Experiences with Web Search on Medical Concerns and Self Diagnosis

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Abstract

The wealth of medical information on the Web makes it convenient for non-experts to conduct their own diagnosis and healthcare assessment based on limited knowledge of signs, symptoms, and disorders. We present the findings of a survey aimed at exploring laypeoples' activities and experiences with using Web search to pursue explanations for symptoms. Survey findings suggest that the Web may influence anxiety levels and behaviors of those searching for information on undiagnosed conditions. A better understanding of consumer experience regarding the use of the Web to interpret symptoms can assist in the refinement of healthcare content and retrieval.

Introduction

Web sites such as WebMD and MayoClinic can provide valuable healthcare information to non-expert consumers about whether their perceived symptoms might indicate a serious condition, or whether such fears are unfounded. However, popular general-purpose Web search engines such as those provided by Google, Yahoo!, and Microsoft are more frequently used by consumers to access online medical information.[1] In response to a query for one or more relatively common symptoms, Web search engines may retrieve pages that contain alarming content that can alert consumers to the possibility of serious illnesses without providing information about their likelihoods versus benign explanations. This may occur for several reasons, including the relatively large quantity of Web content describing serious illnesses compared to benign conditions, and the potential use of ranking algorithms based on historical click-through data.[2] Presenting people with troubling and even worst-case scenarios in the absence of clear likelihood information can raise concerns, as the high availability of concepts on the Web may increase the subjective probability of disorders.[3]

For some time the medical community has expressed concern regarding the reliability of Web-based medical content and the likelihood of erroneous information to mislead users with health concerns.[4] Indeed, studies have shown that, although 80% of American adults have searched for healthcare information online, 75% refrain from verifying key quality indicators such as source validity and source creation date.[1]

Web search may be inappropriate if used as a diagnostic procedure, where queries describing symptoms are input and rank and information of results are interpreted as diagnostic conclusions. In earlier work[2], we used the term *cyberchondria* (coined by the popular press) to refer to the unfounded escalation of concerns about common symptomatology based on the review of search results and literature online. We pursued the hypothesis that information obtained from medical searches can affect peoples' concerns, their decisions about when to engage a physician for assistance with diagnosis or therapy, and their overall approach to maintaining their health or the health of a loved one. We leveraged large quantities of anonymized interaction logs from consenting users of a widely-distributed browser toolbar, allowing us to investigate natural Web search behaviors at scale. Our prior study lacked qualitative data on the pursuit of medical Web content.

In this paper, we describe a comprehensive survey of peoples' experiences in addressing medical concerns via the Web and in performing self diagnosis online. By gathering self-report data from over 500 volunteers, we aim to answer the following research questions: (i) what are characteristics of Web-based medical diagnosis? (ii) are these associated with age or gender? (iii) what key dependencies among characteristics might be discovered? We discuss related research, describe the survey, present relevant findings, and discuss them and their implications.

Related Work

Recently there has been significant interest surrounding health-related information seeking. Search and retrieval studies have been performed on expert and consumer populations. Hersh and Hickam[5] provide a review of the use of information retrieval by physicians to support clinical question-answering and decision-making. Benigeri and Pluye[6] showed that exposing people with no medical training to complex medical terminology may put them at risk of harm from self-diagnosis and self-treatment. Bhavnani[7] examined the search strategies of medical experts and non-experts, and identified a set of domain-specific search strategies that experts employ.

Studies have also been performed on the challenges associated with the perusal of medical Web content.

Cline and Haynes[8] present a relevant review that suggests that public health professionals should be concerned about online health seeking, consider potential benefits, synthesize quality concerns, and identify criteria for evaluating online health information. Eysenbach and Köhler[4] systematically reviewed health Website evaluations and found that the most frequent quality criteria included accuracy, completeness, and design ($e.g.$, visual appeal, readability). They also noted that 70% of studies they examined concluded that the quality of health-related Web content is low.

Sillence et al.[9] studied the influence of design and content on the trust and mistrust of health Websites. They conducted an observational study of a small number of subjects engaged in structured and unstructured search sessions. They found that aspects of design appeal engendered mistrust, whereas the credibility of information and personalization of content engendered trust. Lewis[10] discusses the growing trend towards the general population accessing information about health-related matters online. Lewis performed a qualitative study into young peoples' use of the Web for health material indicating that they are often skeptical consumers of Web-based health material.

Baker et al.[11] examined the prevalence of Web and e-mail use for healthcare, and the effects that they have on users' knowledge of healthcare matters and their use of the healthcare system. Using self-reports, they found that people rarely use email to communicate with physicians and that the influence of the Web on the utilization of healthcare is uncertain. Eastin and Guinsler[12] investigated the relationship between online health information seeking and health care utilization ($e.g.$, visiting a general practitioner). Their findings suggest that an individual's health anxiety moderates the relationship between online health information seeking and healthcare utilization.

The prior studies have not asked searchers about their experiences with the Web when pursuing information on potentially concerning symptoms. We address this shortcoming with the survey we now describe.

Survey

We designed a survey to elicit peoples' perceptions of online medical information, their experiences in searching for this information, and the influence of the Web on their healthcare concerns and interests. The survey was anonymous, contained around 70 open and closed questions, and covered a broad range of issues in the health domain, including medical history and engagement with medical professionals. We pre-tested the instrument with six volunteers and iterated on wording to help ensure question clarity. Five-point scales were used to measure frequency, with the following response options: *Always*, *Often*, *Occasionally*, *Rarely*, and *Never*. The survey is available from the first author upon email request.

The survey was distributed and analyzed electronically. We sent an email invitation to 5,000 randomly-chosen employees within Microsoft's extended campus in Redmond, Washington. In total, 515 volunteers, who indicated in a pre-screening that they searched the Web for medical information, completed the survey, for a participation rate of 10.3%.

Findings

We shall now provide general information about subjects and their medical search behaviors, then focus on how people search for information about undiagnosed medical conditions and the Web's role in supporting the diagnosis and treatment of known conditions. We further condition findings on gender and on answers to pivotal questions about subjects' experiences.[†] To determine the statistical significance of observed differences we use chi-squared tests (χ^2) and independent-measures t-tests, and test for significance at $p < .05$ and $p < .01$. We denote the mean and standard deviation by M and SD respectively.

Background and Medical Web Search Behavior

Subjects provided demographic information about their gender and age. Of the 515 volunteers, 350 were male and 165 were female. The mean average age was 36 years (median = 35 years, SD = 8 years). Subjects reported that they mainly used Google, Live Search, and Yahoo! to search for medical information online, performed 5-10 medical searches per month, and had novice levels of domain knowledge in the medical areas within which they searched. Approximately 4% of subjects were self-reported hypochondriacs and around 5% had been "called a hypochondriac" by friends, family, or medical professionals. Subjects who self-identified as hypochondriacs performed over five times the average number of health-related searches. Three quarters of subjects reported searching for symptoms and two thirds reported searching for professionally-undiagnosed conditions at least once per month. Subjects generally searched for medical information for themselves (rather than family members, friends, or colleagues), although we observed a significant difference in the percentage of men and women searching on their own behalf (66% vs. 53% respectively; $\chi^2(1)=6.2$, $p<.01$). Further analysis indicates that women search on behalf of relatives more frequently than men.

[†] We also tested for age effects by performing correlation analyses and grouping subjects by age ($e.g.$, < 25, 25-30). However, no significant associations between age and survey responses were found. We suspect that this is partly due to the single-digit group sizes obtained when filtering based on age and other criteria simultaneously.

#	Question		Group			Subject marginalizations					
						RankAsLikelihood		*Hypochondriac*		*OverThreshold*	
			All	Male	Female	Always	Never	Yes	No	Yes	No
		N ▸	515	350	165	14	115	18	497	122	393
1	On average, how many health-related Web searches do you perform per month?	M	8.2	9.0	6.6	20.6	5.9	37.5	7.1	11.0	7.4
		SD	35.6	37.8	29.5	34.7	12.8	66.4	30.8	26.7	6.3
2	On average, how many Web searches for professionally-undiagnosed medical conditions do you perform per month?	M	2.1	2.3	1.8	4.9	1.2	4.8	2.0	2.7	1.9
		SD	5.8	6.7	3.2	13.1	2.0	7.5	5.8	5.8	5.9
3	Approximately how many times in the past five years have you been very concerned about a serious medical condition based on your own observation of symptoms *when no condition was present*?	M	3.5	3.9	2.6	3.6	1.9	4.0	3.5	4.8	3.1
		SD	8.6	10.3	4.2	7.1	1.5	5.0	8.8	12.8	4.8
4	On a scale of 1 to 10, how would you rate your overall anxiety about potential medical conditions that are not present or currently undiagnosed?	M	2.8	2.8	2.7	3.3	2.2	5.5	2.7	3.4	2.6
		SD	1.7	1.7	1.7	1.6	1.5	1.2	1.7	1.8	1.6
5	How often do your Web searches for symptoms / basic medical conditions lead to your review of content on serious illnesses?	% *Always/ Often*	21.1	19.3	25.0	28.4	14.8	43.8	20.3	36.9	16.2
6	Has searching for health-related information online ever made you feel *more anxious* about a perceived medical condition?	% *Yes*	38.5	35.4	45.2	45.7	29.6	66.8	37.5	57.4	32.6
7	Has searching for health-related information online ever made you feel *less anxious* about a perceived medical condition?	% *Yes*	50.3	49.6	51.7	37.4	64.3	31.9	51.0	36.3	54.7
8	Does searching the Web for health-related information make you behave differently with respect to a perceived medical condition?	% *Yes*	39.2	38.9	39.9	78.6	32.2	66.7	38.2	58.2	33.3

Table 1. Responses on undiagnosed conditions. Statistically-significant differences are marked on column boundary between the two samples (○ $p < .05$, ● $p < .01$). Rows 1-4: independent-measures t-test, Rows 5-8: chi-squared test.

Undiagnosed Conditions

To establish how subjects searched for undiagnosed conditions, we asked them to estimate the number of health-related searches and the number of searches for undiagnosed conditions they performed per month. Responses to each of these questions are summarized in rows 1-2 of Table 1, along with the question text. Trends suggest that women perform fewer health-related Web searches per month and that Web searches for undiagnosed conditions comprise approximately one quarter of health-related searches.

In addition to gender division, we conditioned our analysis on answers to pivotal questions, seeking to understand associations among key behaviors and assessments. We conditioned answers on:

1. *RankAsLikelihood:* "If your queries contain medical symptoms, how often do you consider the ranking of the Web search results as indicating the likelihood of the illnesses, with more likely diseases appearing higher up on the result page(s)?"
2. *Hypochondriac:* "Do you think that you are a hypochondriac?"
3. *OverThreshold:* "Do you believe that you have ever been in the situation where Web content "put you over threshold" for scheduling an appointment with a health professional, when you would likely have not sought professional medical attention if you had not reviewed Web content?"

We segmented subjects whom responded with *Always* or *Yes* to each of these questions and analyzed their responses to other questions relative to those whom responded with *Never* or *No*. Findings show that those whom report they "always" interpret result rankings as condition likelihoods (*i.e.*, *Always* for *RankAsLikelihood*), those whom self-identify as hypochondriacs (*Hypochondriac*), and those whom report that the Web has put them over the threshold for consultation with a medical professional (*OverThreshold*), all perform more medical searches, and search more frequently for undiagnosed medical conditions, than other subjects (all $t(127|513) \geq 2.0$, all $p \leq .02$).

We asked subjects to recount the number of times in the past five years that they were concerned about an unknown condition when no condition was ultimately present, to rate their overall anxiety about such conditions on a scale from 1 ("don't worry about health issues") to 10 ("severe anxiety"), how frequently they escalate after reviewing Web content (on five-point scale from earlier), and whether this review increases anxiety about a perceived condition. Responses are

#	Question		Group			Subject marginalizations					
						RankAsLikelihood		*Hypochondriac*		*OverThreshold*	
			All	Male	Female	Always	Never	Yes	No	Yes	No
		N ▸	515	350	165	14	115	18	497	122	393
1	Have you used the Web to search on medical conditions that have been diagnosed by a health professional?	% *Yes*	81.4	78.0 ○	88.5	85.7	82.6	83.3	81.3	85.5	80.1
2	Did your use of the Web occur solely after your diagnosis?	% *Yes*	26.8	28.3	23.6	14.3	36.5	9.4	27.4	17.5	29.7
3	Did the Web help reassure you?	% *Yes*	76.0	72.6 ○	83.3	69.8	68.1	50.0 ●	76.9	70.8	77.6
4	Did the Web help you understand the terminology / explanation used by the health professional?	% *Yes*	77.9	75.8	82.4	78.6	76.5	83.3	77.7	82.0	76.6
5	Did the information help you to actively participate in the conversation with the health professional?	% *Yes*	64.9	63.2	68.5	64.3 ○	51.3	83.3 ●	64.2	79.6 ○	60.3
6	Did you inform the health professional that you had gathered health-related information on the Web?	% *Yes*	60.2	55.9 ○	69.2	54.6	55.2	73.3 ●	59.7	71.4 ●	56.7
7	Did you feel uncomfortable in bringing your own research to the health professional?	% *Yes*	13.7	15.2	10.5	14.3	5.2	20.0	13.5	15.9	13.0

Table 2. Responses on diagnosed conditions. Significant differences (with chi-squared test) marked ($^{\circ}$ $p < .05$, $^{\bullet}$ $p < .01$).

summarized in rows 3-6 of Table 1. Although not significant, findings suggest that women experience fewer concerns about unknown conditions, including those originating independently of the Web. They also suggest that the Web increased medical anxiety for 40% of subjects. Although the reported medical anxiety levels of men and women were similar, women more frequently experienced escalation and heightened anxiety from exposure to search results and Web sites (both $\chi^2(1) \geq 4.8$, both $p \leq .03$).

The main factors that contributed to subjects' anxiety when reviewing Web content were the mention of serious conditions (64% of subjects), the presence of escalatory terminology ($e.g.$, grave, fatal) (41%), and the lack of non-serious conditions (36%). Subjects also commented on the reasons behind their increased anxiety. Responses, coded to identify central themes, targeted worst-case outcomes ($e.g.$, "sometimes I learn of all the terrible things that *might* be wrong with me based on symptoms searched for"), relevance ($e.g.$, "sometimes the details can be very graphic or more severe than what your doctor would like you to know and may not be specifically relevant to your level of diagnosis"), and unreliability of content ($e.g.$, "too much panicky and uninformed or totally incorrect noise from unreliable sources on the Web").

When examining the association of the experience of anxiety with Web search and content with other survey responses, we found more anxiety about perceived medical conditions for subjects who responded *Always* or *Yes* to *RankAsLikelihood*, *Hypochondriac*, or *OverThreshold* (all $\chi^2(1) \geq 5.5$, all $p \leq .02$). These subjects' heightened medical anxiety may affect result interpretation and post-review behavior.

Subjects were asked to estimate how frequently Web search reduced anxiety about a perceived condition. Responses, summarized in row 7 of Table 1, show that around half of subjects were calmed by the Web, with little gender difference. They also show that the Web was less calming for those who responded *Always* or *Yes* to *RankAsLikelihood*, *Hypochondriac*, or *OverThreshold* (all $\chi^2(1) \geq 6.3$, all $p \leq .01$).

Subjects reported that their medical concerns were eased by authoritative sources (90% of subjects) or synthesis based on opinions from multiple Websites (48%). Subjects also provided explanations for why the Web reduced anxiety. Responses were on rationalizing concerns ($e.g.$, "sometimes the first thing you read about is a serious illness, but with more searching you find the probability of your symptom resulting in serious illness is small") and physician interaction ($e.g.$, "information is empowering and it enables you to discuss in more clarity with your doctor").

We asked subjects about whether their behavior was affected by searching for medical information related to a perceived medical condition. As shown in row 8 of Table 1, approximately 40% of subjects reported that they had experienced this. Of those who reported behavioral changes, 61% said that searches for potentially serious conditions increased, 72% said visits to Web pages describing their perceived condition increased, 62% said engagement with physicians increased, and 59% reported that engagement with medical specialists increased. Results suggest that

exposure to Web content can have a significant effect on behavior with respect to undiagnosed conditions.

Diagnosed Conditions

We also consider searches for known conditions ($i.e.$, conditions diagnosed by a medical professional). Over 80% of subjects reported that they had used the Web to search for a known condition. We asked whether their use of the Web occurred solely after diagnosis and whether the Web helped to reassure them. Subject responses are summarized in rows 1-3 of Table 2. They demonstrate that women are more likely to use the Web as a medical resource and be reassured by encountered content (both $\chi^2(1) \geq 4.6$, both $p \leq .05$), and that self-identified hypochondriacs were less likely to be reassured by the Web ($\chi^2(1)=5.4$, $p=.02$). Responses also show that most subjects gathered Web information before diagnosis.

We asked subjects if the Web helped them understand the terminology the physician used during their appointment or actively participate in the conversation, if they told the physician about their research, and whether they felt uncomfortable bringing it. The responses, summarized in rows 4-7 of Table 2, show that the Web was useful to subjects in understanding their physician's terminology. Most subjects, especially women, informed their physician that they had searched for information online ($\chi^2(1)=4.8$, $p=.03$). Of those whom shared their own research during the appointment, 37% said that they found the physician was happy to see them informed via the Web, 51% reported that their physicians were neutral, 5% reported that their physician was discontent or irritated, and 7% could not interpret their physician's feelings.

Discussion and Implications

We presented the findings from a survey of 515 participants' experiences with the online investigation of medical concerns and self diagnosis. We found that overall, people report to having a low level of health anxiety, but that Web-based escalation of concerns occurs frequently (*Always* or *Often*) for around one in five people. Two in five people report that interactions with the Web increases medical anxiety and approximately half of people report that it reduces anxiety. Traits such as a person's general anxiety level and predispositions to anxiety may contribute to the levels of medical anxiety experienced and to the likelihood of Web-induced medical escalation. Web content providers must be cognizant of their potential to heighten medical anxiety and consider the ramifications of publishing alarming medical information.

Our survey and analyses underscore the value of the Web in helping people to better understand medical conditions in tandem with professional advice. They show that Web content facilitates patient-physician interaction, but also suggest an opportunity for more receptiveness by clinicians to patients who engage them with findings from online medical research.

Additional surveys and analyses are needed to better understand potential participant selection biases. Also, further analysis can be performed to analyze dependencies among the answers to survey questions, so as to better understand the influence of combinations of demographics ($e.g.$, age, gender, education, location) and general anxiety. As Web content and search are evolving, such surveys conducted periodically and with different cohorts can help the medical informatics community to understand and track perceptions, activities, and outcomes associated with retrieving online health information.

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