Development of a Self-Assessment Method for Patients to Evaluate Health

Information on the Internet

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Abstract

For patients to make efficient use of the plethora of health information available on the Internet, they must be able to determine the quality and relevance of that information to their particular situation. Quality and relevance are conceptualized based on behavior and patterns of users on the web. The development and pilot-testing of a self-assessment method for patients to evaluate health care oriented websites are presented. The data analysis of the pilot-study suggests that the subjects perceived the method as helpful in evaluating quality and relevance of health information on the web.

Introduction

The Internet is an exciting communication medium for all kinds of information: from scientific data to unscientific information, and from objective to biased information. The Internet hosts a large number of accurate health-oriented websites with endless opportunities to inform, teach and connect patients. However, there is also a large amount of incomplete and misleading information on the World Wide Web (WWW) 1 2 3. Consumers of health care information need some protection misinformation whether intentional or unintentional 4. Aside from the inaccurate information, patients also may not be able to put the educational messages into practice because they are unable to comprehend the message. Another issue is that patients often are reluctant to adopt advice that goes against their beliefs. Therefore, information must not only be accurate but must also be consistent with the patients' skills and experiences

Information on the WWW lacks the conventional standards with which traditional editorial resources are evaluated. Though many general evaluation instruments can be used in evaluating health-related websites, most of them are incomplete, and do not always measure what they claim to measure ⁶. In addition, they are more geared toward professional and regulatory organizations. Yet, it is critical that not only librarians and clinicians are able to evaluate health information on the Internet; health care consumers need a way to judge the quality and relevance of the information provided on the Internet.

Purpose

Helping patients determine the quality and relevance of health information found on the Internet is a key responsibility for clinicians who want to use network technologies to promote the health of

patients and provide them with clinical service. HeartCare, an Internet-based cardiac recovery service designed to support patients at home following cardiac surgery, is been developed. HeartCare provides patients with personally tailored World Wide Web (WWW) pages that link to cardiac recovery resources including informational pages, chat groups, and clinical message services ⁷. Additionally, patients who use HeartCare can exit the structured web server and explore the Internet to discover resources that may be of personal interest. A key challenge exists in helping patients discern quality and relevance of WWW resources that they discover.

The purpose of this paper is to present a strategy for development and pilot-testing a self-assessment method for patients to evaluate quality and relevance of health care oriented websites.

Background and Significance

<u>Significance and challenges of Health Information on the Internet</u>

The explosive growth of the Internet is well documented. While there is no doubt that the Internet technology now provides access to an enormous volume and broad variety of health information, consumers are faced with the challenge of finding sources of high-quality information that are accurate, timely, relevant, and unbiased 8. Health information on the WWW may be from a leading expert with excellent documentation and a bibliography, or it may be in the form of emotional support from a friendly user group¹. Unfortunately, there is also a large amount of incomplete and inaccurate information, sales propaganda, or even pseudo-scientific scams ^{4 5 6}. This makes it difficult for the consumer to determine which information is usable and credible, how it can be verified, when it

should be ignored, rejected, or erased, and whether to read and to apply it.

Recently, several journal articles, ^{1 3 6 9 10 11} and on-line publications ^{12 13} have tried to define desirable standards for evaluating healthcare information on the Internet. Because of their objectivity, common criteria for evaluating health related websites are those dealing with content, design and aesthetics, and disclosure of authors, sponsors or publishers, currency of information. Other sources^{9 3 6} mention the conventional standards (e.g. scope, authority, currency, accuracy, purpose) long used by librarians on editorial resources as valid criteria for evaluating websites. Wyatt 9, Silberg and others⁶ claim that in addition, we not only need to evaluate accuracy of medical content through conventional library standards, but also factors such as effective use of technology (e.g. hyperlinks, multimedia), attention to site navigation, the provision for feedback (e.g. email address), and interactivity.

Most authors agree on key criteria for assessing health-related websites. The proposed criteria, however, assume knowledge of medical content and some familiarity with traditional standards for evaluating editorial resources, but none of them focus on helping the patients "filter" the information found on the web. Besides criteria for evaluating the appropriateness or quality of health related web resources, recent surveys 1 brought to light that relevance is an important criterion that benefit the patient and hence, should be included. Relevant and timely clinical knowledge may decrease the perceived threats of one's disease process, increase confidence in self, and will ultimately result in more appropriate behavioral changes related to his/her own health. Consequently exploring the possibility of determining direct and indirect indicators for quality and relevance by analyzing user behavior, user pattern in using the WWW is proposed.

Quality of Information Retrieved on the Internet as Perceived by the Consumer

Several empirical studies of different user communities ¹⁴ ¹⁵ have revealed strong regularities and patterns of web users. Morkes and others ¹⁴ found that consumers might use some of the same criteria as mentioned earlier (e.g. completeness and consistency of the information, accountability of the publishing authority, novelty, etc.) but also different criteria to describe what they perceive as quality. Consumers question how believable the information of an essay on the web is by asking questions like:

"Who posted this information? Is he/she an authority, an expert in the field?" 14

The authors also found that writing style, layout and organization of the content are perceived as important quality indicators. Users want to pick out a few sentences; they don't like long or scrolling pages. They want webpages to make points quickly, and provide factual information in a highly organized manner. The authors mention that users like summaries and the inverted pyramid writing style: news and conclusions come first followed by details and background information. Hypertext structure is mentioned to be helpful, and graphical elements and multimedia are liked if they complement the text. Well-organized websites are eye pleasing, and more likely to be explored. Credibility, the sources' motivation, qualification and trustworthiness are considered as important 14. Users are looking for "that quality feel" - the image the website conveys. Users rely on hypertext links to help assess credibility of information contained in websites ¹⁴.

Quality as perceived by the general users relates not only to accuracy of content but rather to presentation, perceived trust, clear credentials, and other markers that tend to give information 'weight'. It refers to aspects such as readability of material, the quality of links to other sites, graphs and multimedia use in the communication of content material, and ease of site navigation.

Relevance of Information Retrieved on the Internet

Evidence 18 suggests that information seeking for health related issues is based on an actual (i.e. stated or implied) need. Information retrieval is a subjective judgment of the extent to which specific information pertains to given person and situation. It includes aspects of how useful that person perceives the information for decision making related to his/her health. Thus, before patients will accept or use a WWW page, they must perceive that the information presented is relevant. An understanding of how a lay person determines what content from a webpage applies to his/her situation is needed. Wang and Soergel's work¹⁶ on library users provides some insight. The authors describe this process as integrating a set of cognitive cues, about the information presented, and drawing conclusions about it. Information cues can be seen a set of filters the user applies to the information to assess its value/ worth. In general, two kinds of criteria occur: content information criteria (e.g. topic, depth, novelty, etc.) and criteria relating to the user's context (personal knowledge and experience, user's beliefs and values, etc.)¹⁶. Although there is some overlap with the notion of quality, relevance differs from quality in that the information is valued on

purposefulness of the content rather than on presentation of the content.

It is likely that the patient will behave in the same manner as library users. Both seek information in a purposeful fashion and pursue the information if they value a possible use. Therefore, in this proposal, the term relevance is defined as situational relevance ¹⁷. It means that (1) the retrieved information answers actual questions, (2) the information need and the retrieved information are on the same topic¹⁸, and (3) the information has some value for the patient in this stage of the recovery process.

Development of a Self-assessment Method for **Evaluation of Websites**

Criteria/guidelines for evaluating webpages, published in journal articles and on-line publications were summarized. In a first step, criteria were compared based on conceptual descriptions given by the author(s). Subsequently, through a lexical and contextual analysis criteria were sorted into similar groups. Duplicate criteria are consolidated to a single criterion. Some items have been rewritten to clarify the meaning and to distinguish the item from others that have similar meaning. The items were then compared with the items that the literature suggested the general user of the WWW perceives as quality and/or relevance.

Finally, four criteria considered as indicative of quality and relevance as perceived by the general user of information on the Internet are retained. Because of the overlap in the notions of quality and relevance, no one criterion could be assigned to quality or to relevance exclusively, and all criteria contain both subjective and objective elements in different degrees. The selected criteria are conceptualized in table 1.

Table 1 Conceptual descriptions of criteria indicative for "quality and relevance"					
Content	measures the topicality, depth, accuracy, quantity, and clarity of the information offered at the website.				
Design	describes the "eye pleasing" nature of the website; appeals to the audience. The writing style, layout, and the incorporation of graphic elements and multimedia most typically determine this.				
Communication	makes the website easy to read and understand. And, determines how easy is it to locate relevant material within the website.				
Credibility	assesses the authority and qualifications of the author or publishing agency. Also, it refers to the currency of the information, and the possibility of functional feedback.				

These criteria have then been translated in an easy-to-understand and easy-to-use questionnaire that patients can consult any time they access a webpage. It is not the intent to set quality criteria and perform

evaluations for the patient, but to provide patients with a method to filter the information found on the web taking into account patient's context and needs. The wording of the questions should cue patients to evaluate the appropriateness or quality of the information and make them aware that the information, even if highly accurate, may not be relevant or useful to them. The proposed method consists of nine uncorrelated questions and is formulated as follows:

The WWW has useful information, but has also some misleading content

- Before using the information, think about the following questions:

 1. Does the page provide you with information on the topic you are seeking?
- Does the page provide you with enough and clear information to meet you
- Does the page give you any new information related to the topic?
- Did the authors make a good case?
- Do pictures and graphics make things clearer for you?
- Is the page easy to read and to understand?
- Does the information seem to be up-to-date?
- Have you heard of the author or the organization that is publishing the page? Will the information help you to change your behavior?

Pilot-Testing the Self-assessment Method for **Evaluation of Websites**

Participants and setting

To be included in the pilot study participants had to be age 18 or older, and have little or no medical knowledge. Pre-nursing students from a small Midwestern university were invited to participate in the pilot-study after the researcher had explained the purpose of the study. The subjects can be considered similar to the general public for whom the method is designed because of a comparable level of medical knowledge and Internet use. Patients enrolled in the HeartCare project will also be invited to participate in the study.

Attempts were made to recruit students during summer and fall semester; sixteen students consented to participate and completed the test twice within a 3week interval.

Patients are still being recruited at this time. **Procedure**

The test procedure consisted of (1) testing the use of the Self-Assessment Method. Participants were asked to list 3 topics related to a health issue that had some importance to them and to search the web for information on these topics. Once a website was identified, each participant answered each item on the questionnaire with "yes", "no" or "NA". In the next step, subjects were be asked if the questionnaire helped them in reflecting about quality and relevance. (2) During a second part of the test procedure, the four criteria conceptualized (i.e. content, design, communication, credibility) as indicative for quality and relevance were validated using a 4-point Likert scale (1=not relevant, 2=somewhat relevant, 3=quite relevant, 4=very

relevant. (3) A third part matched perceptions of quality and relevance to the items of the questionnaire using the same 4-point Likert scale. All participants were asked to respond to the questionnaire at their convenience (Time 1). The test was to be repeated 3 weeks later (Time 2) using different websites.

Results

The test procedure resulted in evaluation data from 87 websites (3 students evaluated the same website at time 1 and time 2. The concepts content, design, communication and credibility were appraised 32 times, as was the matching of the personal perceptions of quality and relevance to the nine items on the proposed method.

Scoring the Questionnaire

Summative scores for the yes, no and undecided answers were calculated at time 1 and time 2 and that for each item (see table 2).

Table 2		·				
Summative scores for each answer	Time 1 (N=48)			Time 2 (N=48)**		
	Yes	No	Some/	Yes	No	Some/
		l	NA	ŀ	ŧ	NA
Match of interest	41	6	1	40	8	0
Clear and enough info	33	12	3	37	11	0
Novel info	38	9	1	42	5	1
Compelling case	40	6	1*	36	9	2*
Support from graphics and	14	13	19*	20	14	11*
pictures				l	ŧ	
Ease of reading and understanding	39	6	3	44	3	1
Up-to-date info	47	1	0	43	4	1
Familiarity with publisher	11	36	1	12	36	0
Facilitate behavior change	25	14	9	24	18	6

N= number of WebPages evaluated

The number of different websites evaluated is 87, but some evaluation data from the duplicate sites were scored different from time 1 in time2.

The data analysis shows that the number of undecided answers dropped from time 1 to time 2 for most of the items, with one exception for the items 4 and 7 where a slight increase (6%) in undecided answers is noted. Another exception is for item 3 where the number of undecided people stayed the same. The relative high number of undecided answers for item 5 during both time 1 and time 2, is striking. A possible explanation for this result is that the pages selected had no or very few pictures or graphics.

Most subjects report at both times that the questionnaire helped them reflect about the appropriateness or quality and relevance of the webpage. Two (12%) subjects didn't think the tool was helpful at first but stated the second time that the questions "helped them focus on the info that they were looking for." One person reported the questionnaire as helpful in time 1, but not as much in time 2: "... because I already had an idea of what to be looking for " (note: the subject evaluated the same webpages during time 1 and time 2.)

<u>Validity of the criteria in describing aspects</u> <u>of quality and relevance</u>

The theoretical position is that content, design, communication and credibility are indicative of relevance and quality as perceived by the general user of health information resources on the Internet. Subjects overall agree that the description of communication (44%) and credibility (63%) represent quality and relevance of information on the websites. Content, as conceptualized, is still perceived as indicative of quality and relevance but a little less so. In thirteen cases (41%), design was indicated as "somewhat relevant", but not as persuasive as the previous concepts. Table 3 reports on the modal ranking of the concepts. While mode does not provide a complete picture of the data distribution, it is somewhat representative for the central tendency in this sample, especially when we consider also the percentage of subjects who selected that scoring.

Table 3 Criteria indicative for quality and relevance: modal ranking						
	Time 1	Time 2	Overall			
	(% subjects)	(% subjects)	(% subjects)			
	N=16	N=16	N=32			
Credibility	4 (63%)	4 (63%)	4 (63%)			
Communication	4 (38%)	4 (50%)	4 (44%)			
Content	3 (50%)	3 (50%)	3 (50%)			
Design	2 (50%)	3 (44%)	2 (41%)			

<u>Validation of Questions as Indicative of</u> <u>Quality and Relevance</u>

These results are shown in table 4. The subjects reported the following as measures of quality and relevance "Clear and enough information, ease of reading and understanding, up-to-date information". "Novel information, a compelling case and knowledge of the publisher" are also considered as important but less so than previous attributes, while facilitation of behavior change and the graphic support are considered of lesser value.

Table 4									
Perception of quality and relevance: modal ranking									
N=32	Q1	Q6	Q2	Q7	Q3	Q4	Q8	Q9	Q5
Mode	4	4	4	4	3	3	3	2	2
% of subjects	63	63	53	44	63	50	34	41	38

Discussion

The study suggests that users evaluate quality and information on the WWW against a simple set of indirect criteria (i.e. subjective and objective) taking into account user's context and needs. The proposed Self-Assessment Method is an attempt to help users "filter" the information found on the Internet on their own. The attributes synthesized in the questions of the Self-assessment Method are generally perceived as congruous of quality and relevance, and as one of the subjects stated: "Yes because I think that a high

^{*} One or more missing answers

quality webpage will have a lot of yes answers" supports this. However, this statement is not congruent with the high frequency of "no" (75%) when asked about the familiarity with the publisher. The item is rated as "quite-relevant" in 34% of the cases, but as one of the subjects reports "[the questions] may point out something which I had not thought of or possibly was not critical enough about (author, publishing organization)."

Design and facilitation of behavior change are rated as less conformant in evaluating the appropriateness of health information on the web. This is not only suggested by ratings of perceived quality and relevance (table 4), but also during the scoring of the questionnaire. These questions received the highest frequencies of "some/NA" (table 2) answers. The following explanations can be proposed for item 5: the conceptualization of the criterion is incomplete and need some more clarification, or is not as indicative at all. Another explanation can be given by the fact that the retrieved health related webpages did not have as much graphics and pictures that hampered the evaluation of this item. This must be explored in greater depth. For item 9: behavior change may be an indirect consequence of an increased understanding of one's health and/or recovery process and therefore considered as less relevant at the time. This issue also needs further investigation; and also the results of the study with the patients enrolled in HeartCare need to be considered.

Limitations of the study

Study limitations include the limited size of the convenience sample that did not justify the calculation of summary statistics. Another limitation is that the notion quality and relevance are not only overlapping but also carry some subjective and objective weights.

The method does not elicit unrecognized needs, nor does it measure how many steps it may take to locate the information, nor what advice the consumer may come across along the way.

Conclusion

Given the evolving state of the Internet and its potential to be an excellent medium to provide patients with access to health care information, it may be difficult or even inappropriate to develop a static tool for evaluating health related websites. Therefore a simple method is developed that the general consumer, with little or few clinical knowledge can understand and use. The proposed method needs further investigation, and its impact and effectiveness

in assisting the patient with health related decisions should be monitored to ensure its usefulness.

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