Patient-Centered Tools for Medication Information Search

Lauren Wilcox[1,2] Steven Feiner[2] Noémie Elhadad[2] David Vawdrey[2] Tran H. Tran[3]

[1]Georgia Institute of Technology
Atlanta, GA USA
wilcox@cc.gatech.edu

[2]Columbia University
New York, NY USA
feiner@cs.columbia.edu
noemie@dbmi.columbia.edu
david.vawdrey@dbmi.columbia.edu

[3]New York-Presbyterian Hospital
New York, NY USA
tht9016@nyp.org

ABSTRACT

Recent research focused on online health information seeking highlights a heavy reliance on general-purpose search engines. However, current general-purpose search interfaces do not necessarily provide adequate support for non-experts in identifying suitable sources of health information. Popular search engines have recently introduced search tools in their user interfaces for a range of topics. In this work, we explore how such tools can support non-expert, patient-centered health information search. Scoping the current work to medication-related search, we report on findings from a formative study focused on the design of patient-centered, medication-information search tools. Our study included qualitative interviews with patients, family members, and domain experts, as well as observations of their use of Remedy, a technology probe embodying a set of search tools. Post-operative cardiothoracic surgery patients and their visiting family members used the tools to find information about their hospital medications and were interviewed before and after their use. Domain experts conducted similar search tasks and provided qualitative feedback on their preferences and recommendations for designing these tools. Findings from our study suggest the importance of four valuation principles underlying our tools: credibility, readability, consumer perspective, and topical relevance.

Categories and Subject Descriptors

H5.2 [Information interfaces and presentation]: User Interfaces—Graphical user interfaces; J.3 [Computer Applications] Life and Medical Sciences—Health

General Terms

Design, Human Factors

1. INTRODUCTION

Online health education materials are increasingly accessed by the public through popular search engines [28]. A recent Pew Poll surveying online activities of US adults over a 12-month period found that 72% of the 81% who use the Internet say they have looked online for health information—43% of them looking for information on specific treatments or procedures [15]. Searching for information of this sort often involves accessing a range of sites created by a variety of institutions and companies—from international online pharmacies, to personal blogs, to government-agency–supplied literature.

Social media also influence health education and decision-making, including decisions to seek a second opinion [28]. As helpful as reviews by other patients can be, they can also bewilder non-expert patients if they contain claims from misinformed individuals. As patients sift through sites attempting to differentiate between fact and fiction, it can be difficult to detect sensationalistic journalism or purely commercial material disguised as educational content or personal stories [25]. In response to these issues, recent research has explored features of health website credibility [12, 29, 30], while third-party organizations have been established to certify or recommend health-related websites [22]. However, to date, few researchers have studied the role of web search user interfaces in mediating patient access to health resources [32].

In this paper, we describe a formative study focused on the design of non-expert, patient-centered medication-information search tools. Through a review of the literature on personal health information needs and information seeking, we identified four high-level principles that affect patients' valuation of online health information: *credibility, readability, consumer perspective,* and *topical relevance*. We applied these principles in our design and development of a technology probe [17], a high-fidelity medication-information search application (shown in Figure 1). Our probe, called Remedy, displays specific website features and document topics to annotate medication information search results. We created the tools embodied in the probe using text processing techniques and probabilistic generative topic modeling approaches to retrieve and organize medication information across a variety of online sources.

As one phase in a larger iterative design process, Remedy allowed us to observe how hospitalized, post-operative cardiothoracic surgery patients used the novel tools that we introduced, during searches for their actual medications. We present findings from a two-phase study in which these patients and their family members, along with pharmacists, caregivers, and other domain experts, used the tools to conduct searches related to a number of medication-related topics. Qualitative interviews with the patients, family members and domain experts in our study, both before and after their use of the probe, led to rich insights into the search behaviors we observed, enabling us to distill preliminary design goals for this class of search tools. While we have previously demonstrated the tools included in Remedy [37], we make the following contributions in this paper:

1. The four valuation principles underlying our tools for supporting rapid filtering and comparison of medication information search results, based on website features and content topics.

2. Findings from a field study with cardiothoracic surgery patients and visiting family members during a post-operative hospital stay, exploring both their use of the tools and their detailed responses to them.

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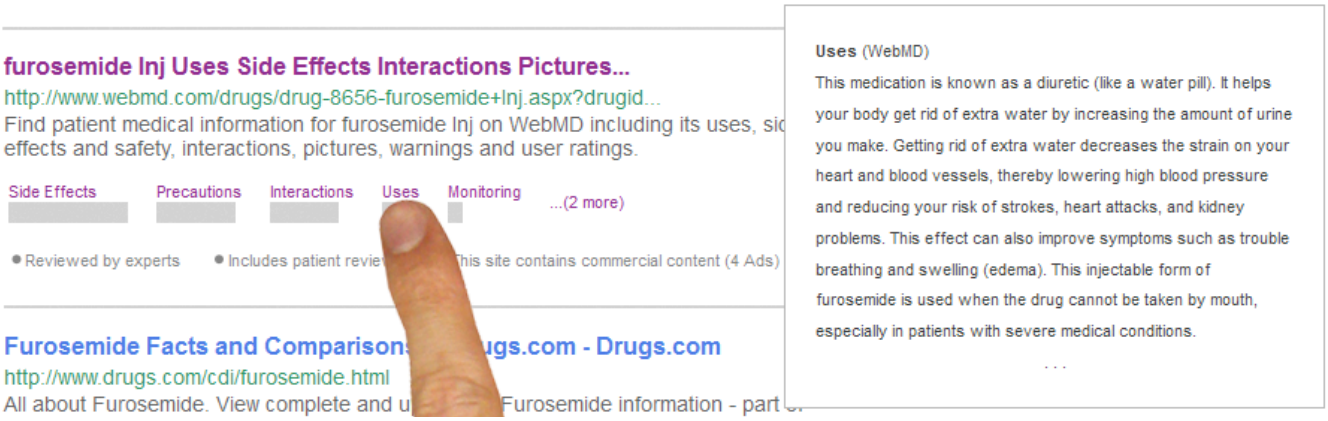

Figure 1: Each result returned in the Remedy user interface contains a topic map, in which the topics discovered in the linked web document are listed with gray bars showing the relative amount of information on that topic. Touching a topic in the topic map (e.g., "Uses" on the left) displays a box (right) containing a topic-specific snippet from the linked web resource.

3. Discussion of preferences and recommendations of domain experts for designing tools to support non-expert, online medication information search, based on usage of Remedy and qualitative feedback.

2. RELATED WORK

Below, we first classify previous work on non-expert, health-related search, according to the four health resource valuation principles that we identified. We then situate the current work with respect to related tools and technologies.

2.1 Valuation Principles

2.1.1 Credibility

Recent research on how lay users seek health information online highlights a heavy reliance on general-purpose search engines [15]. Unfortunately, once search results are returned, users often select information from the first page without awareness of the actual selection criteria [12]. While guidelines have been developed to help users assess information quality [22, 25], their utilization is limited to those who have both the knowledge and time required to access and apply them.

An important area of future work includes the design of automated approaches to flagging inconsistent or unsubstantiated information [1]. In the present study, our goal was to "inform end users" [30] by exposing relevant website and document content features (described in Section 3) in the search result user interface, rather than attempt to predict credibility. This approach is supported by work suggesting that descriptions of health sites should display more information about the source of the content and its commercial intentions [32].

Wang et al. note a lack of studies of usability and effectiveness of popular general-purpose search engines for health-related information [35]. Using breast cancer as an example search topic, they compared the search experience of Ask.com, Yahoo!, Bing, and Google, finding that the page rankings of each corresponded in varying ways to both expert rankings of quality and volunteer rankings of usability.

Sillence et al. observed that patient study participants sometimes rejected high-quality content because of its poor visual design [31]. This is consistent with prior findings showing that graphical design characteristics of a site greatly influenced users' perceptions of credibility [13], further motivating the need for tools to increase consumer recognition of quality indicators [16].

2.1.2 Readability

Martin and colleagues, through their study of older adults taking over-the-counter medications, call for research focused on better supporting laypeople's recognition of keywords, as well as access to simplified explanations [23]. Indicating the literacy level at which a web document was written could help, but readability measures are currently difficult to determine. Currently available screening instruments used to evaluate an individual's health literacy [9] do not provide a comprehensive assessment, and "grading" online resources according to the health literacy level of the text is an important area for future work. We focus instead on the use of tools to permit recognition of concepts discussed in the online literature. Khan et al. highlight the value of displaying pill images in medication management applications, to aid consumers in identifying drugs [20]. However, many medications are available in different shapes, imprints and sizes for varying strengths and brands. To avoid confusing users, we included only binary information about image availability on the linked page, rather than picking representative images.

2.1.3 Consumer Perspectives

A recent Pew Internet Poll found that one in five Internet users have consulted online reviews of particular drugs or medical treatments [15]. Caregivers were most likely to seek out medication reviews: 38% of Internet users in this group have consulted online drug reviews [14]. Respondents consulted these reviews to prepare for visits with their physicians, to learn from peers' experiences with medications, and to aid in making decisions—in collaboration with their care providers—about dosage changes or alternative medication [14]. A similar survey study indicated that 34% of respondents report that social media would impact their decision about taking certain drugs [28].

The quality of consumer-contributed information is a contentious topic [18], as we discuss below. Still, sharing and viewing peer perspectives is a growing trend that consumers are embracing to guide them in decision-making and in evaluating health information [12, 15]. We sought to enable awareness of the presence of consumer reviews during the search process, noting that such awareness can help consumers to either locate or avoid this information.

2.1.4 Topical Relevance

Berland et al. showed that most users searching for online health information searched inefficiently when using simple key terms with general-purpose search engines [3], due in part to a lack of vocabulary to describe health concepts. A key design goal for Remedy included the display of relevant topics to users during the search process, to permit recognition of terms and concepts (Figure 1).

Tasks essential to health-information sensemaking include discovery and synthesis of trustworthy information, spread across multiple locations, and recognition of contradictory information. Sillence et al. propose a multi-stage web resource evaluation process, in which rapid, heuristic processing based on superficial heuristics precedes in-depth examination and information processing during health information search [31]. Based on these findings, we provide techniques for browsing topically-related web page excerpts (Figure 2). We included this ability to support synthesis and comparison of information: key elements of the sensemaking process that Sillence and colleagues describe.

2.2 Related Tools and Interventions

Schwarz and Morris recently explored how credibility signals can be used to assist end users in evaluating website search results, for a number of information domains [30]. We strive in our work to support end-user assessment of website credibility, but tailor our metrics to address medication information search. In addition, we also explore the importance of readability, peer perspectives, and topical relevance.

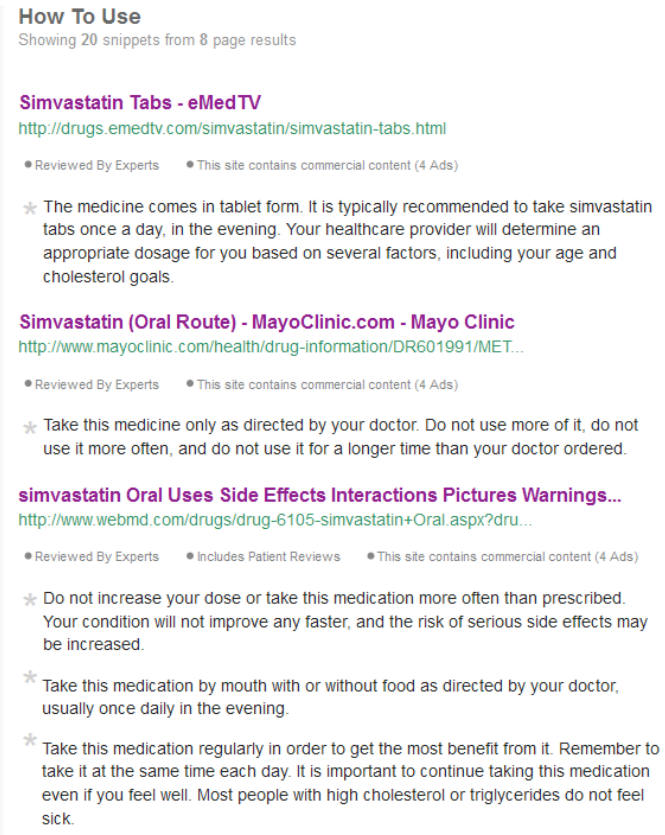

Figure 2: Portion of display presented by the search tools after user selects "How To Use" from topic menu to see relevant snippets for Simvastatin.

Making sense of online health information often involves browsing multiple webpages to compare explanations, descriptions or opinions about a single topic—a time-consuming and cognition-intensive task [4, 10]. To assist users with sensemaking tasks, researchers have designed technologies that combine document summarization techniques with presentation techniques.

Dontcheva et al. allow end users to create and manage their own summaries of web documents that contain similar layout patterns [11]. A complementary approach to end-user–driven tools includes browser technology that recommends web document content at the page-unit level, based on the user's interactions with previously-visited webpages [8]. In contrast, we focus on determining and presenting salient topic information, with the specific goal of augmenting the medication information search experience.

3. TECHNOLOGY PROBE

3.1 Search Tools

We included the following tools in our technology probe, Remedy, based on the design goals described above.

- *Result-specific topic map.* For each page result, a set of horizontal bars indicates the relative amount of page content in each of the set of topics, as determined by our topic analysis (shown in Figure 1).
- *Result-specific feature annotations.* For each page result, certain binary characteristics are listed, including whether the page was reviewed by experts, contains commercial content, or includes patient reviews (shown in Figure 1).
- *Topic Menu: Browse All Results by Topic.* Selecting a topic (e.g., "Dose" or "How to Use") from the topic menu displays topically relevant page excerpts from all page results for the queried medication. For example, Figure 2 shows "How to Use" excerpts for the lipid-lowering drug, Simvastatin.
- *Filters to Select Results Based on Page Features.* Selecting filtering criteria narrows the search to satisfy all selected criteria.

3.2 Topic-Based Browsing

The past decade has seen advances in computational methods to identify and cluster both structured and unstructured text. In particular, several techniques have been developed to discover salient aspects or topics discussed across multiple documents [5, 26].

Our approach to adopting these techniques is guided by work on visual interfaces to large text document sets. Wei et al. explored techniques for interactive browsing of document topics, achieved in part through probabilistic latent topic modeling [36], though they did not apply their work to web search. This type of topic modeling is often applied to documents with varying structure and organization, typically in an unsupervised manner (i.e., without any pre-determined labeling on the documents). Specific topic modeling techniques include latent Dirichlet allocation (LDA) [33], which treats each document in a collection as a mixture of topics—determined by a probability distribution over words. While these techniques play a role in webpage indexing and search, conventional user interfaces do not expose this information when it is available, even though it could be valuable to consumers [5].

To create our tools, we applied LDA-based topic modeling algorithms, drawing on evidence of their effectiveness for similar web content types [6]. We supplemented these techniques with additional text processing and manual content curation (described

below) to approximate what we could expect from a fine-tuned, fully-automated system. We note that the development and evaluation of fully-automated topic modeling techniques for the medication information domain is an important goal, but not one that we focus on here.

Instead, our goal was to explore the future potential of topic-based browsing techniques and the role they might play in assisting consumers in medication information search. Complementary work has demonstrated benefits in modeling topic distributions in combination with readability information to predict user interest in web documents [21], but utilized supervised classification techniques and did not address implications for user interface design. Earlier work in web-based, multi-document summarization presented topic information in the web search user interface, but focused on generating textual synopses of search results, using pre-determined topic structure [19].

3.3 Sources of Information

We draw from a variety of online medication information materials, to simulate what a lay consumer might encounter using general-purpose search engines with basic keyword queries. To collect representative information, we employed Mechanical Turk (MT) workers [2]. We provided approximately 200 workers with the names of a total of 100 unique medications, which were selected by extracting the most frequently used inpatient cardiothoracic surgery medications from the hospital information system of our study site. Workers were asked to use their preferred general-purpose search engine to query a subset of the medication names, and report up to 10 URLs containing consumer-specific information for each medication. Two authors then manually reviewed the list to verify reported results and resolve broken links.

Next, we wrote basic webpage text processing scripts to capture site titles, page article titles and description information provided in the site meta-data for the full list of curated URLs. We also wrote basic page processing scripts to harvest content for the curated URLs. In all, 993 webpages were collected. Using sentence and paragraph extraction tools on the harvested webpages [6], we prepared a text corpus with which we ran topic-modeling experiments. We used MALLET [24] to apply LDA-based topic modeling, using 10–200 topics (with default parameters for the others). Two co-authors reviewed the experiment results, selecting results and labeling strongly agreed-upon resultant clusters. Determining the optimal number of topics for any given modeling task is an open research question. Thus, we ran topic modeling with 10–200 topics and selected the model that resulted in the most semantically meaningful topics from a qualitative standpoint [7].

We further refined topic clusters using heuristic text-processing techniques that utilized structural features of web documents to detect lists and ads, as well as keyword-based filters. After applying these techniques, we selected a subset of 18 medications from the initial 100 to include. We made our selection to prepare for our inpatient field study, basing our choice on medications commonly utilized during and after cardiothoracic surgery. The clinical pharmacist co-author created the "gold standard" for validating content clusters, manually reviewing website excerpts assigned to each cluster, for all 18 medications (described by 148 associated webpages). Final refinements were then made to all topic-based information, based on the pharmacist's review.

3.4 Site- and Page-Content–Based Features

Guided by the work of Schwarz and Morris, we also identified *on-page* and *off-page* features of the included webpages, based on their relevance to our design goals. On-page features included information about the domain type (e.g., .gov and .edu), the number of ads on the page, and whether or not there were patient testimonials or reviews of the medication on the page. Off-page features included the detection of Health on the Net (HON) certification and Utilization Review Accreditation Commission (URAC) accreditation of the hosting institution. HON (www.hon.ch) and URAC (www.urac.org) are nonprofit organizations promoting healthcare quality by verifying that consumer-friendly quality guidelines are followed. The Google "page rank" score of the webpage was also collected. If no score was available for the page, the rank of the hosting site was used. We ordered the search results according to this page rank, to approximate the order of search results one might expect from a general-purpose search engine. While automated approaches to detecting on- and off-page features have been demonstrated to be technologically feasible [30], we collected these data manually to minimize the likelihood of error.

To populate the search user interface, we created a SQL database to store webpage addresses and description information from site meta-data, article titles, URLs, on- and off-page features we collected, and all associated topic information, including topic clusters containing relevant page excerpts. The search interface was created using HTML with JavaScript and PHP, and hosted on one of our institution's secure web servers in a password-protected directory.

4. Two-Phase Study

4.1 Participants

4.1.1 Inpatient Field Study Participants

We conducted the inpatient portion of our study in the surgical cardiac unit at NewYork-Presbyterian Hospital, a large, urban academic medical center. Our study was approved by the medical center's human subjects institutional review board.

Post-operative cardiothoracic surgery patients were invited to participate in the study after consultation with their providers and were included based on their physical and mental capability to participate and ability to speak English. Twelve patients (eight male), age 48–88 (mean=66), participated. In two of these cases, visiting spouses (both female) performed the search task, indicating that they were the most likely to search for information at home. In another two of the cases, family members participated along with the patient in interviews. A review of the patient participants' medical records indicated that each had previous experience managing a heart condition. However, to explore non-expert patient search, the search task included active medication therapies administered to the patient during their care, with which they were unfamiliar.

4.1.2 Domain Expert Participants

We recruited eight domain experts: two nurses (each with two years of experience), four pharmacists (with four to six years of experience), and two fourth-year PhD candidates conducting HCI research on the display of medication information to patients.

4.2 Methods

4.2.1 Inpatient Field Study Methods

Patient and family member participants engaged in study sessions lasting 40–60 minutes, the variation in time being largely due to interruptions related to the administration of care during study interviews.

After providing informed consent, each patient was given a Wi-Fi–connected first-generation iPad computer and, if necessary,

was given a brief training session on its use. The computer was set up to display a password-protected webpage with the patient's inpatient medications, created by software that we had previously created [34]. Patients and participating family members were then asked to comment on medications in the list that they had experience taking, and to point out unfamiliar medications. The study coordinator noted unfamiliar medications as query candidates for a later search task.

4.2.1.1 Prior Experiences with Medication Information Search

Following a semi-structured format, we asked participants to describe prior experiences searching for medication information. These questions covered specific medication-related topics for which participants had searched, and their strategies when seeking web-based medication information. For example, participants were asked to comment on how they identify relevant sites to visit, and how many resources they consult during a typical medication information search.

4.2.1.2 Inpatient Search Activities

Demonstration and Free-Form Use

After discussing participants' previous search experiences, we introduced Remedy and demonstrated the filtering tools and topic browsing capabilities by querying a drug on the inpatient medication list. When possible, we queried a drug already familiar to the participant for training purposes. We then encouraged participants to explore the tools by conducting free-form searches of their choosing.

Structured Search Activities

After free-form use of the tools, we selected an *unfamiliar* medication from the patient's inpatient medication list and explained to participants that we were interested in observing them during a web search related to it.

While it was not our goal to evaluate the tools by comparing them to a benchmark, we wished to explore how the search behaviors elicited by our tools departed from the general-purpose experience. While we ultimately see our techniques and tools as augmenting, not replacing, existing search technologies, we wished to observe the specific preferences and search behaviors elicited by our tools, and to give patients and their family members a basis from which to reflect on their experiences using the probe.

To do this, we asked participants to use a search technology with which they were familiar, in addition to Remedy, explaining to them that we were exploring the applicability of different technologies on medication information search (to mitigate demand characteristics, we did not identify the probe as "ours"). Thus, participants were asked to use both the probe and one general-purpose search engine (Google, Bing, or Yahoo) of their own choosing to perform a query for the same medication information topic. These general-purpose engines detect queried drug names as such, and provide keyword-based text previews in the search interface along with class information and often, chemical structure.

We counterbalanced the order in which Remedy and the general-purpose search engine were used for the search activity. The same search was conducted with both, all in the Safari browser. Participants were randomly asked to search for information on uses, precautions, or factors affecting dosage, and to find this information on a credible health information site (point out to the study coordinator the information relevant to the query, on a page they found to be a credible source of information, once they determined its relevance). The study coordinator manually noted time spent and individual actions taken with each technology (e.g., scroll though first page of results, read result title information, select result, return to view of search results). We then asked the following questions related to their preferences:

1. *If you were given a new medication and wanted to search for web-based information about that medication, which of the two search technologies would you choose to use? Why?*
2. *If these tools were part of the current search engine that you use, would you use them? Why or why not?*

4.2.2 Domain Expert Study Methods

We engaged each domain expert in individual study sessions lasting 30–45 minutes each. These sessions were conducted either in-person in a private conference room or using web conferencing software. We demonstrated the tools by first querying for a drug that they selected, and explained the search tools, including the filtering tools and topic browsing capabilities.

4.2.2.1 Domain Expert Search Activities

As in the inpatient field study, experts were introduced to Remedy and encouraged to use it in a free-form manner before a structured activity. We explained to these participants that we were comparing different technologies to understand their applicability to non-expert, patient-centered medication information search. As in the previous phase, we did not identify the probe as "ours." We asked experts to use both Remedy and one general-purpose search engine (Google, Bing, or Yahoo) of their own choosing to perform a query on the same medication information topic. We counterbalanced the order in which the two search technologies were used to complete the search. Searches were conducted in the participant's preferred browser. (The user experience of the tools was consistent across IE, Firefox, Safari, and Opera.)

We asked domain experts to adopt the role of a non-expert when using the technologies. We randomly selected a medication from the list of available ones and for consistency with the inpatient search task, asked them to search for information on either precautions for using the medication, factors affecting the dosage, or uses of the drug. We noted steps that the participant took, as in the inpatient task described above. Upon completion of the search activity, we asked each participant the following questions:

If you were asked to recommend a search engine for finding web-based information to a patient or non-exert caregiver, which of the two search engines would you recommend? Why?

4.2.2.2 Debriefing Interview

After completing the search task, both inpatient participants and experts were asked to interact with each of the search tools in Remedy (described above) and to comment on their perceptions of the usefulness of each. They were also asked to recommend improvements to the tools, or design refinements.

5. RESULTS AND DISCUSSION

Below, we present findings from our two-phase study. Our findings reinforce the importance of each of the valuation principles underlying our tools, and suggest insights related to the design of future tools based on them.

5.1 Inpatient Search Behavior

5.1.1 Navigating to the Right Information

All inpatient participants chose to use Google as their preferred general-purpose search engine for the search activity. In general, most participants had a domain vocabulary that differed from standard usage—even on consumer-oriented pages. For example,

when using the standard search engine to find information on medication precautions, participants used keywords that were technically incorrect, such as "side effects" and "interactions."

Inpatient participants also spent more time assessing and pointing out relevant, credible information using the general-purpose search engine. Participants spent an average of 72 seconds using the general-purpose search engine, versus 40.5 seconds using the probe, before they could confidently identify relevant, credible, information. They also struggled with incorrect, keyword-based results (e.g., "using the drug" versus "uses of the drug"), which we found were conflated when using the general-purpose search engine. A comparative analysis with a larger participant pool using the tools in a controlled environment is necessary to further validate our findings. Our primary goals in this study phase were to gain preliminary confirmation that using the tools did not instead *slow users down*, and to understand whether and how patients responded to the availability of the search tools.

5.2 Patient and Family Member Responses

5.2.1 Search Interface Preferences

Ten of 12 inpatient participants chose Remedy over the general-purpose search engine when asked which experience they preferred. One patient of the 12 did not choose either, asking us to conclude the interview after he completed the search activities, due to discomfort. The remaining patient mentioned that he felt more comfortable with a well-known search technology. All participants mentioned that, given the opportunity to use the tools within the current web search experience, they would.

5.2.2 Participants Preferred Topic-Based Tools

Participants were uniformly positive about both the display of topic-based information and filtering tools in the probe's search interface. Several mentioned that, while they might not choose to use certain filters, they found them important to include. Most participants (11 of 12) preferred the topic-specific tools to the filtering tools. Of these 11, five participants indicated that the topic map was the most important, while four indicated that "Browse by Topic" was the most useful. The remaining two found the topic map and "Browse by Topic" equally important. Below, we illustrate how inpatient participants made use of the topic-based tools.

When commenting on the importance of the short snippets viewable in the interactive topic map, P1 explained that, "*I don't want to look at a ton of pages. But I want to see where sites agree or disagree. This is concise. I like these [snippets] better*." P3, a family member participating in the search activity, highlighted similar benefits of the topic-based browsing feature after doing a search for Amiodarone dose: "*It's comparative and very specific…if I'm ignorant, [a] number doesn't mean as much to me unless it's reinforced by a judgment type word, weighted. I like seeing the combo*." P11 also appreciated the ability to see multiple topic-related excerpts from the returned results, indicating that she liked "*seeing multiple page excerpts because when I search, I don't just go to one. There [is] always something new in each site I visit unless it's just stats. But even that, I cross-check. It helps to see that sites have the same info.*"

While browsing multiple topic-based excerpts was important to these patients, they also commented on the ability to use the topic-based tools to help find specific information when keywords were unknown. P6 commented on the importance of quickly locating the specific information he needs, explaining, "*I like this 'Browse by Topic' because I can zero in on it.*"

5.2.3 Participants Sought Personal Medication Management Resources in Addition to Factual Information

While study participants mentioned that the search tools embodied in the probe presented relevant information, several also proposed that many of their information needs related specifically to medication management went unmet. For example, several patients desired that additional resources be included in the search result interface—either integrated into the results, or included in a sidebar. Patients suggested links to resources to help manage the cost of a medication and tools to locate articles dealing with differences between generic versus brand-name drugs, tools to simultaneously compare summaries of consumer reviews with professionally-written, and tools to locate articles dealing with differences between generic versus brand-name drugs and alternative and complementary drug therapies. A few patients also suggested that site ownership information be made clearer in the search results. As P11 stated: "*I'd like to know the tie-in to a corporation, [or] who owns the company promoting the site*."

5.2.4 Non-Experts Desired Advanced Content

Though patients in our study considered themselves non-experts in health-information search, all patients had previous experience managing a heart condition, and several had experience reviewing online information related to one or more conditions. While our tools do not currently allow users to filter *out* advanced content, they do provide annotations for individual results that contain information written at an advanced level, to help users identify them. We were interested in patient responses to the annotations in each result, as well as the "Advanced Content" filter.

Half the inpatient participants in our study anticipated that they would filter results to include *only* advanced content during some of their searches. Only four did not find the filter useful, three of whom mentioned that they would prefer instead to be able to *remove* results containing advanced content. This difference in opinion sheds light on the diversity of patients' needs: once experienced at managing a condition, patients often conducted further research to clarify side effects versus symptoms, or determine if they should request a change in their medication. P8 commented that he searched for information online, rather than consulting only one credible site, to find more in-depth information on his medications, explaining, "*I would go to an FDA site, but you know they don't really provide that much info.*"

5.2.5 Participants Desired Additional Tools to Curate Consumer Perspectives

Five participants of 12 did *not* find the "Patient Reviews" filter to be useful, yielding the most divergence in preferences. P1 commented that: "*I don't want just generic reviews. People don't know what they're talking about*." However, five inpatient participants mentioned that they found patient-contributed reviews particularly useful to them, and two indicated that this filter was one of the *most* important to include in the search tools. These patients also noted that caution might be needed in interpreting peer advice. As P12 explained, "*I also want to see, what are* good *reviews*."

Patients who valued quick access to patient reviews commented on the potential to learn from peers when making decisions about changes in therapies or treatments. They also mentioned the potential for encouragement in pursuing similar or complementary therapeutic goals. As P7 expressed, "*I'm interested in the effectiveness of the brand versus generic. The patient reviews would be useful for that*." P13 mentioned his desire to learn from similar

patients, but mostly about measures they took to reduce their reliance on pharmaceutical drugs when exploring therapies for his condition. He commented, "*I would like to see, this person, he walked more and so he doesn't need the medication now*." This comment points to the need for tools to help consumers not only to locate trustworthy information about a specific therapy, but also to explore, in the context of health-related information search, the experiences of peers who have related conditions, therapeutic regimens, and goals.

5.2.6 Participants Used Multiple Tools to Determine Credibility, Applying Them to Suit Individual Needs

We found that all patients expressed interest in tools to permit greater verification of information and selection of trustworthy resources. Five patients of 12 found the "Reviewed by Experts" filter to be the most useful, while several volunteered that using the "Academic/Non-profit" filter to view non-commercial information would help them to find credible content. For his search activity P15 looked for information from a credible source, on uses of the antibiotic, Vancomycin. Afterward, he commented that when searching using Google, the first result returned was a Wikipedia page. *"[Wikipedia] might give me a snapshot, but I wouldn't rely on it.*" Using our tools, this patient filtered results using the "Reviewed by Experts" filter.

Interestingly, some patients expressed their feeling that the non-commercial content filter (labeled Academic/Non-Profit) might yield more trustworthy results than certain commercial sites—even commercial sites certified by an expert review panel. P11 did *not* find the "Reviewed by Experts" filter to be useful, but valued the "Academic/Non-Profit" filter the most. She said, "*Who is the expert? Bogus things happen*." Her preferences, shared by other participants, point to a valuable area of future work focused on better supporting recognition of trustworthy information based on combining expert- *and* user-defined criteria.

5.2.7 Identifying Advertisements was Difficult

During her search activity, P2 encountered difficulty while searching for Heparin precautions. Mistaking an advertisement for an educational video, she was redirected to different page. This patient had initially navigated to a site not deemed credible by organizations such as HON, but that appeared in the top set of results of the general-purpose search engine. P3 had an easier time with the task, but recalled cases during the interview in which she was confused by ads: *"I've gone to pages where there are a lot of ads… and I just turn the whole thing off*." We found that most participants appreciated annotations showing the number of ads on the page of each result. While P4 commented that the annotations were not particularly useful since "ads are unavoidable", several other patients, such as P14, thought that awareness of ads in the search results would help him "*go to sites without too many ads*."

5.3 Expert Responses

5.3.1 Search Tools Preferences

Experts were also uniformly positive in their review of the tools. However, three of the four pharmacists objected to allowing easy navigation to consumer-contributed information. These pharmacists mentioned that reviews describing negative experiences might originate from patients who incorrectly followed treatment instructions, or who took additional medications that were not accounted for in the review. These pharmacists also had concerns that reviewers might confuse symptoms related to their illness with side effects of medications, making it harder for the reader to objectively weigh the risks of taking the medication. As E8 explained, *"It's just too hard to tell how reliable it is."*

Expert participants in our study viewed the remaining tools favorably. Two experts found the topic map included with each search result to be the most helpful, while the remaining six highlighted the importance of the "Reviewed by Expert" filter, the non-commercial content filter, and the pill images filter. Many of the participants suggested that information about how the filter worked be included directly in the user interface (e.g., explaining HON and URAC accreditation for the "Reviewed by Experts" filter).

5.3.2 Experts Emphasized a Need for Safety-Related Information in the Search Result Interface

Experts made several recommendations for improving the medication-information search user interface. Four of the eight recommended that a static view be provided when medication search results are returned, including a summary of uses, the generic name with popular brand names of the drug, and its drug class. One nurse in our study, E1, mentioned the importance of the order in which the topics are listed in the "Browse all results by topic" section of the user interface. This nurse commented that, "*For different meds, the relative importance of the topic might change. It might be good to reflect that somehow. For example, for Tylenol 'overdose' is really important, maybe the most important topic, because acetaminophen is in so many OTC [Over-the-Counter] drugs."*

Pharmacists recommended that medication search results indicate whether or not the queried medication is included in the therapeutic guidelines of organizations such as the American Heart Association. Pharmacists also recommended that web resources addressing different strengths of medication, and immediate versus extended release formulas, be more clearly indicated. As E6 mentioned, "*Some people have more difficulty than others when switching from the 'immediate release' form [of a medication] to an 'extended release' one*."

Several experts in our study mentioned dissatisfaction with the quality of the online medication information they encountered during the search activities. Pharmacists and nurses stated they would encourage consumers to avoid a general-purpose search technology, preferring instead that experts directly supply information from resources such as PubMed (pubmed.gov), UpToDate (uptodate.com), and Micromedex (micromedex.com). Interestingly, these preferences stress the inclusion of an expert to vet these resources and overlook the role of credible consumer resources (e.g., WebMD and MedlinePlus).

6. CONCLUSIONS

We presented results of a study incorporating qualitative interviews and use of Remedy, a technology probe embodying tools to support patient-centered evaluation of medication-related web search results. Our tools draw from four health resource valuation principles that we distilled from a literature search: *credibility, readability, consumer perspectives* and *topical relevance*. Through an inpatient field study with cardiothoracic surgery patients and their family members, and expert usage sessions and interviews, we found that the tools provided in our probe were well received. Our findings reinforce the importance of each of the valuation principles underlying our tools, and suggest important insights for the design of additional future tools.

Inpatient participants in our study found several of the tools to be important, largely favoring the topic-based tools. Experts in our

study were also positive about the search tools we introduced, but found many of the resources designed for consumers to be of low quality, emphasizing the usefulness of the "Reviewed by Experts" filter and the need for safety-related features to augment the search result user interface.

The positive responses we observed suggest that this problem space is important to investigate further. Work at the intersection of HCI, machine learning, and public health is needed to develop tools to further aid consumers in evaluating online health information.

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8. REFERENCES

[1] Abbasi A, Zahedi F, Kaza S. Detecting Fake Medical Web Sites Using Recursive Trust Labeling. *Proc ACM TOIS 2012*. 30(4): 22.

[2] Amazon. *Mechanical Turk*. https://www.mturk.com/ Accessed on March 08, 2014.

[3] Berland GK, Elliott MK, Morales LS, et al. Health information on the Internet. *JAMA*, 285(20), 2001, 2612-2621.

[4] Billman D. and Bier E. Medical sensemaking with entity workspace. *Proc ACM CHI 2007*, 229-232.

[5] Blei D and Lafferty J. *Text mining: Theory and applications, chapter topic models*. 2009, Taylor and Francis, London.

[6] Brody S and Elhadad N. Detecting salient aspects in online reviews of health providers *Proc AMIA 2010*, 202.

[7] Chang J, Boyd-Graber J, Gerrish S, Wang C, Blei DM. Reading tea leaves: How humans interpret topic models. *Proc Advances in neural information processing systems 2009*, 288-296.

[8] Cheng W-H and Gotz D. Context-based page unit recommendation for web-based sensemaking tasks. *Proc ACM IUI 2009,* 107-116.

[9] Collins SA, Currie LM, Bakken S, Vawdrey DK, Stone PW. Health literacy screening instruments for eHealth applications: A systematic review. *J. Biomed Informatics*, 45(3) 2012, 598-607.

[10] Dalgaard L, Gronval E, Verdezoto N. Accounting for medication particularities: Designing for everyday medication management. *Proc PervasiveHealth 2013*, 137-144.

[11] Dontcheva M, Drucker S, Salesin D, Cohen M. Relations, cards, and search templates: User-guided web data integration and layout. *Proc ACM UIST 2007*, 61-70.

[12] Eysenbach G and Köhler C. How do consumers search for and appraise health information on the World Wide Web*? British Med Journal*, 2002. 324(7337):573.

[13] Fogg B, Soohoo C, Danielson D, Marable L, Stanford J, Tauber E. How do users evaluate the credibility of web sites?: a study with over 2,500 participants. *Proc Designing for User Experiences 2003*. ACM, 1-15.

[14] Fox S. *The social life of health information*, in *Pew Internet & American Life Project* 2011. http://www.pewinternet.org

[15] Fox S and Duggan M. *Health Online 2013*, Pew Internet & American Life Project. http://www.pewinternet.org

[16] Greenberg L, D'Andrea G, Lorence D. Setting the public agenda for online health search. *Journal of Medical Internet Research*, 2004. 6(2).

[17] Hutchinson H, Mackay W, Westerkund B, et al. Technology probes: Inspiring design for and with families. *Proc ACM CHI 2003*, 17-24.

[18] Jadad A and Gagliardi A. Rating Health Information on the Internet: Navigating to Knowledge or to Babel? *JAMA*, 1998. 279(8): 611-614.

[19] Kan M-Y, McKeown K, and Klavans J. Domain-specific informative and indicative summarization for information retrieval. *Proc Document Understanding Conference 2001.*

[20] Khan D, Seik K, Meyers J, Haverhals L, Cali S, Ross S. Designing a personal health application for older adults to manage medications. *Proc ACM IHI 2010.* 849-858.

[21] Kim J, Collins-Thompson K, Bennett P, Dumais S. Characterizing web content, user interests, and search behavior by reading level and topic. *Proc ACM Conf Web Search and Data Mining 2012.* 213-222.

[22] Marcus S. *Library of Congress Guide to Locating Health and Medical Information*. http://www.loc.gov/rr/ scitech/SciRefGuides/medicalinfo.html.

[23] Martin A, Jones J, and Gilbert J. A spoonful of sugar: Understanding the over-the-counter medication needs and practices of older adults. *Proc IEEE Pervasive Health 2013.*

[24] McCallum AK. *Mallet: A machine learning for language toolkit*. http://mallet.cs.umass.edu.

[25] NLM. *MedlinePlus guide to healthy web surfing*. http://www.nlm.nih.gov/medlineplus/ healthywebsurfing.html.

[26] Pang B and Lee L. Opinion mining and sentiment analysis. *Foundations and trends in information retrieval, 2008*. 2(1-2): p. 1-135.

[27] Peterson G, Aslani P, Williams K. How do consumers search for and appraise information on medicines on the Internet? *Journal of Medical Internet Research*, 2003. 5(4).

[28] PriceWaterhouseCoopers. *HRI Social Media Consumer Survey*, in *PwC Health Industries Registration* 2012.

[29] Rains SA and Karmikel CD. Health information-seeking and perceptions of website credibility. *Computers in Human Behavior,* 2009. 25(2):544-553.

[30] Schwarz J and Morris M. Augmenting web pages and search results to support credibility assessment. *Proc ACM CHI 2011*, 1245-1254.

[31] Sillence E, Briggs P, Harris P, Fishwick L. How do patients evaluate and make use of online health information? *Social Science & Medicine*, 2007. 64(9):1853-1862.

[32] Slater MD and Zimmerman DE. Descriptions of web sites in search listings: a potential obstacle to informed choice of health information. *American Journal of Public Health*, 2003. 93(8):1281.

[33] Steyvers M and Griffiths T, Probabilistic topic models. *Handbook of Latent Semantic Analysis*, 2007, 424-440.

[34] Vawdrey D, Wilcox L, Collins S, et al. A tablet computer application for patients to participate in their hospital care. *Proc AMIA 2011*, 1428-1435.

[35] Wang L, Wang J, Wang M, Li Y, Liang Y, Xu D. Using Internet search engines to obtain medical information: a comparative study. *Journal of Medical Internet Research*, 2012. 14(3): e74.

[36] Wei F, Liu S, et al. Tiara: A visual exploratory text analytic system. *Proc ACM SIGKDD 2010,* 153-162.

[37] Wilcox L, Feiner S, Elhadad N, Vawdrey D, Tran T. Remedy: supporting consumer-centered medication information search. *Proc PervasiveHealth 2013,* 317-318.