: all words • Burn antibacterial crème: all words • Burns changing dressings: all words • Burns debridement: all words • Burns sterile dressings: all words • Burns topical antibacterial agents: all words • Burns wound care: all words, exact • Changing dressings: exact • Debridement: all words • Eschar: all words • Non-adhering dressing: exact • Occlusive dressings: exact, all words • Primary excision: exact • Skin damage: all words, exact • Sterile dressings: exact • Wound care management: all words, exact • Wound healing: exact • Wound management: exact

Step 3: From Copernic-Pro® URLs to Off-Line Collections

Creating lists of unique URLs

- We exported the results of each search run in Copernic® as a cvs. file, which we then imported to an Access database.
- We merged the results of related queries and removed duplicate entries. The URL field of each result, (defined as a text string and not as a hyperlink) was used as a primary key, to avoid duplicate values.
- Subsequently, we merged duplicate-free results across all queries run for the corresponding thematic collection and again removed any identified duplicates, creating a collection of unique Web pages per topic (6 sub-collections in total).

Downloading the Web pages

- We exported the URLs of unique pages from Access.
- URLs were 'fed' to the W-get freeware to download and store the pages locally (files in .asp and .ppt format were not downloaded, neither were any images that were embedded in the Web pages).

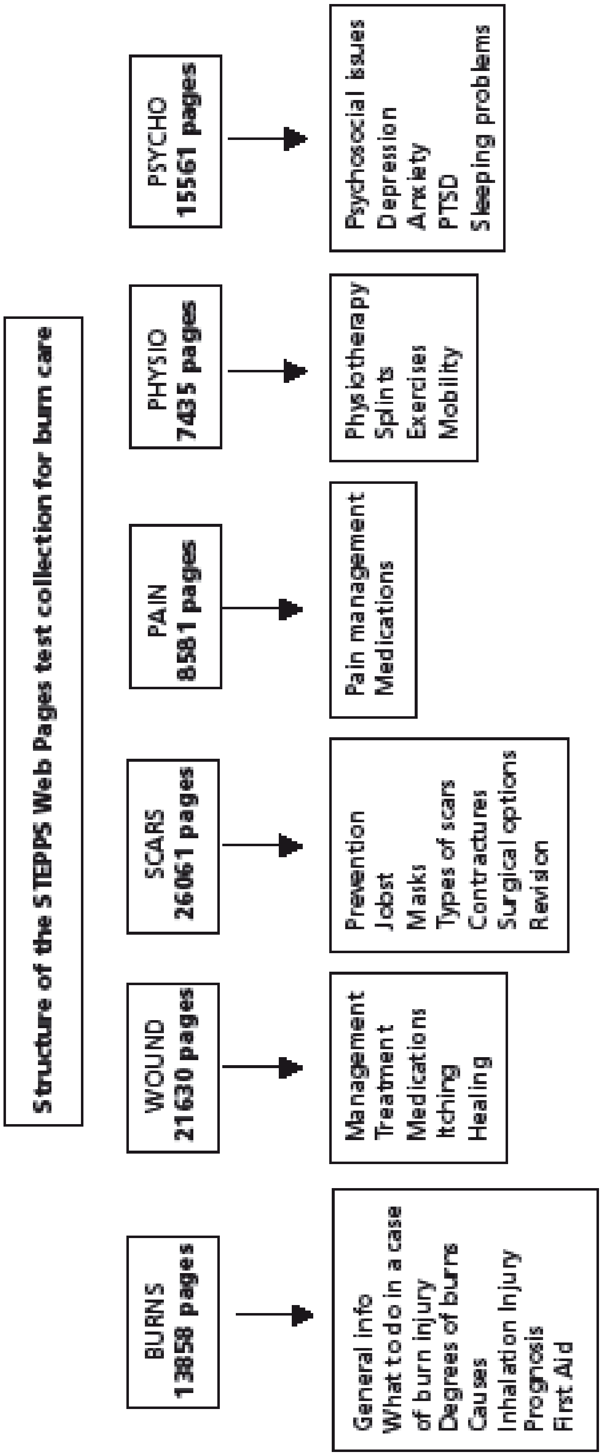
Step 4: Indexing - Creation of Collexis® Catalogues

- The downloaded Web pages were indexed by the ImportBulk tool of Collexis®, using the UMLS Metathesaurus 2001 as the indexing vocabulary.
- The generated 'fingerprints' of each Web page were stored in the corresponding catalogues and links to the locally stored copies of the Web pages were created.

Field Names of Catalogues

	FIELD NAMES	DATA TYPE	DESCRIPTION
1.	ID	AutoNumber	Primary Key Access
2.	Index	Text	Key issued by Copernic
3.	Title	Text	Title of Web page
4.	Address	Hyperlink	URL of page
5.	Description	Text	Page content description
6.	Score	Text	Relevance for specific query
7.	Hit Count	Text	# of search engines that retrieved the page
8.	Date/Time	Text	Date/Time of search
9.	New	Text	New retrieval
10.	Valid	Text	Not applicable
11.	Invalid	Text	Not applicable
12.	Downloaded	Text	Status of page with regard to download
13.	Refined	Text	If original query has been refined
14.	Checked	Text	Not applicable
15.	Visited	Text	Not applicable
16.	Local File	Text	Path to local file (if page downloaded)
17.	Query	Text	Original query submitted to search engines
18.	Type of query	Text	Exact phrase, All words, Any word
19.	Download Date	Text	Date of downloading the page
20.	Cvs. File Name	Text	File where Copernic® results were stored
21.	Address Text	Text	URL in text (to identify duplicates)

The following figure displays the current structure of the STEPPS test collection of Web pages, with some indications of each sub-collection's contents.


Structure of the STEPPS Web Pages test collection for burn care
BURNS 13858 pages
General info
What to do in a case of burn injury
Degrees of burns
Causes
Inhalation Injury
Prognosis
First Aid
WOUND 21630 pages
Management
Treatment
Medications
Itching
Healing
SCARS 26061 pages
Prevention
Jobst
Masks
Types of scars
Contractures
Surgical options
Revision
PAIN 8581 pages
Pain management
Medications
PHYSIO 7435 pages
Physiotherapy
Splints
Exercises
Mobility
PSYCHO 15561 pages
Psychosocial issues
Depression
Anxiety
PTSD
Sleeping problems

Appendix II

Using STEPPS – a case example

Background

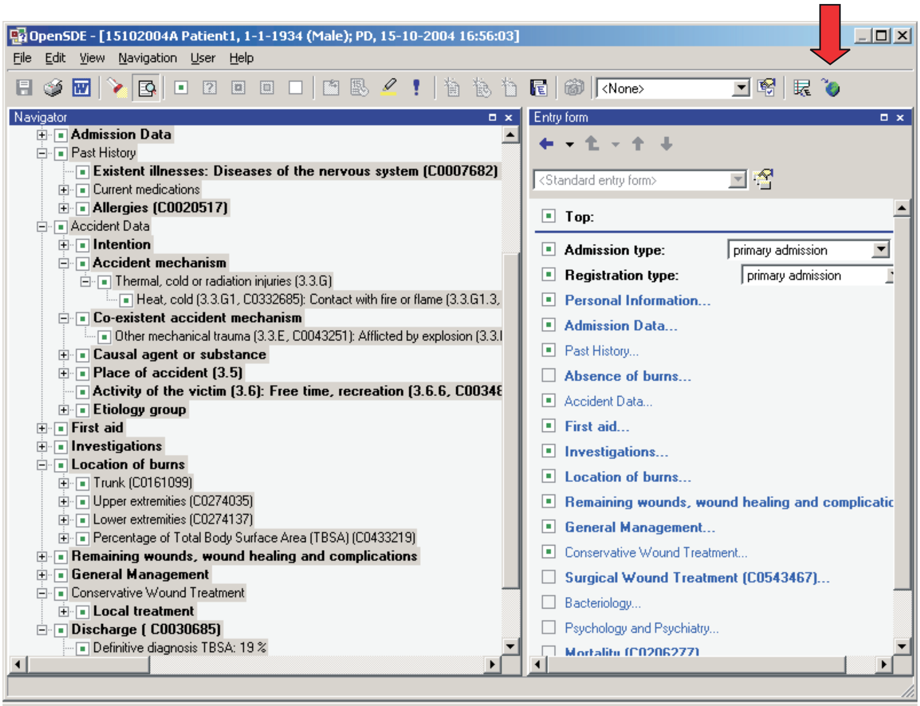
For the link between STEPPS-SDE and Collexis® to function 'seamlessly', Collexis® needs to be already running in the background when the user starts the STEPPS-SDE Wrapper (the tool where patient record data is entered and viewed).

For the matching process, the thesaurus on the basis of which the matching is performed must also be loaded in the Abstraction component of Collexis® (for the STEPPS prototype, the UMLS 2001 Metathesaurus). Then the Collexis® engine is ready for use.

Step 1: Opening the patient record in the STEPPS-SDE Wrapper module

Entry of patient data, as well as viewing and editing of existing data in a patient's record is performed through the STEPPS-SDE Wrapper module. The various features of the Wrapper interface are not presented in detail here. In this example we will use an existing patient record as the starting point.

As it is shown in Figure 1, on the left hand side, the patient's data appears in detail (only entered data). On the right hand side, the user sees an overview of the STEPPS-SDE domain model, indicating which sections contain data in the case of the specific patient (boxes with a green dot in the center).



OpenSDE - [15102004A Patient1, 1-1-1934 (Male); PD, 15-10-2004 16:56:03]

Navigator

- Admission Data
- Past History
  - Existent illnesses: Diseases of the nervous system (C0007682)
  - Current medications
  - Allergies (C0020517)
- Accident Data
  - Intention
  - Accident mechanism
    - Thermal, cold or radiation injuries (3.3.G)
      - Heat, cold (3.3.G1, C0332685): Contact with fire or flame (3.3.G1.3,
  - Co-existent accident mechanism
    - Other mechanical trauma (3.3.E, C0043251): Afflicted by explosion (3.3.I
  - Causal agent or substance
  - Place of accident (3.5)
  - Activity of the victim (3.6): Free time, recreation (3.6.6, C0034
  - Etiology group
- First aid
- Investigations
- Location of burns
  - Trunk (C0161099)
  - Upper extremities (C0274035)
  - Lower extremities (C0274137)
  - Percentage of Total Body Surface Area (TBSA) (C0433219)
- Remaining wounds, wound healing and complications
- General Management
- Conservative Wound Treatment
  - Local treatment
- Discharge (C0030685)
  - Definitive diagnosis TBSA: 19 %

Entry form

- Top:
- Admission type: primary admission
- Registration type: primary admission
- Personal Information...
- Admission Data...
- Past History...
- ☐ Absence of burns...
- Accident Data...
- First aid...
- Investigations...
- Location of burns...
- Remaining wounds, wound healing and complicatic
- General Management...
- Conservative Wound Treatment...
- ☐ Surgical Wound Treatment (C0543467)...
- ☐ Bacteriology...
- ☐ Psychology and Psychiatry...
- ☐ Mortality (C0206277)

FIGURE 1. Screen shot of Patient1 STEPPS record
The arrow points to the button that activates the link to Collexis®.

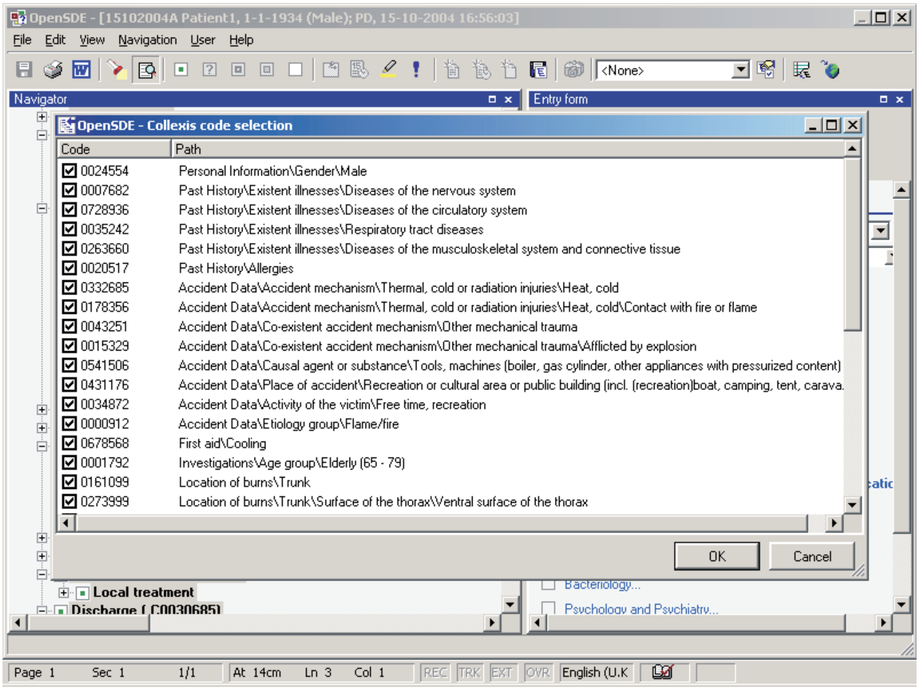
Step 2: Activating the link between STEPPS-SDE and Collexis® – Generating the patient profile fingerprint

When the user clicks on the button that activates the connection between SDE-STEPPS and Collexis® a window containing an overview of the coded items of the record appears, i.e. of the STEPPS patient profile, as shown in Figure 2.

At this stage, it is possible to *manually* de-select codes which are perceived as redundant, incorrect, not relevant etc.

Notice that the text appearing next to the code is ***not*** the corresponding UMLS concept, but rather the term as present in the SDE-STEPPS (the UMLS concept maybe narrower or broader in meaning, i.e. a more or less accurate approximation of the patient record term).

By clicking on the OK button, the fingerprint of the patient's record (the patient profile in STEPPS) is passed on from STEPPS-SDE to the Collexis® engine, where it is used for matching against the fingerprints of the test collection Web pages.

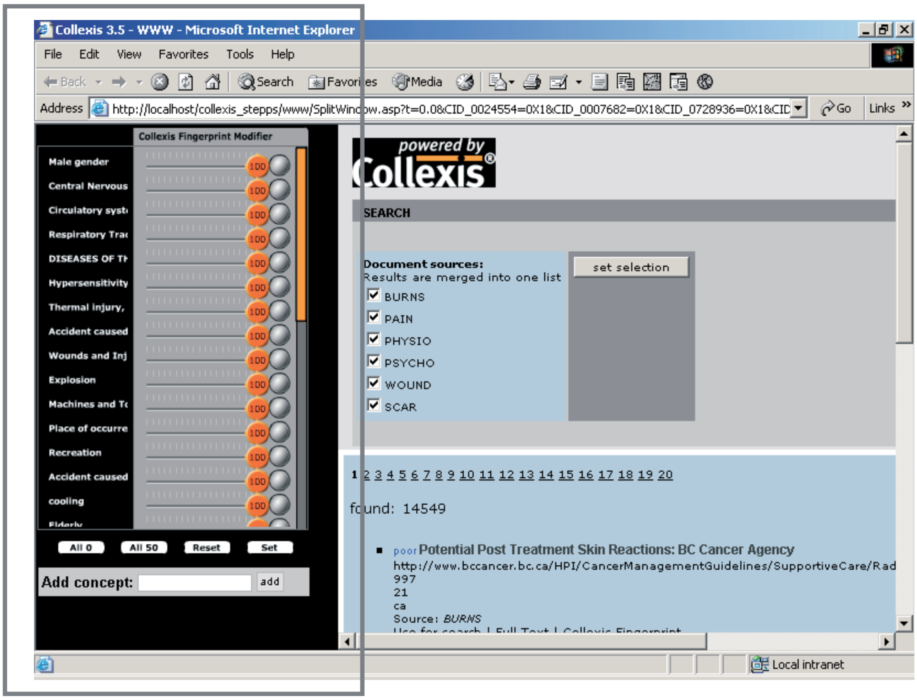


Code	Path
☑ 0024554	Personal Information\Gender\Male
☑ 0007682	Past History\Existent illnesses\Diseases of the nervous system
☑ 0728936	Past History\Existent illnesses\Diseases of the circulatory system
☑ 0035242	Past History\Existent illnesses\Respiratory tract diseases
☑ 0263660	Past History\Existent illnesses\Diseases of the musculoskeletal system and connective tissue
☑ 0020517	Past History\Allergies
☑ 0332685	Accident Data\Accident mechanism\Thermal, cold or radiation injuries\Heat, cold
☑ 0178356	Accident Data\Accident mechanism\Thermal, cold or radiation injuries\Heat, cold\Contact with fire or flame
☑ 0043251	Accident Data\Co-existent accident mechanism\Other mechanical trauma
☑ 0015329	Accident Data\Co-existent accident mechanism\Other mechanical trauma\Afflicted by explosion
☑ 0541506	Accident Data\Causal agent or substance\Tools, machines (boiler, gas cylinder, other appliances with pressurized content)
☑ 0431176	Accident Data\Place of accident\Recreation or cultural area or public building (incl. (recreation)boat, camping, tent, carava
☑ 0034872	Accident Data\Activity of the victim\Free time, recreation
☑ 0000912	Accident Data\Etiology group\Flame/fire
☑ 0678568	First aid\Cooling
☑ 0001792	Investigations\Age group\Elderly (65 - 79)
☑ 0161099	Location of burns\Trunk
☑ 0273999	Location of burns\Trunk\Surface of the thorax\Ventral surface of the thorax

FIGURE 2. The appearance of the STEPPS patient profile, coded in UMLS concept IDs

Step 3: Viewing the matching results

A few seconds later, the results of the matching by Collexis® are displayed in a new window, as shown in the screen shot in Figure 3.



Address: http://localhost/collexis_stepps/www/SplitWindow.asp?t=0.0&CID_0024554=0X1&CID_0007682=0X1&CID_0728936=0X1&CID

Concept	Weight
Male gender	100
Central Nervous	100
Circulatory syst	100
Respiratory Trac	100
DISEASES OF TH	100
Hypersensitivity	100
Thermal injury,	100
Accident caused	100
Wounds and Inj	100
Explosion	100
Machines and To	100
Place of occurre	100
Recreation	100
Accident caused	100
cooling	100

Document sources:
Results are merged into one list
☑ BURNS
☑ PAIN
☑ PHYSIO
☑ PSYCHO
☑ WOUND
☑ SCAR

found: 14549

- poor Potential Post Treatment Skin Reactions: BC Cancer Agency
http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/SupportiveCare/Rad
997
21
ca
Source: *BURNS*

FIGURE 3. Presentation of the matching results screen
The frame highlights the Fingerprint modifier area of the window.

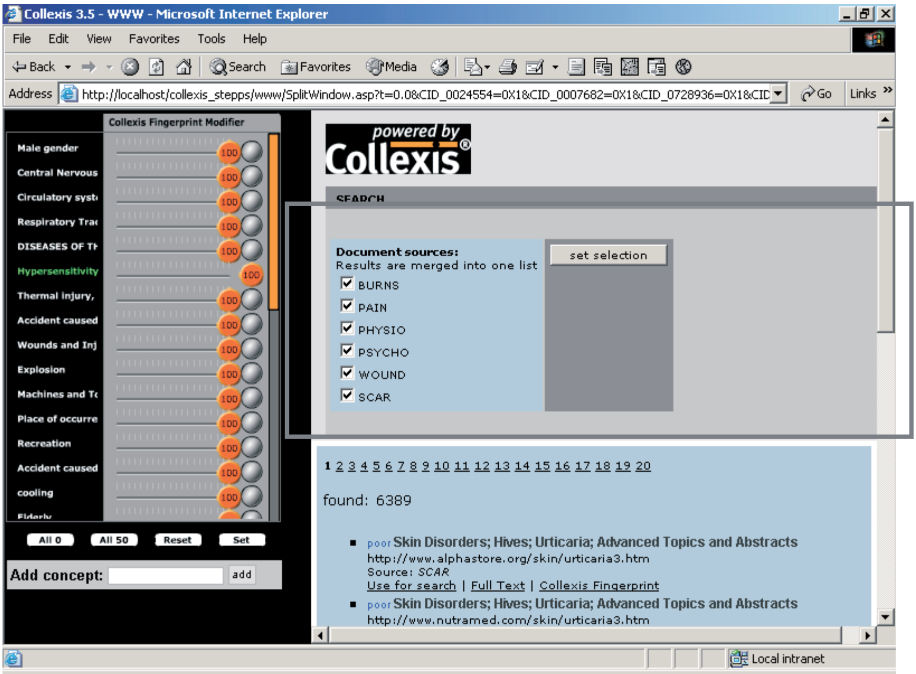
The Fingerprint modifier

On the left window panel, the fingerprint used for the search is displayed (Figure 3). In this case, this is the fingerprint of the STEPPS patient record or patient profile.

Here the weight of all concepts is set to 100, since there has been no prior indexing of the patient record terms by Collexis®

Manual manipulation of the fingerprint is possible, like it is demonstrated in the example in Figure 4 (p. 146): here the concept "Hypersensitivity" has been set as an absolute requirement.

The effect is a shifting of the retrieved results emphasis towards documents concerning allergic type reactions, as well as a reduction in the number of matched documents.



http://localhost/collexis_stepps/www/SplitWindow.asp?t=0.0&CID_0024554=0X1&CID_0007682=0X1&CID_0728936=0X1&CID

Document sources:
Results are merged into one list

☑ BURNS
☑ PAIN
☑ PHYSIO
☑ PSYCHO
☑ WOUND
☑ SCAR

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

found: 6389

- poor **Skin Disorders; Hives; Urticaria; Advanced Topics and Abstracts**
  http://www.alphastore.org/skin/urticaria3.htm
  Source: *SCAR*
  Use for search | Full Text | Collexis Fingerprint
- poor **Skin Disorders; Hives; Urticaria; Advanced Topics and Abstracts**
  http://www.nutramed.com/skin/urticaria3.htm

FIGURE 4. The results of a search where the term 'Hypersensitivity' has been set as an absolute requirement for the matching

Selecting the targeted document collection(s)

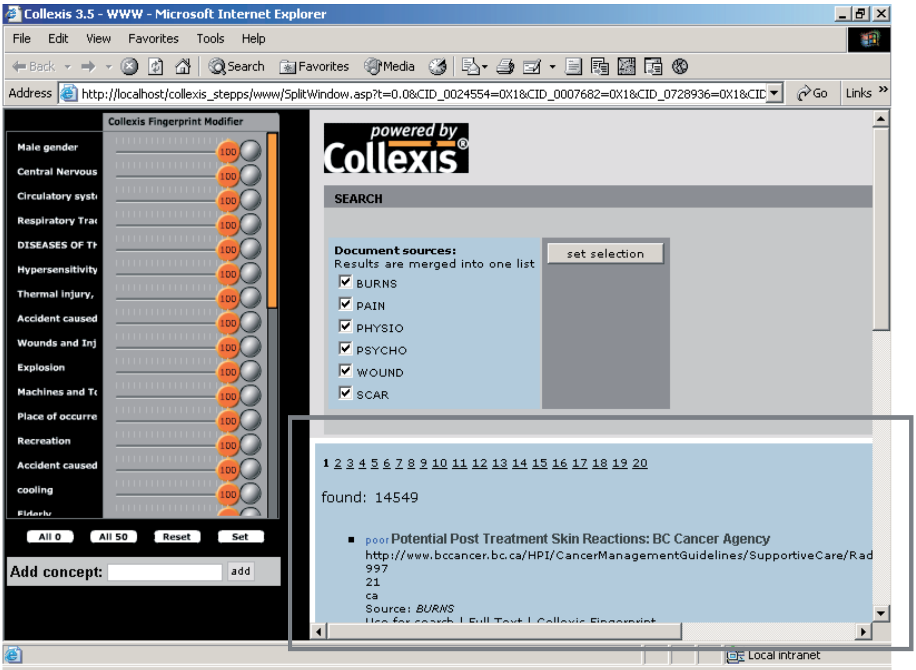
On the upper half of the right window panel in Figure 4, highlighted by a frame, we can see the document collections from which the matching documents were retrieved.

In this example, all of the STEPPS test collections have been used, therefore they are all checked.

The user can choose to de-select collections which are not perceived as relevant for a specific or more focused search.

Exploring the matching results

In the lower half of the right window panel, highlighted by a frame in Figure 5, the actual results of the matching process are displayed.



Collexis 3.5 - WWW - Microsoft Internet Explorer

Address http://localhost/collexis_stepps/www/SplitWindow.asp?t=0.0&CID_0024554=0X1&CID_0007682=0X1&CID_0728936=0X1&CID

Add concept:

Document sources:
Results are merged into one list

☑ BURNS
☑ PAIN
☑ PHYSIO
☑ PSYCHO
☑ WOUND
☑ SCAR

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

found: 14549

- poor **Potential Post Treatment Skin Reactions: BC Cancer Agency**
  http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/SupportiveCare/Rad
  997
  21
  ca
  Source: *BURNS*

FIGURE 5. Presentation of the matching results screen, where the corresponding panel has been highlighted

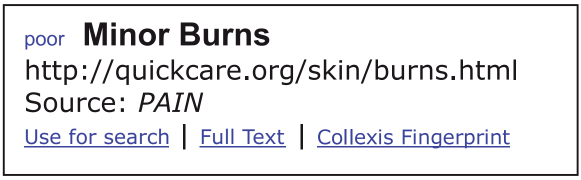
At the top, the user sees the total number of matching documents that were identified, in this case 14,549 documents.

By using the scroll bar on the right, the user can view the returned results, displayed in batches of ten. To browse through the batches, one can use the link to the corresponding display page.

Through the “entry” of each document in the results screen, several pieces of information are provided, as well as options for further steps.

A closer look to the results entries

Here we analyze in more detail a document or Web page entry as displayed in the results window.



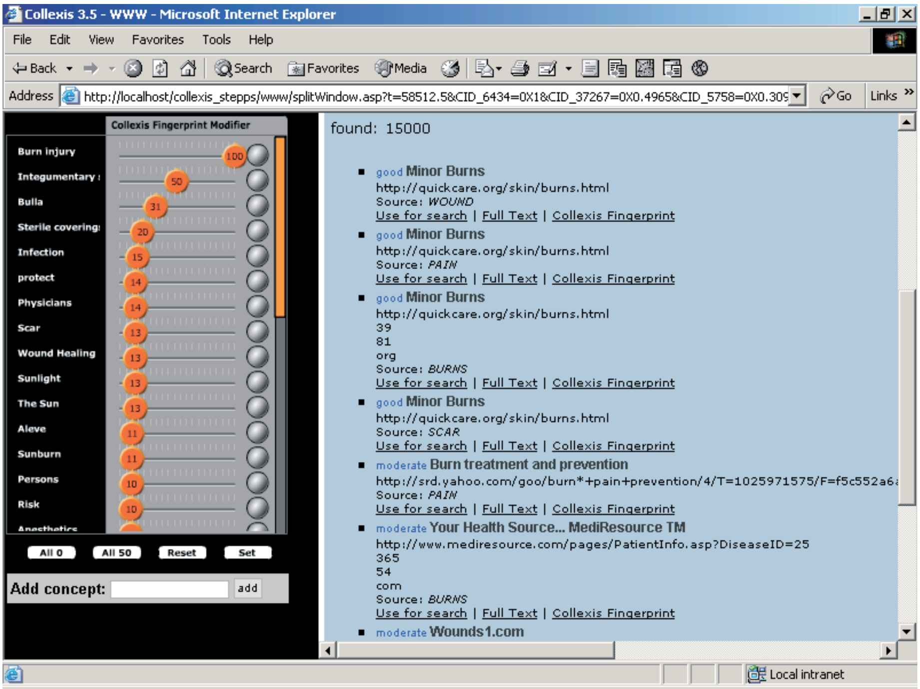
poor **Minor Burns**
http://quickcare.org/skin/burns.html
Source: *PAIN*
Use for search | Full Text | Collexis Fingerprint

poor :	indicates the quality of the matching between the search fingerprint and the fingerprint of the document, as assessed by the Collexis® engine. In the pilot STEPPS version, it is likely that the quality will often be indicated as poor, due to the non-weighted fingerprint of the patient record.
Minor Burns	Title of the corresponding Web page in the collection.
http://quickcare.org/skin/burns.html	URL of the corresponding Web page
Source: *PAIN*	Source collection in which the document can be found; in this example PAIN (for pain-related issues).

The last line of the entry provides several options for follow-up actions:

Use for search | Full Text | Collexis Fingerprint

Use for search By clicking on this link, the fingerprint of the chosen document will be used as the search fingerprint, so that related documents will be retrieved, as shown in Figure 6.



http://localhost/collexis_stepps/www/splitWindow.asp?t=58512.5&CID_6434=0X1&CID_37267=0X0.4965&CID_5758=0X0.309

Burn injury	100
Integumentary :	50
Bulla	31
Sterile covering:	20
Infection	15
protect	14
Physicians	14
Scar	13
Wound Healing	13
Sunlight	13
The Sun	13
Aleve	11
Sunburn	11
Persons	10
Risk	10
Anesthetics	

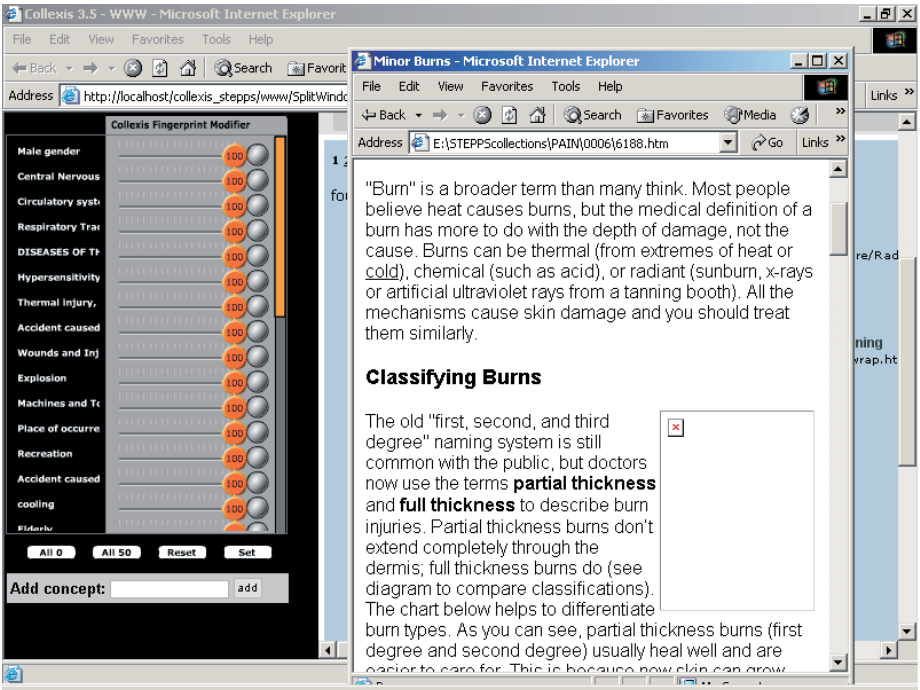
found: 15000

- good **Minor Burns**
  http://quickcare.org/skin/burns.html
  Source: *WOUND*
  Use for search | Full Text | Collexis Fingerprint
- good **Minor Burns**
  http://quickcare.org/skin/burns.html
  Source: *PAIN*
  Use for search | Full Text | Collexis Fingerprint
- good **Minor Burns**
  http://quickcare.org/skin/burns.html
  39
  81
  org
  Source: *BURNS*
  Use for search | Full Text | Collexis Fingerprint
- good **Minor Burns**
  http://quickcare.org/skin/burns.html
  Source: *SCAR*
  Use for search | Full Text | Collexis Fingerprint
- moderate **Burn treatment and prevention**
  http://srd.yahoo.com/goo/burn*+pain+prevention/4/T=1025971575/F=f5c552a6
  Source: *PAIN*
  Use for search | Full Text | Collexis Fingerprint
- moderate **Your Health Source... MediResource TM**
  http://www.mediresource.com/pages/PatientInfo.asp?DiseaseID=25
  365
  54
  com
  Source: *BURNS*
  Use for search | Full Text | Collexis Fingerprint
- moderate **Wounds1.com**

FIGURE 6. Screen shot of the matching results of a search based on the fingerprint of one of the original results documents

Observe the difference between the fingerprint of this document (the terms of which have weights assigned to them) and the fingerprint of the patient record in Figure 3 (p. 145), where all terms have equal weights.

Full Text Clicking on this link opens in a new window the corresponding Web page of the collection, as shown in Figure 7:



"Burn" is a broader term than many think. Most people believe heat causes burns, but the medical definition of a burn has more to do with the depth of damage, not the cause. Burns can be thermal (from extremes of heat or cold), chemical (such as acid), or radiant (sunburn, x-rays or artificial ultraviolet rays from a tanning booth). All the mechanisms cause skin damage and you should treat them similarly.

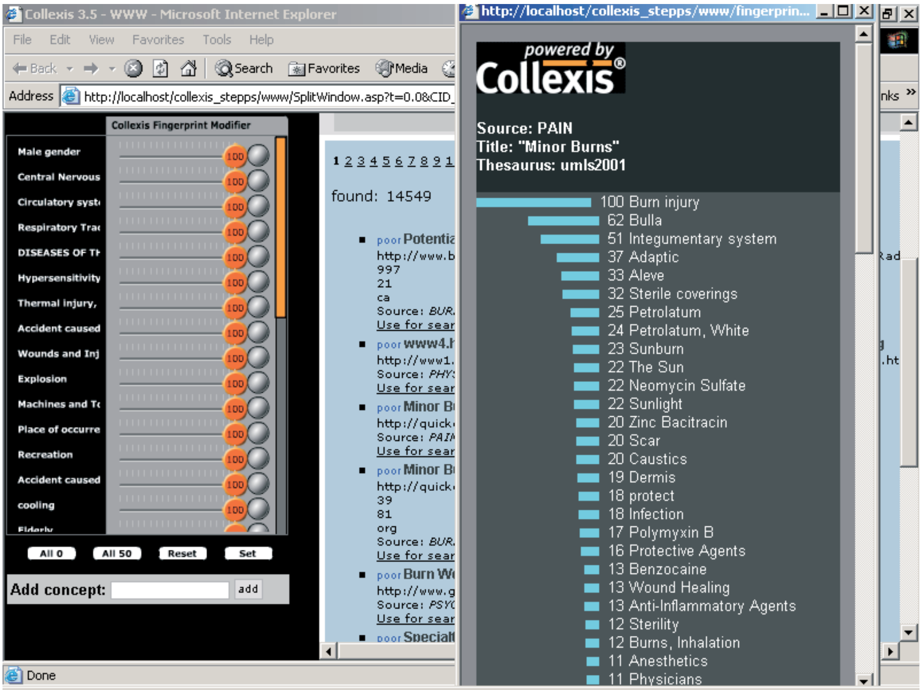
Classifying Burns

The old "first, second, and third degree" naming system is still common with the public, but doctors now use the terms **partial thickness** and **full thickness** to describe burn injuries. Partial thickness burns don't extend completely through the dermis; full thickness burns do (see diagram to compare classifications). The chart below helps to differentiate burn types. As you can see, partial thickness burns (first degree and second degree) usually heal well and are easier to care for. This is because new skin can grow

FIGURE 7. Screen shot of the full-text page for one of the matching results documents

Collexis® Fingerprint

Clicking on the Collexis® fingerprint link, opens in a new window the fingerprint of the selected document (in this case, Web page) that has been created by the Collexis® indexing tool (Figure 8).



Source: PAIN
Title: "Minor Burns"
Thesaurus: umls2001

100 Burn injury
62 Bulla
51 Integumentary system
37 Adaptic
33 Aleve
32 Sterile coverings
25 Petrolatum
24 Petrolatum, White
23 Sunburn
22 The Sun
22 Neomycin Sulfate
22 Sunlight
20 Zinc Bacitracin
20 Scar
20 Caustics
19 Dermis
18 protect
18 Infection
17 Polymyxin B
16 Protective Agents
13 Benzocaine
13 Wound Healing
13 Anti-Inflammatory Agents
12 Sterility
12 Burns, Inhalation
11 Anesthetics
11 Physicians

FIGURE 8. Screen shot of the Collexis® fingerprint window for one of the documents in the matching results

Summary

Summary

For patients and their carers, information seeking and processing is an integral part of managing disease or coping with a health condition. Traditionally, healthcare professionals have been expected to function as the main information resource through patient education activities. The Internet and World Wide Web have opened up a new and frequently used channel for accessing health-related information. Although online health information has limitations, primarily in terms of quality and ease of navigation, it also presents characteristics which – when fully exploited – make the Web a good candidate source for patient education purposes. These characteristics include currency of material and easiness of update, adaptation to variable audiences, ability to access the information at the time and place it is needed, and opportunity to consult supplementary information resources. An additional quality that makes online health information a suitable candidate for inclusion in patient education strategies is the ability for personalization. Personalization or tailoring of content has been one of the desiderata of patient education strategies, as an effective response to the fact that individual patients have differing information needs. Thus far, though, the possibility of utilizing Web content in patient education activities has not been explored.

This thesis examines the feasibility of a novel strategy for personalized patient education, where material derived from online health information resources is selected on the basis of structured and coded electronic patient record data. When data is entered in the electronic patient record, a profile of the patient is automatically generated and used in retrieving among a collection of Web pages the ones most relevant for the characteristics of the specific individual. The prototype system we developed in order to demonstrate and test our approach – STEPPS (STructured Evaluated Personalized Patient Support) – addresses the needs of burn care, more specifically the support of patients and their families at the period after discharge from a specialized burn care centre.

The thesis is divided into two parts. In Part I, comprising Chapters 1 to 3, we explore online health information quality and the challenges of knowledge representation in supporting the collection of structured and coded electronic patient record (EPR) data. In Part II, comprising Chapters 4-6, we address various facets of the problem of integrating EPR data and Internet health information for the purpose of personalized retrieval of patient education material. Our examples and experiences are drawn from the design, development and evaluation of the prototype STEPPS system for burn care. The last chapter, General Discussion, reviews our findings and suggests target areas for future research.

Part I

In *Chapter 1* we report on a study where we use information on prescription medications as a focus area to explore the impact of quality criteria for online health information on web sites targeted to the general public. Our results reveal insufficient adherence to the proposed quality criteria: none of the fourteen web sites we review fulfil all of the quality requirements. We argue that these findings should not lead directly to the conclusion that online health information is of low quality and hence of no use. We suggest that another possible explanation is the inadequate suitability of quality standards used for scientific publications to information available in the online environment.

An aspect of health information quality that we investigate in more detail in this study is comprehensiveness of topic coverage as an indicator of both a resource's ability to provide answers to topic-specific information needs and also of the safety of the provided information. By applying comprehensiveness criteria in the review of web site content we discover that there is a considerable amount of relevant information available online. This information, however, is spread over a number of resources, demanding of the end user both advanced information search skills, as well as an investment of extra time and effort in order to locate it. STEPPS, the prototype system we have developed, proposes a possible method to facilitate the process of identifying relevant information.

For a number of years, considerable efforts have been placed in creating and refining criteria and other methods meant to ensure the quality of health information on the Internet. However, a systematic and comprehensive analysis of the concept of quality in the online environment has not been undertaken. Likewise, the element of trust – a crucial factor for the impact of information on the recipient- has not yet been addressed in the context of online health-related information. In the work reported in *Chapter 2* of the thesis, we attempt to clarify the origins, nature and interrelations of the quality dimensions underlying the proposed health information quality criteria, in order to assist further progress in the area. In addition, we aim (a) to clarify the relationship between quality of online health information and trust, and (b) to determine whether the proposed initiatives are actually contributing to the development of trust or whether further adjustments are necessary. We distinguish four dimensions of health information quality online: the epistemic, the ethical, the economic and the technological dimension. We argue that all of these dimensions need to be integrated and considered as a whole in order to achieve qualitatively adequate online health resources. In addition, by exploring quality and trust and their interrelation from various perspectives, we provide a framework for further analysis of the proposed quality criteria and assessment of their ability to facilitate trust building among health web site users.

One of the assumptions underlying this research work is that the electronic patient record can be a valuable starting point for personalizing patient education; the data in the record describe the health issues a particular patient is confronted with. The approach we propose for utilizing EPR data in the personalization process and explore in the development of STEPPS is the use of data entered in a *structured and coded* fashion, as part of daily clinical documentation. We use the ORCA-SDE knowledge modeling methodology and tools that have been developed with the primary goal of ensuring flexible and intuitive collection of structured data. *Chapter 3* reports on our work on physical examination, where one of the main shortcomings we identify is the inability of the modeling approach to account reliably for semantic equivalence. The solution we propose to problems of semantic equivalence is the use of terminological systems. We have tested this approach in the domain of burn care, using the minimum patient data set agreed upon among Dutch burn care specialists. We have found that it is possible to map almost 80% of the minimum data set terms to concepts provided in the UMLS Metathesaurus (2001 edition). The granularity of representation, however, is not always optimal, resulting in mapping to broader or narrower terms. Although these are only preliminary results, the use of terminological systems in combination with structured data entry appears to be a promising approach in bridging the distance between clinicians' language of documentation and controlled vocabularies. Achieving such a mapping is an important step on the road towards integration of EPR data and information resources.

Part II

In developing the prototype version of the STEPPS system we have aimed to test the feasibility of a novel solution to the challenge of personalized retrieval of patient education material. In *Chapter 4* we describe in more detail the elements required by the STEPPS architecture and present the issues that must be addressed in their development and integration. The components of the STEPPS architecture are the following:

1. **An EPR interface for collection of structured and coded data.**

For the burn-care interface of STEPPS we have expanded the minimum data set with non-medical aspects that are relevant for the patient's course after discharge. During system development, we have tagged the terms that constitute the patient's profile with UMLS Metathesaurus concept codes that enable the automated matching between patient data and information material.

2. Collections of relevant online health information material.
We have identified central topics of interest for burn patient education and using meta-search software we have created a collection of Web pages, indexed on the basis of the UMLS Metathesaurus.

3. A tool for indexing and matching.
We have used the Collexis® suite that integrates both indexing and matching functionalities. The benefits are the reduced burden of indexing the collection of online materials, as well as the ability for integration with the STEPPS SDE interface that has allowed us to create a seamless experience for the end user. When a patient's data is entered through the SDE interface of STEPPS, the matching engine of Collexis® accepts as input the UMLS codes of the patient profile, and retrieves among the Web pages present in the system collections the ones that are most relevant for the specific individual.

Identifying and developing the necessary components for the architecture of STEPPS was only one of the design phases of the system. In a parallel process, which we discuss in *Chapter 5* of the thesis, we needed to define the configuration of these components from the viewpoint of system users, taking specifically into account the realities of health care practice environments. We have selected the specialist burn care team as the targeted user group for the system prototype. As a result we have been able to minimize the burden of responding to security and privacy requirements resulting from the use of EPR data.

Utilizing Web content as a resource for patient education activities also places restrictions on system design and implementation. In STEPPS we explore the feasibility of using freely available Web material with no predefined selection of the source. We show that it is possible to utilize a broad range of online health material for patient education purposes. However, due to the responsibility of healthcare professionals and institutions to ensure the well-being of patients, the content of the provided information must be assessed for its accuracy. As a result, the architecture of STEPPS assumes the appraisal of online material by healthcare professionals, before it is offered to patients and their families.

Chapter 6 of this thesis reports on the pilot evaluation study of STEPPS. This formative evaluation study has provided preliminary evidence of the feasibility of our novel approach to personalized patient education, utilizing online health information material selected on the basis of structured and coded EPR data. We have shown that STEPPS achieves its stated goal of personalized retrieval by returning significantly better results than a random selection of Web pages from the system's test collection.

We have also provided indicative evidence that STEPPS has the capacity of making the retrieval of online content more effective in terms of topical relevance compared to the experience that is currently available to end users through a search engine, thereby offering a plausible alternative for health-related information seekers.

The Internet and World Wide Web are still a comparatively new medium for information production and dissemination, as well as for communication and collaboration. As information technology applications are becoming increasingly integrated with healthcare practices and Internet-based health information and services abound, new patterns of interaction between healthcare professionals and patients begin to emerge, based on the formation of partnerships. Personalized patient education systems such as STEPPS could be employed to promote and assist the evolution of this new, co-operative model of health care practice.

Samenvatting

Samenvatting

Voor patiënten en hun verzorgers is het zoeken van informatie een integraal onderdeel van het omgaan met een ziekte. Traditioneel wordt van zorgverleners verwacht dat ze optreden als belangrijkste bron van informatie door het geven van voorlichting aan patiënten. Het Internet en het World Wide Web hebben een nieuw en frequent gebruikt kanaal geopend om zorggerelateerde informatie op te zoeken. Alhoewel online zorg informatie beperkingen heeft, met name in termen van kwaliteit van informatie en gemak van navigatie, heeft het ook karakteristieken die – wanneer ze volledig worden benut – het Web een goede kandidaat maken voor patiëntenvoorlichting. Deze karakteristieken omvatten de mogelijkheid om het materiaal actueel te houden door het frequent te wijzigen, het aanpassen van de informatie aan verschillende doelgroepen, het raadplegen van de informatie vanaf de plaats en op het moment waar dat nodig is, en de mogelijkheid aanvullende informatiebronnen te raadplegen. Een extra eigenschap die online zorginformatie een geschikte kandidaat maakt voor een rol in patiëntenvoorlichting is de mogelijkheid de informatie toe te snijden op het individu. Het toesnijden van informatie op de behoefte van een individuele patiënt is al lang een wens bij het geven van voorlichting; het geeft een antwoord op de verschillen die er bestaan in de informatiebehoefte van verschillende patiënten. Tot nu toe is echter de mogelijkheid van het gebruiken van informatie beschikbaar op het Web in het kader van patiëntenvoorlichting nog niet onderzocht.

Dit proefschrift onderzoekt de mogelijkheden van een nieuwe strategie voor het geven van geindividualiseerde patiëntenvoorlichting waarbij het materiaal uit online informatie bronnen wordt geselecteerd op basis van de gestructureerde en gecodeerde informatie in een elektronische patiënten dossier. Wanneer gegevens worden ingebracht in het elektronische patiënten dossier, dan wordt automatisch een profiel van de patiënt aangemaakt. Dit profiel wordt gebruikt om uit een collectie Web pagina's de voor de patiënt meest relevante informatie te selecteren. Het prototype systeem dat we ontwikkelden om de haalbaarheid van onze aanpak te demonstreren en testen – STEPPS (STructured Evaluated Personalized Patient Support) – richt zich op de zorg voor brandwonden; in het bijzonder op het ondersteunen van patiënten en hun families in de periode nadat de patiënt ontslagen is uit een gespecialiseerde brandwondencentrum.

Dit proefschrift bestaat uit twee delen. In **Deel I**, bestaande uit de *Hoofdstukken 1* tot en met *3*, onderzoeken we de kwaliteit van online informatie. Ook gaan we in op de uitdagingen op het gebied van kennis representatie wanneer we gestructureerde en gecodeerde gegevens in het elektronische patiënten dossier willen opslaan. In **Deel II**, bestaande uit de **Hoofdstukken 4** tot en met *6*, gaan we in op verschillende aspecten van de problematiek die aan de orde is wanneer we data in het elektronische dossier willen benutten om geindividualiseerde voorlichtingsmateriaal te vinden op het Internet. Onze voorbeelden en ervaring zijn gebaseerd op het ontwerpen, ontwikkelen en evalueren van het prototype systeem STEPPS voor brandwonden zorg. Het laatste Hoofdstuk, *General Discussion*, vat onze bevindingen samen en geeft suggesties voor onderzoek in de toekomst.

Deel I

In **Hoofdstuk 1** doen we verslag van een studie waarin we, met geneesmiddelen als focus, de impact van kwaliteitscriteria voor online zorginformatie op web sites voor het algemene publiek exploreren. Onze resultaten laten een slechte adherentie aan de voorgestelde kwaliteitseisen zien: geen van de veertien onderzochte sites voldeed aan alle kwaliteitseisen. We beargumenteren dat deze bevindingen niet onmiddellijk moeten leiden tot de conclusie dat online informatie van slechte kwaliteit is en bijgevolg nutteloos. We geven in overweging dat een andere mogelijke verklaring gelegen is in het feit dat de kwaliteitseisen die we stellen aan wetenschappelijke literatuur mogelijk niet geschikt zijn voor de omgeving van het Internet.

Een onderdeel van de kwaliteit van de zorginformatie die we in deze studie nader onderzochten is de volledigheid van informatie. Wij gebruiken volledigheid als een indicator voor enerzijds de mogelijkheid van een site om onderwerpspecifieke informatie te geven en anderzijds voor de veiligheid van die informatie. Door het toepassen van volledigheidscriteria bij het beoordelen van de inhoud van web sites ontdekten we dat er een substantiële hoeveelheid relevante informatie online beschikbaar is. Deze informatie, echter, is verspreid over meerdere bronnen. Hierdoor wordt er van de gebruiker geavanceerde kennis geëist over het zoeken naar informatie op het Internet en extra tijd om deze bronnen te lokaliseren. STEPPS, het prototype dat we ontwikkelden, geeft een mogelijke alternatieve methode om het proces van het vinden van relevante informatie te ondersteunen.

In de afgelopen jaren is een substantiële hoeveelheid tijd en energie besteed aan het creëren en verfijnen van criteria en methoden om de kwaliteit van informatie op het internet te beoordelen. Een systematische analyse van het concept kwaliteit van online informatie ontbreekt. Ook het element van vertrouwen – een cruciale factor voor de invloed die informatie heeft op de ontvanger van die informatie – is nog nooit benaderd in de setting van online gezondheidsinformatie. In **Hoofdstuk 2** van dit proefschrift exploreren we de oorspong, aard en relatie tussen de verschillende dimensies van kwaliteit voor online informatie. Verder pogen we (a) de relatie tussen kwaliteit van online zorginformatie en vertrouwen te verhelderen, en (b) na te gaan of de huidige initiatieven daadwerkelijk bijdragen aan vertrouwen of dat aanpassing noodzakelijk is. We onderscheiden vier dimensies van kwaliteit: de epistemologische, ethische, economische en technologische dimensie. We argumenten dat deze dimensies geïntegreerd moeten worden en als een geheel moeten worden gezien. Daarnaast geven we door het exploreren van kwaliteit en vertrouwen, en hun interrelatie, een kader voor verder onderzoek naar de kwaliteitscriteria en de beoordeling van hun vermogen om vertrouwen op te bouwen bij gebruikers van zorggerelateerde web sites.

Een van de aannames die ten grondslag ligt aan dit onderzoek is dat het elektronisch patiënten dossier een waardevol startpunt kan zijn voor het toesnijden van informatie op een individuele patiënt; de data in dat dossier beschrijven de specifieke omstandigheden waar de patiënt mee wordt geconfronteerd. De aanpak die we voorstellen voor het gebruiken van gegevens in dat dossier om informatie toe te snijden op een individuele patiënt is het vastleggen van gestructureerde en gecodeerde gegevens als deel van de routine documentatie van zorg. We maken gebruik van de ORCA-SDE methodologie die als primair doel heeft een flexibele en intuïtieve verzameling van gestructureerde informatie mogelijk te maken. In **Hoofdstuk 3** doen we verslag van een studie waarbij het lichamelijk onderzoek centraal staat; we laten zien dat één van de tekortkomingen van de methodologie bestaat uit het onvermogen om op betrouwbare wijze rekening te houden met semantische equivalentie. De oplossing die we voorstellen voor deze problematiek van semantische equivalentie is het gebruik maken van terminologie systemen. We analyseren deze aanpak op het gebied van brandwonden waarbij we gebruik maken van de minimale data set die is beschreven door de Nederlandse brandwonden specialisten. We stellen vast dat het mogelijk is bijna 80% van deze minimale data set af te beelden op de concepten zoals beschreven in de UMLS (Unified Medical Language System) Metathesaurus (editie van 2001). De granulariteit van de representatie is echter niet altijd optimaal met als gevolg het afbeelden naar bredere of smallere termen. Alhoewel het hier uitsluiten initiële resultaten betreft lijkt het gebruik van terminologie systemen in combinatie met gestructureerde data invoer een mogelijke brug tussen de taal van de clinicus in het documenteren van zorg en gecontroleerde vocabulaires. Het overbruggen van deze kloof is een belangrijke stap op weg naar de integratie van elektronische patiënt dossier en informatie bronnen.

Deel II

Bij het ontwikkelen van het prototype STEPPS was het doel het testen van de haalbaarheid van een nieuwe aanpak van het zoeken naar geindividualiseerde voorlichtingsmateriaal. In **Hoofdstuk 4** beschrijven we in meer detail de architectuur van STEPPS en bespreken we de onderwerpen die aan de orde zijn bij ontwikkeling en integratie. De onderdelen van de STEPPS architectuur zijn de volgende:

1. **Een gebruikersinterface voor het elektronische patiënten dossier die gestructureerde en gecodeerde gegevensinvoer mogelijk maakt.**

Voor het domein brandwonden hebben we de minimale dataset van de specialisten uitgebreid met niet-medische aspecten die relevant zijn voor de patiënt na ontslag. Bij de ontwikkeling van het systeem voegen we aan data van de patiënt codes uit de UMLS Metathesaurus toe met als doel een automatische vergelijking van patiënt gegevens met informatie bronnen mogelijk te maken.

2. **Een collectie van relevant online voorlichtingsmateriaal.**

We identificeren onderwerpen die van belang zijn voor brandwonden patiënten en gebruiken meta-zoek software om een collectie van Web pagina’s samen te stellen die vervolgens geïndexeerd zijn op basis van de UMLS Metathesaurus.

3. **Gereedschap voor indexeren en vergelijken.**

We gebruiken de faciliteiten voor indexeren en vergelijken die beschikbaar zijn in Collexis®. De voordelen zijn een eenvoudiger indexering van het beschikbare materiaal en de integratie met de STEPPS SDE interface waardoor we voor de eindgebruiker een naadloze overgang kunnen creëren.

Wanneer de gegevens van een patiënt ingevoerd worden in de SDE interface van STEPPS, dan accepteert de zoekmachine van Collexis® de UMLS coderingen die aan de patiënt zijn toegekend en worden de pagina’s die het meest relevant zijn voor deze patiënt geselecteerd.

Identificeren en ontwikkelen van de noodzakelijke componenten voor de STEPPS architectuur was slechts een deel van het ontwikkelproces. Parallel daaraan, zoals beschreven in **Hoofdstuk 5** van dit proefschrift, moeten we de configuratie van deze componenten bepalen vanuit het perspectief van de eindgebruiker met bijzondere aandacht voor de omgeving waarin de zorg zich afspeelt. Als doelgroep van eindgebruikers van het systeem nemen we de brandwonden specialisten die de patiënt behandelen. Door deze keuze zijn de privacy en security eisen die het gevolg zijn van het gebruiken van patiëntgegevens uit elektronische dossiers minimaal.

Het gebruik van materiaal beschikbaar op het Web voor patiëntenvoorlichting legt ook beperkingen op aan ontwerp en implementatie van het systeem. In STEPPS onderzoeken we de haalbaarheid om vrij beschikbare informatie van het Web te gebruiken zonder vooraf een selectie van bronnen te maken. We laten zien dat het in principe mogelijk is een breed scala aan informatie te gebruiken voor patiëntenvoorlichting. De verantwoordelijkheid van artsen en instellingen noopt tot een beoordeling van het gevonden materiaal. STEPPS gaat er daarom van uit dat artsen of andere deskundigen het gevonden materiaal beoordeelen voordat het beschikbaar wordt gesteld aan patientën en hun familie.

In **Hoofdstuk 6** van dit proefschrift doen we verslag van een initiële evaluatie van STEPPS. Deze formatieve evaluatie geeft preliminair bewijs van de haalbaarheid van onze aanpak om patiëntenvoorlichting toegesneden op het individu op het Web te selecteren op basis van gestructureerde en gecodeerde data in het elektronische patiënten dossier. We laten zien dat STEPPS uit een collectie Web pagina's in vergelijking met random geselecteerde pagina's uit dezelfde collectie betere resultaten geeft. Daarnaast, laten we indicatief bewijs zien dat STEPPS, in vergelijking met nu gangbare zoekmachines, effectiever is; daarmee wordt een plausibel alternatief gegeven voor zorg-gerelateerd zoeken.

Het Internet en het World Wide Web zijn relatief nieuwe media voor het produceren en verspreiden van informatie, alsmede ook voor communicatie en samenwerking. Nu het toepassen van informatie technologie in toenemende mate geïntegreerd wordt met zorgverlening en internetgebaseerde informatie en diensten toenemen, zullen nieuwe patronen van interactie tussen zorgverleners en patiënt ontstaan. Systemen zoals STEPPS die het mogelijk maken patiëntenvoorlichting op het individu toe te snijden zouden kunnen worden aangewend om de evolutie van nieuwe, coöperatieve vormen van zorg te stimuleren en te ondersteunen.

Περίληψη

Περίληψη

Για τους ασθενείς και για εκείνους που τους παρέχουν φροντίδα, η αναζήτηση και κατανόηση πληροφοριών είναι αναπόσπαστο μέρος της διαχείρησης της ασθένειας ή της διαβίωσης με ένα χρόνιο πρόβλημα υγείας. Κατά παράδοση, οι επαγγελματίες υγείας αναμενόταν να λειτουργήσουν ως η κύρια πηγή πληροφόρησης, μέσω δραστηριοτήτων εκπαίδευσης των ασθενών. Το Διαδίκτυο (Internet) και ο Παγκόσμιος Ιστός (World Wide Web) άνοιξαν ένα καινούργιο και δημοφιλές κανάλι για την πρόσβαση σε πληροφορίες υγείας. Παρ'όλο που οι πληροφορίες υγείας που διατίθενται στο Διαδίκτυο παρουσιάζουν συγκεκριμένους περιορισμούς, κυρίως από πλευράς ποιότητας και ευκολίας εντοπισμού, ταυτόχρονα διαθέτουν χαρακτηριστικά που – εφόσον αξιοποιηθούν πλήρως – καταστούν τον Παγκόσμιο Ιστό ενδιαφέρουσα πηγή υλικού για την εκπαίδευση ασθενών. Στα χαρακτηριστικά αυτά συμπεριλαμβάνονται η επικαιρότητα και ευκολία ανανέωσης του περιεχομένου, η προσαρμοστικότητα στις ανάγκες μιας ποικιλίας παραληπτών, η ευχέρεια πρόσβασης στις πληροφορίες στον χρόνο και τόπο όπου είναι απαραίτητες, καθώς και η δυνατότητα χρησιμοποίησης συμπληρωματικών πηγών ενημέρωσης. Μία επιπλέον ιδιότητα που ανάγει την ηλεκτρονική, διαδικτυακή πληροφορία υγείας σε κατάλληλο υποψήφιο για ένταξη σε προγράμματα εκπαίδευσης ασθενών είναι η δυνατότητα για εξατομίκευση. Η εξατομίκευση ή προσαρμογή του περιεχομένου στα χαρακτηριστικά του τελικού αποδέκτη είναι ένας από τους επιθυμητούς στόχους των προγραμμάτων εκπαίδευσης ασθενών, σαν αποτελεσματική ανταπόκριση στο γεγονός ότι κάθε ένας ασθενής έχει διαφορετικές ανάγκες πληροφόρησης. Μέχρι σήμερα ωστόσο, η δυνατότητα αξιοποίησης διαδικτυακού περιεχομένου σε προγράμματα εκπαίδευσης ασθενών δεν έχει διερευνηθεί.

Η διατριβή αυτή εξετάζει τη δυνατότητα υλοποίησης μιας καινοτόμου τεχνικής για την εξατομικευμένη επιλογή υλικού για την εκπαίδευση ασθενών, προερχόμενου από διαδικτυακές πηγές πληροφόρησης, στη βάση δομημένων και κωδικοποιημένων δεδομένων από τον ηλεκτρονικό φάκελο του ασθενούς. ‘Οταν τα δεδομένα εισάγονται στον ηλεκτρονικό φάκελο, το “προφίλ” του ασθενούς δημιουργείται αυτόματα και εν συνεχεία χρησιμοποιείται για να επιλεγούν ανάμεσα από μια συλλογή ιστοσελίδων εκείνες που παρουσιάζουν τη μέγιστη συνάφεια προς τα χαρακτηριστικά του συγκεκριμένου ατόμου. Το πρωτότυπο σύστημα που αναπτύξαμε προκειμένου να επιδείξουμε και να δοκιμάσουμε την μέθοδο που προτείνουμε – το σύστημα STEPPS (ακρώνυμο από τα Αγγλικά: STructured Evaluated Personalized Patient Support – Δομημένη Αξιολογημένη Εξατομικευμένη Υποστήριξη Ασθενών) απευθύνεται στις ανάγκες του τομέα της φροντίδας εγκαυματιών, πιο συγκεκριμένα στην υποστήριξη των ασθενών και των οικείων τους στην περίοδο που ακολουθεί την έξοδό τους από εξειδικευμένες

μονάδες περίθαλψης εγκαυμάτων.

Η διατριβή χωρίζεται σε δύο μέρη. Στο Πρώτο Μέρος, που απαρτίζεται από τα Κεφάλαια 1 έως 3, διερευνούμε την ποιότητα των πληροφοριών υγείας στο Διαδίκτυο, καθώς και τις προκλήσεις της αναπαράστασης γνώσης με στόχο την υποστήριξη της συλλογής δομημένων και κωδικοποιημένων στοιχείων στον ηλεκτρονικό φάκελο του ασθενούς. Στο Δεύτερο Μέρος, αποτελούμενο από τα Κεφάλαια 4 έως και 6, αναλύουμε διάφορες πτυχές του προβλήματος της διασύνδεσης δεδομένων από τον ηλεκτρονικό φάκελο του ασθενούς και διαδικτυακής πληροφορίας υγείας, με σκοπό την εξατομικευμένη επιλογή εκπαιδευτικού υλικού για τους ασθενείς. Τα παραδείγματα και οι εμπειρίες που χρησιμοποιούμε προέρχονται από το σχεδιασμό, την ανάπτυξη και την αξιολόγηση του πρωτότυπου συστήματος STEPPS για τον τομέα των εγκαυμάτων. Το τελικό κεφάλαιο, Γενικός Σχολιασμός, ανακεφαλαιώνει τα ευρήματά μας και προτείνει αντικείμενα ως στόχους μελλοντικών ερευνών.

ΜΕΡΟΣ ΠΡΩΤΟ

Στο **Κεφάλαιο 1** παραθέτουμε μία μελέτη στην οποία χρησιμοποιήσαμε τις πληροφορίες που αφορούν φάρμακα χορηγούμενα αποκλειστικά με ιατρική συνταγογράφηση προκειμένου να διερευνήσουμε την απήχηση των κριτηρίων ποιότητας για την διαδικτυακή πληροφορία υγείας σε ιστότοπους που απευθύνονται στο ευρύ κοινό. Τα αποτελέσματά μας αποκαλύπτουν ανεπαρκή υιοθέτηση των προτεινόμενων κριτηρίων ποιότητας: κανένας από τους δεκατέσσερεις συνολικά ιστότοπους που αναλύσαμε δεν πληρούσε όλες τις προϋποθέσεις ποιότητας. Υποστηρίζουμε πως τα ευρήματα αυτά δεν θα πρέπει να οδηγήσουν απευθείας στο συμπέρασμα ότι η πληροφορία υγείας στο Διαδίκτυο είναι χαμηλής ποιότητας και άρα μη αξιοποιήσιμη. Προτείνουμε πως μια άλλη πιθανή ερμηνεία έγκειται στην ανεπαρκή καταλληλότητα των κριτηρίων ποιότητας που εφαρμόζονται σε επιστημονικού χαρακτήρα έντυπες δημοσιεύσεις για την αξιολόγηση πληροφοριών που διατίθενται στο Διαδίκτυο.

Μία παράμετρος της ποιότητας πληροφορίας υγείας που εξετάζουμε σε μεγαλύτερο βάθος στη μελέτη αυτή είναι η πληρότητα της κάλυψης του γνωστικού αντικειμένου, ως δείκτης της ικανότητας μιας πηγής πληροφόρησης να προσφέρει απαντήσεις στις πληροφοριακές ανάγκες που αφορούν σε ένα συγκεκριμένο θέμα, όπως και της ασφάλειας της παρεχόμενης πληροφορίας. Εφαρμόζοντας κριτήρια πληρότητας στην ανάλυση διαδικτυακού πληροφοριακού υλικού διαπιστώσαμε πως υπάρχει σημαντικός όγκος χρήσιμων πληροφοριών στο Διαδίκτυο. Αυτές οι πληροφορίες ωστόσο είναι διασκορπισμένες σε μια πληθώρα ιστοτόπων, γεγονός που απαιτεί από τον τελικό χρήστη αφ’ ενός ανεπτυγμένες ικανότητες αναζήτησης πληροφοριών, αφ’ ετέρου επιπλέον επένδυση χρόνου και προσπάθειας προκειμένου να τις εντοπίσει. Το STEPPS, το πρωτότυπο σύστημα που αναπτύξαμε, προτείνει μια πιθανή μέθοδο απλοποίησης της διαδικασίας εντοπισμού χρήσιμων πληροφοριών.

Επί σειρά ετών, σημαντικές προσπάθειες καταβλήθηκαν με στόχο τη δημιουργία και εκλεπτυσμό κριτηρίων και άλλων μεθόδων που αποσκοπούν στη διασφάλιση της ποιότητας της πληροφορίας υγείας στο Διαδίκτυο. Παρ' ολ' αυτά, μια συστηματική και πλήρης ανάλυση της έννοιας της ποιότητας στο περιβάλλον του Διαδικτύου δεν είχε πραγματοποιηθεί. Αντίστοιχα, το στοιχείο της εμπιστοσύνης – ένας καθοριστικός παράγοντας για την επίδραση της πληροφορίας στον αποδέκτη – δεν είχε διερευνηθεί στο πλαίσιο της διαδικτυακής πληροφορίας υγείας. Στην εργασία που παρατίθεται στο **Κεφάλαιο 2** της διατριβής, αποπειρούμεθα να αποσαφηνίσουμε τις πηγές, τη φύση και τους συσχετισμούς των διαστάσεων της ποιότητας στις οποίες βασίζονται τα προτεινόμενα κριτήρια πληροφοριών υγείας, με σκοπό να υποβοηθήσουμε την περαιτέρω πρόοδο στον τομέα αυτό.

Επιπλέον, στοχεύουμε α) να διευκρινήσουμε τη σχέση ανάμεσα στην ποιότητα της διαδικτυακής πληροφορίας υγείας και την εμπιστοσύνη και β) να προσδιορίσουμε κατά πόσο οι προτεινόμενες πρωτοβουλίες ποιότητας συμβάλλουν πραγματικά στην ανάπτυξη εμπιστοσύνης ή κατά πόσο περαιτέρω αναπροσαρμογές είναι απαραίτητες. Διακρίνουμε τέσσερεις διαστάσεις της ποιότητας διαδικτυακής πληροφορίας υγείας: την επιστημολογική, την ηθική, την οικονομική και την τεχνολογική διάσταση. Υποστηρίζουμε πως όλες αυτές οι διαστάσεις πρέπει να ενοποιηθούν και να αντιμετωπιστούν ως σύνολο προκειμένου να επιτευχθεί επαρκής ποιότητα στις διαδικτυακές πηγές πληροφόρησης. Επιπλέον, διερευνώντας την ποιότητα και την εμπιστοσύνη καθώς και τους συσχετισμούς τους από διάφορες απόψεις, παραθέτουμε ένα πλαίσιο για περαιτέρω ανάλυση των προτεινόμενων κριτηρίων ποιότητας, καθώς και για την αξιολόγηση της ικανότητάς τους να προωθούν την ανάπτυξη σχέσεων εμπιστοσύνης ανάμεσα στους διαδικτυακούς τόπους υγείας και τους επισκέπτες τους.

Μία από τις υποθέσεις που στηρίζουν την ερευνητική εργασία αυτής της διατριβής είναι πως ο ηλεκτρονικός φάκελος ασθενών μπορεί να αποτελέσει ένα πολύτιμο σημείο εκκίνησης για την εξατομίκευση της εκπαίδευσης ασθενών · τα δεδομένα στον φάκελο περιγράφουν τα προβλήματα υγείας που αντιμετωπίζει ένας συγκεκριμένος ασθενής. Η προσέγγιση που προτείνουμε για την αξιοποίηση των δεδομένων του ηλεκτρονικού φακέλου ασθενούς στη διαδικασία εξατομίκευσης, και εν συνεχεία διερευνούμε στην ανάπτυξη του συστήματος STEPPS, είναι η χρήση δεδομένων που εισάγονται σε δομημένη και κωδικοποιημένη μορφή, στα πλαίσια της καθημερινής καταγραφής κλινικών στοιχείων. Χρησιμοποιήσαμε τη μεθοδολογία αναπαράστασης γνώσης και τα συναφή εργαλεία ORCA-SDE, τα οποία έχουν αναπτυχθεί με πρωταρχικό στόχο τη διασφάλιση της εύκαμπτης και διαισθητικής συλλογής δομημένων δεδομένων. Το **Κεφάλαιο 3** καλύπτει το έργο μας στο αντικείμενο της φυσικής εξέτασης του ασθενούς, όπου ένας από τους περιορισμούς που διαπιστώσαμε ήταν η αδυναμία της συγκεκριμένης μεθόδου αναπαράστασης ιατρικής γνώσης να αντιμετωπίσει ζητήματα νοηματικής ισοδυναμίας. Η λύση που προτείνουμε για τα προβλήματα νοηματικής ισοδυναμίας είναι η χρήση ορολογικών συστημάτων. Δοκιμάσαμε αυτή την προσέγγιση στον τομέα της φροντίδας εγκαυμάτων, κάνοντας χρήση του ελάχιστου συνόλου δεδομένων ασθενούς (minimum data set) που έχουν προσδιορίσει Ολλανδοί ειδικοί στον τομέα των εγκαυμάτων. Ανακαλύψαμε πως είναι δυνατό να αντιστοιχιστεί περίπου το 80% των όρων του ελάχιστου συνόλου σε έννοιες που παρέχονται από τον Μετα-θησαυρό του UMLS [Unified Medical Language System – Ενοποιημένο Σύστημα Ιατρικής Ορολογίας] (έκδοση 2001). Ο βαθμός λεπτομέρειας στην αναπαράσταση, ωστόσο, δεν είναι πάντοτε ιδανικός, με αποτέλεσμα την αντιστοίχηση είτε σε ευρύτερες, είτε στενότερες έννοιες. Παρ’ όλο που τα αποτελέσματά μας είναι προκαταρκτικά, η χρήση ορολογικών συστημάτων σε συνδυασμό με τη δομημένη συλλογή (ιατρικών) δεδομένων φαίνεται να αποτελεί μια ενδιαφέρουσα προσέγγιση στη γεφύρωση της απόστασης ανάμεσα στη γλώσσα των κλινικών και τα ελεγχόμενα λεξιλόγια. Η επίτευξη μιας τέτοιας αντιστοίχησης είναι ένα σημαντικό βήμα στην πορεία προς την ολοκλήρωση των δεδομένων του ηλεκτρονικού φακέλου ασθενούς με πηγές πληροφόρησης.

ΜΕΡΟΣ ΔΕΥΤΕΡΟ

Με την ανάπτυξη του πρωτότυπου συστήματος STEPPS στοχεύσαμε να δοκιμάσουμε την δυνατότητα πραγματοποίησης μιας πρωτότυπης λύσης στην πρόκληση της εξατομικευμένης ανάκτησης υλικού εκπαίδευσης ασθενών. Στο **Κεφάλαιο 4** περιγράφουμε με περισσότερη λεπτομέρεια τα στοιχεία που απαιτούνται για την αρχιτεκτονική του STEPPS και παρουσιάζουμε τα θέματα που πρέπει να επιλυθούν στην ανάπτυξη και ολοκλήρωσή τους. Τα επιμέρους τμήματα της αρχιτεκτονικής του STEPPS είναι τα ακόλουθα:

1. ***Ένα πρόγραμμα για την συλλογή δομημένων και κωδικοποιημένων δεδομένων στον Ηλεκτρονικό Φάκελο του Ασθενούς.***

Για την εφαρμογή του STEPPS στον τομέα των εγκαυμάτων επεκτείναμε το ελάχιστο σύνολο δεδομένων με μη ιατρικές πληροφορίες που είναι σημαντικές για την πορεία ανάρρωσης του ασθενούς μετά την έξοδό του από το νοσοκομείο. Στα πλαίσια της ανάπτυξης του συστήματος, εφοδιάσαμε τους όρους που αποτελούν το προφίλ του ασθενούς με κωδικούς εννοιών από τον Μετα-θησαυρό του συστήματος UMLS. Κατ’ αυτό τον τρόπο ενεργοποιείται το αυτόματο ταίριασμα ανάμεσα στα δεδομένα του ασθενούς και το πληροφοριακό υλικό.

2. Συλλογές συναφούς διαδικτυακής πληροφορίας υγείας

Εντοπίσαμε θέματα κεντρικού ενδιαφέροντος για την εκπαίδευση ασθενών με εγκαύματα και κάνοντας χρήση προγραμμάτων μετα-αναζήτησης δημιουργήσαμε μια συλλογή (συναφών) δικυο-σελίδων, οι οποίες εν συνεχεία καταλογοποιήθηκαν στη βάση του Μετα-θησαυρού UMLS.

3. ’Ενα εργαλείο για την καταλογοποίηση και αντιστοίχηση πληροφοριών

Χρησιμοποιήσαμε τα εργαλεία της οικογένειας προϊόντων Collexis® τα οποία συνδυάζουν λειτουργικότητα καταλογοποίησης και αντιστοίχησης (ταιριάσματος) πληροφοριών, καθώς και τη δυνατότητα της ενσωμάτωσης στο πρόγραμμα δομημένης συλλογής δεδομένων (Structured Data Entry – SDE) του STEPPS, γεγονός που μας επέτρεψε να δημιουργήσουμε μια απρόσκοπτη εμπειρία για τον τελικό χρήστη (του συστήματος). Όταν τα δεδομένα ενός ασθενούς καταχωρούνται μέσω του SDE προγράμματος του STEPPS, η μηχανή αντιστοίχησης του Collexis® τροφοδοτείται με τους κωδικούς του UMLS που εμφανίζονται στο προφίλ του ασθενούς και ανασύρει ανάμεσα από τις δικτυοσελίδες που περιέχονται στις συλλογές του συστήματος εκείνες που παρουσιάζουν τη μέγιστη συνάφεια για τον συγκεκριμένο παραλήπτη.

Ο προσδιορισμός και η ανάπτυξη των επιμέρους τμημάτων της αρχιτεκτονικής του STEPPS δεν ήταν παρά ένα από τα στάδια σχεδιασμού του συστήματος. Σε μια παράλληλη διαδικασία, την οποία παραθέτουμε στο **Κεφάλαιο 5** της διατριβής, ήταν αναγκαίο να προσδιορίσουμε τον διαμόρφωση αυτών των επιμέρους τμημάτων από την οπτική γωνία των χρηστών του συστήματος, λαμβάνοντας συγκεκριμένα υπ’όψη τις πραγματικές συνθήκες των χώρων παροχής υπηρεσιών υγείας. Επιλέξαμε την ομάδα ειδικών του κέντρου θεραπείας εγκαυμάτων ως την ομάδα-στόχο τελικών χρηστών για την πρωτότυπη έκδοση του συστήματος. Σαν αποτέλεσμα, είχαμε τη δυνατότητα να ελαχιστοποιήσουμε το βάρος της ανταπόκρισης στις απαιτήσεις ασφάλειας και προστασίας της ιδιωτικότητας που απορρέουν από τη χρήση στοιχείων του Ηλεκτρονικού Φακέλλου Ασθενούς.

Η χρησιμοποίηση διαδικτυακού περιεχομένου ως υλικού για δραστηριότητες εκπαίδευσης ασθενών επίσης επιβάλλει περιορισμούς στο σχεδιασμό και την εφαρμογή του συστήματος. Στο STEPPS διερευνούμε τη δυνατότητα χρησιμοποίησης ελεύθερα διαθέσιμου υλικού στον Παγκόσμιο Ιστό, χωρίς προεπιλογή των πηγών προέλευσης. Δείχνουμε ότι είναι εφικτό να αξιοποιηθεί ένα ευρύ φάσμα ηλεκτρονικού πληροφοριακού υλικού για τους σκοπούς της εκπαίδευσης ασθενών. Ωστόσο, εξαιτίας της ευθύνης που φέρουν τόσο οι επαγγελματίες, όσο και οι οργανισμοί που παρέχουν υπηρεσίες υγείας να διασφαλίζουν την υγεία των ασθενών, το περιεχόμενο της παρεχόμενης πληροφόρησης πρέπει να αξιολογείται ως προς την ακρίβειά του. Κατά συνέπεια, η αρχιτεκτονική του STEPPS προϋποθέτει την αξιολόγηση του διαδικτυακού πληροφοριακού υλικού από επαγγελματίες υγείας, πριν τη διανομή του σε ασθενείς και στους οικείους τους.

Το **Κεφάλαιο 6** αυτής της διατριβής περιγράφει την πιλοτική μελέτη αξιολόγησης του συστήματος STEPPS. Αυτή η διαμορφωτική μελέτη αξιολόγησης παρήγαγε αρχικές αποδείξεις για την δυνατότητα εφαρμογής της πρωτοποριακής μεθόδου μας στην εξατομικευμένη εκπαίδευση ασθενών, αξιοποιώντας διαδικτυακό πληροφοριακό υλικό υγείας επιλεγμένο στη βάση δομημένων και κωδικοποιημένων δεδομένων από τον Ηλεκτρονικό Φάκελο του Ασθενούς. Αποδείξαμε ότι το STEPPS επιτυγχάνει τον δεδηλωμένο στόχο του της εξατομικευμένης ανεύρεσης πληροφοριών, επιστρέφοντας σημαντικά καλύτερα αποτελέσματα σε σύγκριση με μια τυχαία επιλογή ιστοσελίδων από τη συλλογή του συστήματος.

Προσφέραμε επίσης ενδεικτικά στοιχεία ως προς την ικανότητα του STEPPS να παράσχει πιο αποτελεσματικό από άποψη θεματικής συνάφειας εντοπισμό διαδικτυακού περιεχομένου, σε σύγκριση με την εμπειρία που είναι επί του παρόντος διαθέσιμη στους τελικούς χρήστες μέσω των μηχανών αναζήτησης. Κατά συνέπεια, το σύστημα STEPPS προσφέρει μια πιθανή εναλλακτική λύση σε όσους αναζητούν πληροφορίες για θέματα υγείας.

Το Διαδίκτυο και ο Παγκόσμιος Ιστός είναι ακόμη συγκριτικά νέα μέσα για την παραγωγή και διανομή πληροφοριών, καθώς και για επικοινωνία και συνεργασία. Καθώς οι εφαρμογές των τεχνολογιών πληροφορικής γίνονται όλο και περισσότερο αναπόσπαστο κομμάτι της παροχής υπηρεσιών υγείας και οι διαδικτυακές υπηρεσίες και πληροφορίες αφθονούν, νέα σχήματα αλληλεπίδρασης ανάμεσα στους επαγγελματίες υγείας και τους ασθενείς αρχίζουν να εμφανίζονται, βασισμένα στη δημιουργία συνεργασιών. Συστήματα εξατομικευμένης εκπαίδευσης ασθενών όπως το STEPPS μπορούν να εφαρμοστούν για να προωθήσουν και να υποβοηθήσουν την εξέλιξη αυτού του νέου, συνεργατικού μοντέλου φροντίδας υγείας.

Tiivistelmä

Tiivistelmä

Persephone Doupi. Personalized Patient Education and the Internet: Linking health information to the Electronic Patient Record. STEPPS in burn care [Yksilöllistetty potilasohjaus ja Internet. Terveystiedon yhdistäminen sähköisiin potilasasiakirjoihin. STEPPS-järjestelmä palovammahoidossa]. National Research and Development Centre for Welfare and Health (STAKES), Research Report 152. Helsinki 2005. ISBN 951-33-1779-X

Potilaiden ja heidän hoitajiensa kannalta tiedon haku ja käsittely on olennainen osa sairauden tai terveydentilan hoitoa ja siihen sopeutumista. Tärkeimpänä tiedonlähteenä on perinteisesti pidetty terveydenhoidon ammattilaisten antamaa potilasohjausta. Terveystiedolle on Internetin ja WWW:n myötä avautunut uusi, runsaasti käytetty kanava. Vaikka verkosta saatavassa terveystiedossa on lähinnä laatuun ja navigointiin liittyviä heikkouksia, sillä on myös ominaisuuksia, joiden ansiosta Internet on tehokkaasti hyödynnettynä hyvä keino potilasohjauksessa. Verkosta saatava tieto on muun muassa ajantasaista, ja sitä on helppo päivittää ja mukauttaa erilaisille yleisöille. Tietoa on saatavissa juuri oikeaan aikaan siellä missä sitä tarvitaan, ja sitä voi täydentää muista tietolähteistä. Verkosta saatava terveystieto kannattaa liittää potilasohjauksen strategioihin myös siksi, että sitä voi kohdentaa potilaalle henkilökohtaisesti. Yksilöllistämistä eli sisällön räätälöintiä on strategioissa kaivattukin, sillä se vastaa tehokkaasti eri potilaiden tiedonsaantitarpeisiin. Verkkosisällön mahdollista hyödyntämistä potilasohjauksessa ei tähän mennessä ole kuitenkaan tutkittu.

Tässä väitöskirjassa tutkitaan yksilöllistetyssä potilasohjauksessa käytettävää uudenlaista strategiaa. Verkossa olevista terveystietolähteistä saatava aineisto haetaan valikoidusti sähköisen potilaskertomuksen sisältämien rakenteisten ja koodattujen tietojen perusteella. Kun potilaan tiedot merkitään potilaskertomukseen, potilaasta muodostuu automaattisesti profiili. Tätä profiilia voidaan käyttää hänen ominaisuuksiensa kannalta merkityksellisten verkkosivujen hakemiseen. Tämän lähestymistavan havainnollistamiseksi ja testaamiseksi kehitimme STEPPS-prototyyppijärjestelmän (STructured Evaluated Personalized Patient Support: rakenteinen, arvioitu ja yksilöllistetty potilastuki), joka vastaa palovammahoidon tarpeisiin ja keskittyy erityisesti sairaalahoidosta kotiutettujen palovammapotilaiden ja heidän omaistensa tarvitsemaan tukeen.

Väitöskirja jakaantuu kahteen osaan. I osassa (luvut 1–3) tarkastelemme verkossa olevan terveystiedon laatua sekä niitä tietämyksen esittämisen haasteita, jotka liittyvät sähköisten potilasasiakirjojen rakenteisten ja koodattujen tietojen kokoamiseen. II osassa (luvut 4–6) käsittelemme potilasohjausaineiston yksilöllistettyyn hakuun liittyviä kysymyksiä, jotka koskevat sähköisten potilasasiakirjojen sisäl-

tämien tietojen ja Internetissä olevan terveystiedon yhdistämistä. Tutkimuksessa kuvatut esimerkit ja kokemukset ovat peräisin palovammojen hoitoon liittyvän STEPPS-järjestelmän prototyypin suunnittelusta, kehittämisestä ja arvioinnista. Viimeisessä luvussa (Tulosten pohdinta) tarkastellaan tutkimustuloksia ja ehdotetaan jatkotutkimuskohteita.

I osa

Luvussa 1 raportoimme tutkimuksen, jossa selvitimme terveystiedon laatukriteerien vaikutusta yleisölle suunnattuihin web-sivustoihin. Kohteena olivat reseptilääkkeitä koskevat tiedot. Tulokset osoittavat, että kyseiset sivustot eivät täytä esitettyjä laatukriteereitä riittävän hyvin. Yksikään tarkastelluista sivustoista (14 kpl) ei täyttänyt kaikkia laatuvaatimuksia. Tuloksista ei kuitenkaan pidä tehdä sellaista suoranaista johtopäätöstä, että verkosta saatava terveystieto olisi heikkolaatuista ja siten hyödytöntä. Pikemminkin syynä voi olla se, etteivät tieteellisille julkaisuille asetetut laatuvaatimukset täysin sovellu verkkoympäristössä saatavilla olevaan tietoon.

Tässä tutkimuksessa tarkastelemme terveystiedon laadun osalta muun muassa sitä, kuinka kattavasti aihetta käsitellään tiedonlähteissä. Pidimme kattavuutta indikaattorina, joka heijastaa tietolähteen kykyä vastata aihekohtaisiin tietotarpeisiin sekä annetun tiedon turvallisuutta. Kattavuuskriteerien soveltaminen verkkosivujen sisällön tarkastelussa osoitti, että verkosta saa huomattavan paljon relevanttia tietoa. Tieto on kuitenkin hajallaan useissa eri lähteissä. Siksi loppukäyttäjällä on oltava sekä varsin hyvät tiedonhakutaidot että runsaasti aikaa ja viitseliäisyyttä tiedon löytämiseen. Kehittämämme STEPPS-järjestelmän prototyyppi voisi olla yksi tapa helpottaa relevantin tiedon löytämistä.

Internetin sisältämän terveystiedon laadun varmistamista koskevia kriteereitä ja muita menetelmiä on jo vuosien ajan pyritty kehittämään ja tarkentamaan monin tavoin. Verkkoympäristön laadun käsitettä ei kuitenkaan ole analysoitu järjestelmällisesti ja kattavasti. Luottamusta verkosta saatavaan terveystietoon ei myöskään ole aiemmin käsitelty. Tällä luottamuksella on kuitenkin ratkaiseva merkitys sille, kuinka tieto vaikuttaa tiedon vastaanottajaan. Väitöskirjan *luvussa 2* pyrimme selventämään terveystiedolle esitettyjen laatukriteerien perusteena olevien laadun ulottuvuuksien alkuperää, luonnetta ja keskinäisiä suhteita, jotta alan tutkimus voisi kehittyä edelleen. Lisäksi pyrimme selvittämään a) verkosta saatavan terveystiedon laadun ja luotettavuuden välistä suhdetta ja b) sitä, lisäävätkö esitetyt aloitteet käyttäjän luottamusta vai onko niitä edelleen tarkennettava. Verkosta saatavan tiedon laadussa voidaan erottaa neljä ulottuvuutta: episteeminen, eettinen, taloudellinen ja tekninen. Jotta verkossa olevat lähteet olisivat laadullisesti riittäviä, kaikki neljä ulottuvuutta on yhdistettävä ja niitä on tarkasteltava kokonaisuutena. Tutkimme laatua ja luotettavuutta sekä niiden välistä suhdetta eri näkökulmista. Näin luomme viitekehyksen esitettyjen laatukriteerien tarkemmalle tutkimiselle sekä sen arvioimiselle, kuinka ne edistävät verkkosivustoilla kävijöiden luottamuksen kehittymistä.

Tämän tutkimustyön perusolettamuksena on muun muassa se, että sähköiset potilasasiakirjat voivat olla arvokas lähtökohta potilasohjauksen yksilöllistämiselle, sillä niiden sisältämät tiedot koskevat nimenomaan yksittäisen potilaan ongelmia. Se lähestymistapa, jota ehdotamme hyödynnettäväksi silloin kun sähköisen sairauskertomuksen tietoja käytetään yksilöllistämisessä, perustuu tiedon syöttämiseen *rakenteisessa ja koodatussa muodossa* osana päivittäistä kliinistä dokumentointia. Tarkastelimme tätä lähestymistapaa STEPPS-järjestelmän kehittämisessä.

Käytimme ORCA-SDE-tiedonmallintamismenetelmää ja -työkaluja, jotka on ensisijaisesti kehitetty rakenteisen tiedon joustavaa ja intuitiivista keruuta varten. *Luvussa 3* selostamme potilaan fyysiseen tutkimiseen liittyvää työtä. Tässä yhteydessä tunnistimme yhtenä ongelmana sen, että käyttämämme mallinnuksen avulla on vaikea saavuttaa semanttista ekvivalenssia luotettavasti. Semanttiseen ekvivalenssiin liittyvien ongelmien ratkaisuksi ehdotamme terminologisten järjestelmien käyttöä. Kokeilimme tätä lähestymistapaa palovammojen hoidossa siten, että käytössä oli hollantilaisten palovamma-asiantuntijoiden hyväksymä määritelmä potilaan ydintiedoista. Kävi ilmi, että lähes 80 prosentille ydintietojen termeistä voidaan määrittää vastaavuudet UMLS-Metathesauruksessa (v. 2001 painos) esitettyihin käsitteisiin. Esitystavan yksityiskohtaisuus ei kuitenkaan aina ole paras mahdollinen. Siksi käsitteiden vastaavuuksien määrittämisessä on päädytty laajempiin tai suppeampiin termeihin. Vaikka tulokset ovat vasta alustavia, terminologisten järjestelmien käyttö yhdessä rakenteisen tiedon kanssa vaikuttaa lupaavalta toimintatavalta, kun halutaan lähentää kliinistä työtä tekevien lääkäreiden asiakirjakielenkäyttöä ja kontrolloituja sanastoja toisiinsa. Tällaisen määrityksen aikaansaaminen on merkittävä askel sähköisten potilasasiakirjatietojen ja tietolähteiden yhdistämisessä.

II osa

STEPPS-järjestelmän prototyypin kehittelyssä on pyritty selvittämään, kuinka hyvin tällainen uusi ratkaisu pystyy potilasohjausaineiston yksilöllistettyyn hakuun. *Luvussa 4* kuvailemme tarkemmin STEPPSin arkkitehtuurissa tarvittavia elementtejä ja selostamme niiden kehittämisessä ja integroinnissa huomioon otettavat seikat. STEPPSin arkkitehtuuri koostuu seuraavista osista:

1. **Sähköisen potilaskertomuksen käyttöliittymä rakenteista ja koodattua tietoa varten.**

STEPPSin palovammahoidon käyttöliittymää varten tarvittaviin ydintietoihin on lisätty tietoja, jotka eivät ole lääketieteellisiä mutta jotka ovat kotiutetun potilaan toipumisen kannalta olennaisia. Potilaan profiilia kuvaavat termit on järjestelmää kehitettäessä merkitty UMLS Metathesauruksen käsitekoodeilla. Niiden avulla potilastiedot voidaan täsmäyttää automaattisesti tietoaineistoon.

2. **Olennaisten terveysaiheisten verkkoaineistojen kokoelmat.**

Tunnistimme palovammoihin liittyvän potilaskoulutuksen keskeiset aiheet ja laadimme metahakuohjelmien avulla verkkosivukokoelman, joka indeksoitiin UMLS-Metathesauruksen pohjalta.

3. **Indeksointi- ja täsmäytystyökalu**.

Työssä on käytetty Collexis®-ohjelmaa, joka sisältää sekä indeksointi- että täsmäytystoiminnot. Sen ansiosta verkkoaineiston indeksointi sujuu helpommin, ja sen voi integroida STEPPSin SDE-käyttöliittymään. Näin saadaan aikaan loppukäyttäjän kannalta saumaton kokemus.

Kun potilaan tiedot syötetään STEPPSin SDE-käyttöliittymän kautta, Collexis®-ohjelma ottaa vastaan potilasprofiilin UMLS-koodit ja hakee järjestelmään kootuista verkkosivuista kyseisen yksilön kannalta olennaisimmat sivut.

STEPPSin arkkitehtuurissa tarvittavien komponenttien määrittäminen ja kehittäminen olivat vain yksi järjestelmän suunnitteluvaiheista. Kuten kirjan *luvussa 5* esittelemme, nämä rakenneosat oli määriteltävä myös järjestelmän käyttäjien näkökulmasta. Tällöin oli erityisesti otettava huomioon terveydenhuollon toimintaympäristön käytännön näkökohdat. Järjestelmän prototyypin kohderyhmäksi on valittu palovammahoidon ammattilaiset. Näin sähköisiin potilasasiakirjoihin liittyvien turvallisuus- ja salassapitovaatimusten noudattaminen on voitu saada mahdollisimman helpoksi.

Järjestelmän suunnittelua ja toteuttamista rajoittaa myös verkkosisällön hyödyntäminen potilasohjauksessa. STEPPSissä tutkitaan sitä, voidaanko potilasohjauksessa käyttää vapaasti saatavilla olevaa, ennakkoon valikoimatonta verkkoaineistoa. Tutkimus osoittaa, että potilasohjauksessa voidaan käyttää hyvin monenlaista verkossa esiintyvää terveystietomateriaalia. Tiedon sisällön oikeellisuus on kuitenkin arvioitava, sillä terveydenhuollon ammattilaiset ja hoitolaitokset ovat vastuussa potilaiden hyvinvoinnin varmistamisesta. Tämän vuoksi STEPPSin arkkitehtuurissa oletetaan, että terveydenhuollon ammattilaiset arvioivat verkkoaineiston ennen tämän tarjoamista potilaille ja näiden omaisille.

Tutkimuksen *luvussa 6* selostetaan STEPPSin koearviointia. Kyseessä oli formatiivinen arviointitutkimus, joka antoi alustavaa tutkimustietoa uudesta lähestymistavasta yksilöllistettyyn potilasohjaukseen, jossa hyödynnetään rakenteisten, koodattujen potilasasiakirjatietojen perusteella valittua verkossa olevaa terveydenhuoltoaineistoa. STEPPS osoitti saavuttavansa sille asetetut yksilöllistetyn tiedonhaun tavoitteet, ja sillä saatiin merkittävästi parempia tuloksia kuin satunnaisella valinnalla järjestelmään kootuista sivustoista.

Tutkimus antoi myös viitteitä siitä, että STEPPS on verkkosisällön aihekohtaisessa haussa tehokkaampi kuin loppukäyttäjille nykyisin tarjolla olevat hakukoneet. Se tarjoaa terveystiedon hakijoille siten varteenotettavan vaihtoehdon.

Internet ja WWW ovat yhä suhteellisen uusi väline tiedon tuottamisessa ja levittämisessä sekä viestinnässä ja yhteistyössä. Kun terveydenhuoltoon liitetään yhä uusia informaatioteknologian sovelluksia ja Internet-pohjaista terveystietoa ja palvelutarjontaa on olemassa yllin kyllin, alkaa terveydenhuollon ammattilaisten ja potilaiden välille syntyä uudenlaisia, kumppanuuteen perustuvia vuorovaikutustapoja. STEPPSin kaltaisten yksilöllistettyjen potilasohjausjärjestelmien avulla voidaan edistää ja avustaa tämän uuden, yhteistyöhön perustuvan terveydenhuoltokäytännön kehittymistä.

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As you set out for Ithaka
hope your road is a long one,
full of adventure, full of discovery.

Ithaka, 1911 – C. P. Kavafis
Translated from Greek by E. Keeley & P. Sherrard

The path towards achieving the doctorate degree has certainly been a long, exciting and educating journey. Many organizations, groups and individuals have contributed towards the completion of this task. As this book marks this journey's end, it is also the appropriate place to express my gratitude.

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Bringing my research in the field of burn care would not have been possible without the backing of the Dutch Burns Foundation. The Foundation and its people ensured my access to the facilities, material and information I needed and later on also assisted with the complicated logistics in the final phases of the Ph.D.

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May 2005

Curriculum Vitae

Curriculum Vitae

Persephone Doupi was born on February 15, 1969 in Athens, Greece.

She attended the American College of Greece (Pierce College), under the Gina Bachauer scholarship, and she graduated as valedictorian in 1986. She then studied medicine in the National and Kapodistrian University of Athens, Greece, where she obtained her medical degree in 1996.

In 1997, with the partial support of the Erasmus University Research Institute for Decision Support and Information Systems (EURIDIS) she joined the Netherlands Institute for Health Sciences (NIHES) program of post-graduate studies at Erasmus University Rotterdam, The Netherlands. As a student in the Department of Medical Informatics of Erasmus University, she obtained a Master and a Doctor of Science Degree in Medical Informatics, in 1998 and 1999 respectively. She proceeded with her research work towards the Ph.D. degree, with the support of the Greek Scholarships Foundation and in collaboration with the Dutch Burns Foundation.

Since 2002 she has been working as Senior Researcher in the National Research and Development Centre for Welfare and Health (STAKES) in Helsinki, Finland.