Health Information Use: Preliminary Results from a Systematic Review

Laura Fry  
ExxonMobil  
Spring, TX  
Laura.a.Fry@ExxonMobil.com

Yleana E. Santos  
School of Information  
University of Texas at Austin  
yleana_santos@utexas.edu

Yan Zhang  
School of Information  
University of Texas at Austin  
yanz@ischool.utexas.edu

ABSTRACT
Searching for health information online is a popular behavior, yet little is known about how people use the information they find. As an initial step towards understanding this important aspect of consumer health information behavior, we conducted a systematic review. We searched three major health-related databases, CINAHL, Medline, and PsycINFO and identified 31 articles that report consumers’ use of health information found online. Thematic analysis of these articles revealed that the most common uses of online health information were to make health decisions and lifestyle changes, and to discuss the information with healthcare professionals.

Keywords
Consumer health information searching, information behavior, information use.

INTRODUCTION
According to the Pew Health and Technology research, 72% of the internet users in the U.S. look online for health information, indicating that the internet has become a major source of health information (Fox, 2013). In the past decade, studies of consumer health information seeking behavior have significantly increased (Anker, 2011). However, these studies primarily focus on consumers’ access to the internet (and a related phenomenon, digital divide) and their information seeking behaviors, with comparatively little research being available on how consumers use the information once found. Effective use of information is a prerequisite for better decision making and patient empowerment. Thus, there is an urgent need to understand how consumers make use of the information that they obtain from the internet. As an initial step towards filling this gap, we conducted a systematic review of published peer-reviewed literature to gain an overview of how consumers utilize the health information they found online.

METHODS
Systematic review is a literature review that identifies and selects relevant research concerning a particular research question in an exhaustive manner, and then summarizes and synthesizes the research evidence in an unbiased way (Hemingway & Brereton, 2009). In March 2015 we conducted a systematic search using three electronic databases: CINAHL, PsycINFO, and Medline. We chose these databases for two reasons. First, they are major health-related databases and their coverage of health-related peer-reviewed journals is comprehensive. Second, we expected that searching on the topic of consumer health information use could return too many results, due to the general nature of the key words. Beginning with the three major databases would serve as a reasonable starting point for exploring the scope of the final review.

The search query that we used was: (patient OR client OR consumer) AND (internet OR web OR online) AND (health information) AND (use OR usage). Medline returned 5,937 results; we included the first 1,000 (ranked by relevance) for the review. CINAHL returned 870 results, and PsycINFO returned 432. All results were imported into EndNote, where 169 duplicate articles were removed, resulting in 2,138 articles to be reviewed.

Two authors (LF and YS) reviewed the titles of the articles and removed another 1,279 records, leaving 859 to be reviewed by abstract. In the process, all of the authors met to discuss borderline articles and further clarified the inclusion/exclusion criteria to guide the screening. We decided to include articles if they reported specific consumers’ voluntary use of health information found online. The information could come from any form of online information sources, including health forums, social media platforms, health websites, and patient portals. Articles were excluded if they just reported that patients looked online for health information, but did not specify how that information was used. Articles were also excluded if using the internet for health information was not voluntary, that is, patients were incentivized for the purpose of specific studies. We also excluded articles that only indicate intentions to use health information found online, ...
but did not report that use actually occurring. Articles that compared the use of online health information to the use of other health information resources also were excluded.

After reviewing the abstracts of the 859 articles, 41 were retained for full-text review. At this stage three articles were removed because the full-text was not available, and seven were removed because, upon closer review, they did not report a specific use of health information found online. As a result, 31 articles were included in the review.

The goal of this systematic review is to identify how consumers utilize health information found online. Thus we read the full text of the included articles and used the thematic content analysis method to code the instances of information use (Zhang & Wildemuth, 2009). LF and YS each coded a subset of the articles. In addition, basic characteristics of the articles, such as publication year, country of origin, and research methods used were coded as background information to provide a context for the results. Coding was performed in Excel. In the coding process, discussions were held to solve discrepancies. The data analysis is ongoing and we report in this poster the preliminary results.

RESULTS

The 31 articles were published between 2002 and 2014. About half (15 articles) studied patients/participants in the United States; 10 studied users in other countries, including the United Kingdom, the Netherlands, Saudi Arabia, Norway, Italy, Finland, Australia, New Zealand, and Croatia. Five of the articles studied members of online communities that involved participants from multiple countries. In terms of research methods, 19 articles (61%) used the survey method, 8 (26%) used focus groups or interviews, 1 (3%) monitored users’ use of online forums, and the remaining 3 (10%) used any combination of those three methods.

Five major uses of online health information were identified, with many of the articles identifying more than one use. Figure 1 shows the number of articles in which each use appeared.

The most common use of health information gathered online (reported in 18 articles out of the 31 articles included) was to make better health decisions and lifestyle changes. This includes, but is not limited to, considering or reconsidering an alteration to a medication, changes of diet, and an increased level of activity (e.g., exercise).

Facilitating the discussion with their healthcare providers (HCP) was the second most common use of the information found online (reported in 11 articles). For example, Dickerson et al. (2006) reported that online health information helped their participants find information regarding medical terminologies, which enabled them to ask meaningful questions of their providers, and therefore received care that best fit their needs.

The third most common use of online health information was for general informational purposes (reported in 10 articles). That is, the information did not directly result in any actions. Instead, users used the information to fulfill cognitive needs, such as gaining clarification on a subject, satisfying curiosity, and gaining reassurance or confirmation of an existing belief.

An equally common use of health information found online was for chronic disease and/or health management (reported in 10 articles). For example, Thomson, Siminoff, and Longo (2012) found that owing to the anonymity provided by the internet, it was common among colorectal cancer patients to use information found online to manage their conditions in lieu of going through their healthcare professionals to gain information, particularly when they experienced embarrassing symptoms.

Finally, of the 31 articles reviewed, eight listed patient empowerment as the main use of the information procured from online health information searching. Patient empowerment may include outcomes such as increased confidence in participating in decision-making (Bass, et al., 2006), or an increased sense of social support (Bartlett and Coulson, 2011). Different from general informational use, patient empowerment emphasizes more on emotions.

DISCUSSION

Information use is an important aspect of human information behavior, which has been historically under-researched compared to information seeking. This is also the case for health information behavior research (Johnson & Case, 2012). This systematic review was conducted to identify how consumers use the health information that they found online. It revealed five major uses: to make better health decisions and lifestyle changes, to facilitate discussions with healthcare providers, to enhance one’s ability to manage chronic conditions or one’s health in general, to become informed, and to empower oneself. The first three uses are manifested in actions, whereas the latter two are often manifested in changes in individuals’ cognitive and emotional statuses. These findings suggest...
that when measuring the usefulness of health information, it is necessary to go beyond the actions resulted from the information to the impact of information on users’ cognitive and emotional states.

We recognize that the results of this review are constrained by the articles in the sample. As reported in the results, more than 60% of the included articles relied on surveys to investigate the use of online health information. One limitation of the survey method is that it predefines the use using leading questions, for example, “Have you ever taken information found online to a healthcare professional?” As a result, it may not capture all the possible uses. The second most widely used methods among the included articles, interviews and focus groups, allow users to freely describe their uses of health information. However, like the survey method, these methods still are only able to elicit stated or claimed information use, which is not equivalent to the actual information use. In further analysis, we will attempt to differentiate stated use and actual use. An improved understanding of how patients/participants use online health information will allow us to provide better information to fit their needs.

There are some limitations with our review process. First, we only searched three databases that focus on health content. Given the fact that the final sample in this study is of reasonable size, in further study, it is worthwhile to include other databases that contain consumer health content, such as EBSCOHost, Web of Science, ScienceDirect, and Springer Link. Second, in this preliminary analysis, we held discussions to resolve uncertain cases (including whether include a particular article or whether not to code an information use instance into a particular category). This coding process can be improved by involving double coding to examine coding reliability.

The results reported in this poster are general categories of the use of online health information by consumers. In our future analysis, we will further identify sub-categories of information use under each general category to provide a more fine-grained view of how online health information is being used.

REFERENCES