Evolving Facets of Cyberchondria: *Primum non nocere* "First, do no harm"

Iryna Berezovska
Department of Computer Sciences, Ternopil State Technical University
56 Ruska St., Ternopil 46001, Ukraine
iberezov@hotmail.com

Karen Buchinger, BSN, MLS
Editorial Consultant
Central/Eastern New York Lead Poisoning Prevention Resource Center
Upstate Medical University, Department of Pediatrics
Room 5600, 750 E. Adams Street, Syracuse, NY 13210, USA
mylibrary@earthlink.net

Oleksandr Matsyuk
Department of Computer Sciences, Ternopil State Technical University
56 Ruska St., Ternopil 46001, Ukraine
kuba.molva@ukr.net

Abstract. *The phenomenon of cyberchondria continues to be hotly debated in periodicals and other media.*

This paper will continue the discussion of the concept in broad context and present an overview of some of the recent design recommendations developed by search engine architects that are intended to reduce the likelihood that health care information consumers who use the internet as a source of health information become excessively anxious about their health.

Findings from a recent survey, carried out in a population of Ukrainian and International students attending Ternopil National Technical University (TTNU, Ukraine) will be summarized to compare the search habits and health related-anxiety data of the student survey population to data related to the concept of cyberchondria that has been previously reported in other research populations.

Keywords. Consumer health information, The Internet, Information seeking, Cyberchondria, Cyberchondriac.

1. Introduction

The proliferation of consumer oriented health care information on the Internet and the deceptive ease of locating and accessing such resources through search engines have produced what is being considered a new phenomenon, and a new term for this phenomenon and its sequelae has arisen----*cyberchondria* [1]. *Cyberchondria* is still hotly debated in periodicals and other media, and recent studies have outlined a number of issues facing health care information consumers, healthcare providers and IT professionals related to this phenomenon [2].

This paper will continue discussing *cyberchondria* in broad context, present recent survey data, and review recent design recommendations developed by search engine architects to reduce the likelihood that health care information consumers may become excessively anxious about their health.

2. Online health-related information searching; motives, habits, and levels of anxiety

The ongoing amount of health care consumers' Internet search activity is so seemingly stable that the Pew Internet & American Life Project, Harris Interactive, Inc. and other researchers have stopped updating their reports; at least no additional recent data on Internet health information search activity is available on their public web-sites.

Although most health consumers persist in using a general search engine for online health information gathering, the search results now look somewhat different than in previous years,

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with sponsored links appearing first in combination with a more limited number of information sources that dominate the health information supply [3].

The motives behind healthcare consumers' decisions about whether and how to engage in health information seeking vary, depending on individual needs and circumstances. In order to understand more about online health information seeking activities we carried out a survey to determine health-related search habits and levels of health-related anxiety in Ukrainian and International students at Ternopil National Technical University (TNTU, Ukraine).

The survey form shown in the Appendix includes some similar questions from Table IV and Table X , used by the Microsoft researchers in their recently reported survey research [4].

White and Horvitz distributed their survey within the Microsoft Corporation, to randomly selected employees (350 males and 165 females; average age 36.3 years). They argue that they "have no evidence that the employees' experiences with medical Web search differ significantly from those of the general user population" [5].

At the TNTU, survey forms were completed by 66 students (49 males and 17 females; average age 21.7 years) who study computer science. Their responses to the survey questions are summarized in Table 1. In the discussion section we compare some of the survey data obtained from the student population to data reported by White and Horvitz [6].

Table 1. Responses to the survey questions at TNTU, Ukraine (66 student respondents)

1. Average number of health online searches per month	1.72
2. Average number of health-related online searches (for *professionally undiagnosed medical conditions)*	1.05
3. End-consumer of online search results: • Yourself • Relative • Friend or work colleague • Other	 65.91 % 6.82 % 11.36 % 15.91 %
4. Type of information saught: • Information on symptoms • Information on serious medical conditions • Medical diagnoses • Forums or pages describing others' experiences with similar conditions • Other	 34.09 % 9.09 % 29.55 % 27.27 % 29.55 %
5. Average self-rating of health-related anxiety (1-10 scale)	4.37
6. Being a hypochondriac – self-opinion: • Yes • No	 0 % 100 %
7. Being a hypochondriac – opinion of the people around: • Yes • No	 2.27 % 97.73 %
8. Unjustified self-diagnosis of a serious medical condition: • Yes • No	 29.55 % 70.45 %
9. Escalation of illness anxiety fueled by online search: • Always • Often • Occasionally • Rarely • Never	 2.27 % 13.64 % 27.27 % 29.55 % 27.27 %
10. The ranking of online search results is considered an indicator of the likelihood of diseases: • Always • Often • Occasionally • Rarely • Never	 0 % 0 % 43.18 % 29.55 % 27.27 %
11. The use of online search as a medical expert system: • Yes • No	 29.55 % 70.45 %
12. Scheduling an appointment with a health professional may be urged by the online health care information obtained during searches: • Yes • No	 29.55 % 70.45 %
13. The appointment disproved health concerns: • Yes • No	 34.09 % 65.91 %

3. Discussion of survey results

Of some note is that the student population in our survey performed far fewer online health-related searches per month than the Microsoft employees in the White and Horvitz study– 1.72 versus 10.22 per month, however the students' average health anxiety rating is much higher: 4.37 versus 2.78 in the Microsoft study. (Rating scale 1-10). High morbidity in Ukraine where 10 % of the students suffer from chronic diseases may explain the elevated health anxiety level reported by this student population group. The students in our survey population primarily search for themselves as the end-consumer and target information on general symptoms and possible medical diagnoses, not on the serious medical conditions that were typical search targets of the Microsoft employee survey population.

Nearly three (instead of four in the Microsoft study) in ten respondents reported self-diagnosing a serious medical condition based on their own observations, when no professionally diagnosed condition was present. The students were also far less inclined to review search content on more serious illnesses – 27 % of the student population responded that they never did so versus only 8 % in the Microsoft survey population.

There is an interesting difference in the data related to how respondents interpreted the ranking of online search results between the student survey and the Microsoft study population. While close to one-quarter of Microsoft respondents interpreted the ranking of online search results as indicating the likely presence of disease, all (100%) of the student respondents interpreted search results in this way only occasionally, rarely or never. Perhaps students' knowledge of probability theory and ranking algorithms plays a role in this case, although a significant proportion of them (29.5 %) had used Web search engines as if Web search functioned as a medical expert system.

Comparable proportions of both groups of respondents were persuaded to visit a health professional based on their review of online medical content. However more of the student population (65.9%) reported that they actually had a medical condition that warranted consulting a health care professional (their worries were justified) while only one in four of the Microsoft respondents were reassured that their worries were justified after consulting.

Our findings show that this group of young Internet users could be typified as rather discriminating consumers of online health information.

4. Consensus seems to arise in the doctor-patient-Internet triangle

A recent research study indicates that many patients do not consider the Internet as a substitute for a doctor consultation anymore [7]. They use the Internet as a convenient "first contact" in health-related information access because it is easy to do a search unobtrusively especially if they consider a health concern as too minor to ask a physician or other health care provider. These health-related information consumers then often turn to health care professionals for help in interpreting the confusing nature of online information or to assist in making important health-related decisions regarding diagnosis or treatment. Consumers do need this kind of doctors' support since focused and accurate information retrieval has become an increasing challenge. Even health care professionals who go through special training were found to be only moderately successful at gathering evidence for clinical question-answering with the assistance of literature searching through MEDLINE [8], so it is no surprise that consumers with far lower health literacy might be even less successful in obtaining accurate, relevant and understandable health information online.

The data from the Health Information National Trends Survey (HINTS) [9] agrees with Pew Internet's findings and shows that health consumers' trust in physicians has increased (odds ratio 1,29) with the rise of the Internet, while their trust in Internet information has declined slightly (odds ratio 0.74) over the time from 2002 to 2008.

Thus the Internet seems to take a more proper third party position in the doctor-patient-Internet communication triangle.

5. Conclusion

Since its identification, the main focus of efforts for reducing *cyberchondria* have been devoted to the development of specialized ranking algorithms and techniques for recognizing health-related queries so that they

can be specially handled. The Microsoft study authors suggest some opportunities [10]:

- detection of diagnostic intent
- providing expertise
- debiasing search results and searchers
- evaluating search results to flag candidates for escalation
- click-through tuning

Some IT-based solutions would involve:

- displaying additional information above search results, such as the overall incidence rates of relevant search terms
- linking a small set of the most popular queries with focused lists of results, in automated and handcrafted modes, that are less likely to create unjustified concerns about more serious diseases
- describing symptoms and signs in more detail and in terms that are clearer to information searchers
- creating a handcrafted list of queries flagged as candidates for escalation
- providing special ranking of Web pages frequently present in escalatory events; or submitting them for expert review
- adjusting of rank optimization methods based on input click-through and dwell data "to handle medical queries in a special manner, such that the escalatory potential of a page is also considered alongside interaction features such as the click-through frequency and dwell time when ranking search results" [11].

All these relatively sophisticated solutions, which may be expected to be implemented in the future, tend to formalize both health data presentation and diagnosis making. However, this may further complicate health information acquisition due to conceptual and linguistic mismatches between health care consumers and the architects of search engines.

Information system designers and architects of search engines frequently assume that health care consumers desire formal, objective, scientific, biomedical information, "while patients, their families, and their friends often prefer more subjective, informal information about the realities of coping with illness in daily life" [12].

When consumers fail to find materials relevant to their customary reading level, they may rely on "professional help in the process of retrieving credible information and in applying such information to their own health or illness situation by eliciting discussion with their healthcare professionals" [13].

According to the HINTS data [14], it is physicians who most frequently are asked to "translate" medical literature for their less health- and IT-literate patients. Such HINTS findings refer us again to the important subject of health literacy defined by the Institute of Medicine as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [15].

The survey we completed at the TNTU (Ukraine) illustrates that the student population we surveyed are not only skeptical consumers of online health information, they also are more analytical in interpreting online search results, and more careful in applying the retrieved information to their health problems and seem more balanced in seeking professional medical advice to interpret the information they have retrieved online. In other words, they appear to be less likely to become cyberchondriacs and they do not consider themselves to be hypochondriacal. We assume that any possible explanation of the survey responses should include a consideration of the younger age of the student population. In addition, their IT proficiency and general literacy which could be seen to be at a higher level than in the public in general, once again brings up the question of the impact of heath literacy.

Our findings encourage an alternate view of how the incidence of cyberchondria might be reduced in the future. Strategies of consumer education to develop health information literacy have already been well elaborated in the published literature elsewhere. Such health literacy education would be an effective supplement to the ongoing IT research regarding the improvement of search engine design.

C*yberchondria* is rooted in human behaviour and potentially exascerbated by some of the fundamental properties of Internet-based information systems and as such is not a "foreign body" in a health related Internet search which can be completely eliminated. The concept of *cyberchondria* requires continued examination and research study to be properly managed in the future so that the medical ethics

maxim of *Primum non nocere* "First, do no harm" can be upheld.

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Appendix

Health-related search habits and levels of health-related anxiety survey

1. On average, how many health-related Web searches do you perform per month?

2. On average, how many health-related Web searches for *professionally undiagnosed medical conditions* do you perform per month?

3. Who are your health-related Web searches primarily for?

4. When you seek health-related information online you generally search for? (multiple responses permitted)

5. 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 (1 = don't worry about health issues, 10 = severe anxiety)

6. Do you think that you are a hypochondriac?

7. Have you ever been called a "hypochondriac" by friends, family, or a health professional (e.g., a physician)?

8. Have you ever been concerned about having a serious medical condition based on your own observation of symptoms *when no condition was present*?

9. How often do your Web searches for symptoms / basic medical conditions lead to your review of content on serious illnesses?

10. If your queries contain medical symptoms, how often do you consider the ranking of Web search results as indicating the likelihood of the illnesses, with more likely diseases appearing higher up on the result page(s)?

11. Have you ever used Web search as a medical expert system where you input symptoms and expect to review possible diseases ranked by likelihood?

12. Do you believe you have been in the situation where Web content "put you over the 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?

13. Did the appointment reassure you that your worries were not justified?