Women's Health Information Communities

Lucy Palasek

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San Jose State University

Abstract

Women health information consumers are a diverse community that engage in everyday life information seeking to manage their health and the health of their families. By examining the scholarly literature about their information needs and the behaviors, this paper seeks to explain how and why women use different resources, including the internet, in their search processes and better understand the different research findings regarding whether or not the digital divide affects health information searching. It will further investigate online user-created health communities in order to understand how web 2.0 and peer-to-peer online healthcare serve the emotional needs of women health information seekers and their preferences for interpersonal resources. Lastly, this paper will address the ways in which libraries can serve women health information seekers, by providing access to the internet and print resources, through programming, and by offering digital literacy instruction in order to improve this community's online search techniques.

Introduction

Although Fisher and Durrance (2003) emphasize the use of the internet in exploiting the information sharing qualities of technology, women's health information communities can be traced back to the feminist self-help movements of the 1970s, which valued sharing experiences and information about women's bodies and healthcare experiences as a way to liberate women from a male-dominated medical system (Howes & Allina, 1994). While present-day women's health information communities take advantage of the multiplier effects of the internet, understanding the environment from which these communities grew gives context for why they are frequently created with a feminist viewpoint and share information about policy and activist issues related to women's health as well as consumer health and medical information.

Women's health information communities today are increasingly operated and organized in digital spaces. This allows them to reach women who use the internet in their searches for health information. According to the Pew Internet & American Life Project, 35% of US adults have gone online to figure out a medical condition, with women being more likely than men to look for health information online. Of the female internet users surveyed, 62% looked online for information about a specific disease or medical problem, 49% looked for information about a treatment or procedure, and 13% looked for information about pregnancy or childbirth. Additionally, half of smartphone users have looked for health information on their phones (Fox & Duggan, 2013).

Searching for health information is a form of Everyday Life Information Seeking, defined by Savolainen (2009) as information seeking that is not related to job or school tasks. Savolainen explains that "the needs for problem-specific information arise from the situations in which

information seekers find themselves; that is, any need for information is situationally based and

dependent on a particular context" (p. 1786). Women's health information communities serve

women of different ages, ethnicities, locations, sexualities, socio-economic statuses, and other

variables that inform this context. Because these differences affect both the types of information

needed and the context in which it is needed (Wathen & Harris, 2007), it is important for

information professionals and health information communities to consider the diversity of their

users and constituencies when studying their behaviors and creating resources.

This paper will examine women's health information seeking behaviors, including online

health information seeking, and the demographic differences that are associated with different

rates of resource uses. It will also investigate how women's health information communities

address those search behaviors and needs and provide suggestions on how libraries can meet the

information needs of women looking for health information.

<div align="center">**Literature Review**</div>

Reasons for Searching and Uses of Information

Women seek out health information in order to manage their own health and the health of

their families (Harris & Wathen, 2007) and to take an active role in their health by seeking

information both before and after visiting medical professionals as a way to supplement or better

understand information provided by doctors (Warner & Procaccino, 2004, 2007). Women who

use the internet to look for health information cited convenience (Cotten & Gupta, 2004; Pandey,

Hart, & Tiwary 2003; Wathen & Harris, 2007; Yoo & Robbins, 2008) and privacy (Harris &

Wathen, 2007; Rowlands, Loxton, Dobson, & Mishra 2015; Shifren, Johannes, Monz, Russo,

Bennett, & Rosen, 2009; Yoo & Robins, 2008) as primary motivations for their resource choice.

The sources women consult in their health-information seeking include both formal and informal, interpersonal and print resources, and hybrid sources. An example of a formal interpersonal resource would be a doctor, nurse, or other medical professional; an informal interpersonal resource could be a friend or family member; formal print resources include magazines, books, and websites produced by professionals, whereas web 2.0 content such as blogging and bulletin boards can be classified either as an informal print resource, a hybrid source, or an informal interpersonal source, depending on the level of interaction (Warner & Procaccino, 2004). Across the literature, women cited interpersonal resources more frequently than others as their preference for health information. Several studies showed doctors or other medical professionals as the preferred source of health information, followed by friends or relatives, and then media and print resources (Cotten & Gupta, 2004; Pandey et al., 2003; Rowlands et al., 2015; Warner & Procaccino, 2007). In contrast, Harris and Wathen (2007) found in their study that rural Canadian women cited the internet, books, and the library as sources they would consult for a nagging health concern with greater frequency that doctors, although they still preferred hospitals and doctors for urgent health concerns. Shifren et al. (2009) also had results that differed from the norm, finding greater rates of women who sought informal information and care for sexual problems than those who consulted medical professionals.

Differences Between Web Users and Non Web Users

Several authors focused their attentions on the differences between women who search for health information online and those who do not. The most consistent finding across the literature is that internet health information searching is correlated with higher education levels, higher income, and higher levels of health concern (Cotten & Gupta, 2004; Pandey et al., 2003;

Warner & Procaccino, 2007; Yoo & Robbins, 2008). Age was also correlated with internet

useage, as Warner and Procaccino (2007) found that internet users were on average 11 years

younger than non-users. They also found that web users had greater familiarity with a range of

both print and online health resources than non-web users. Shifren et al. (2009) found that

women who consulted the internet or other anonymous sources about distressing sexual

problems reported a greater level of embarrassment about their health concerns than those who

consulted medical professionals, and Rowlands et al. (2015) found that women who experienced

stigmatizing conditions, women who were looking for sexual health information, and pregnant

women and mothers, were more likely to use the internet for health information than others.

Several authors explained the higher rates of internet health searching among women

with higher income and education levels as a function of the digital divide (Bell, 2014; Cotten &

Gupta, 2004; Pandey et al. 2003). However, Kim (2015) examined the digital divide in regards to

health information searching and came to a different conclusion. Looking at the impact of

income on health problems, and the impact of health problems on online information seeking,

Kim found that low income was correlated with a greater number of health problems, as

hypothesized, but, contrary to predictions, low income individuals with health problems were

just as likely to use the internet to search for health information as high income individuals,

although their rates of general online information seeking remained lower.

Efficacy of Online Search Methods

The web users in Warner and Procaccino's (2004) research gave conflicting answers

about their information habits. Although they reported a 95% success rate in finding the

information they were looking for, they also expressed concerns about finding the right

information and uncertainty about its credibility. Warner and Procaccino explain this discrepancy

as part of Kulthau's Information Search Process model, in which users may feel confusion,

frustration and doubt during the exploration stage of their search process. Users also reported

search methods that researchers view as weak or suboptimal, relying on search engines and not

verifying the credentials of websites.

Eysenbach and Köhler (2002) conducted usability testing in order to analyze search

methods, which resulted in similar results. In pre-testing focus groups, users discussed their

desires for authoritative sites which provided credentials. When given health questions to

research on their own, however, the 17 study participants did not explore websites to find out

whether or not they were trustworthy. They also almost universally used search engines, usually

typing in only one or two keywords. Only one participant used BOOLEAN operators, and search

phrases, or string of words surrounded by quotation marks, were used in only 3.5% of 280

recorded searches. Participants overwhelmingly chose the first results produced by search

engines, with 97.2% of clicks occurring on a link in the first 10 results, and 71.3% occurring in

the first five. In spite of these methods, study participants were able to correctly answer the

majority of the health questions they were tasked with researching.

Weaknesses and Gaps

While several researchers have examined the effect of socioeconomic status on women's

health information behaviors, and factors such as age and location on rates of internet usage, the

research does not address whether or not ethnicity or sexual orientation affects women's health

information behaviors. Given the emphasis on intersectionality in current feminist movements,

and the roots of women's health information communities in the feminist movement, this is an

area in which further study would be worthwhile. Additionally, the research focuses on women's

health information seeking behavior, and does not discuss their sharing behaviors, or how they

create resources. As such, this research applies to women as individuals and collectively, but

does not give a complete picture of them as an information community.

Methodology

I located scholarly articles on women's health information behaviors by searching King

Library Information science databases such as Library Literature and Information Science Full

Text and Library, Information Science & Technology Abstracts with Full Text (LISTA) with a

variations of search terms related to consumer health information seeking behavior and women. I

then turned to Google Scholar with similar search terms in order to locate research published in

other disciplines; this lead me to articles published in health science and medical journals. I also

engaged in citation following by examining the reference lists of the articles I had located to see

what was frequently referenced or looked like it would be a relevant to my research.

Although I was able to locate articles and books about the history of the women's health

movement, I was not able to find scholarly materials related to current women's health

information sharing as it occurs in online spaces. For information about these communities

themselves, I consulted their web pages, starting with sources that I was previously aware of -

Our Bodies Ourselves, and Vagina Pagina, - and explored their links page to see what other

communities they networked with. Other community resources I investigated include the

National Women's Health Network, the GynePunk page of Hackteria, and RH Reality Check. I

focused on general women's reproductive and sexual health communities in my investigations,

but there are countless other online information communities related to individual women's

health concerns which offer information, networking, advocacy and discussion opportunities, on subjects such as endometriosis, breast cancer, infertility, abortion, and many others.

Discussion

Community Based Resources and Peer-to-Peer Healthcare

In my research, I found two main types of women's health communities: expert-created and user-created. Expert-created communities such as Our Bodies Ourselves and the National Women's Health Network produce materials, both print and online, that have been fact-checked by doctors and other experts, and have an emphasis on information and advocacy. User-created communities also share information, but additionally function as sites of emotional connection, reassurance, and interactivity. There is some overlap, as expert-created communities still have opportunities for users to interact, or comment on blog posts, though the bulk of their materials are researched, edited documents. Similarly, user-created communities also link to vetted sources and share information, but the heart of the community lies in discussion boards or other conversations.

One user-driven community is Vagina Pagina, (VP) which describes itself as" an online community that offers a supportive, progressive, body- and sex-positive environment in which to discuss issues related to female sexual and reproductive health and wellness …(our goal is to build knowledge and combat misinformation by sharing personal experiences and reliable information from credible sources" (Vagina Pagina, n.d.). The main facets of the community are a livejournal discussion community created in 2001 with a current membership of 25,839 users, a wiki covering frequently addressed topics called the Vulvapedia, and a link section connecting users to other resources. Users post in the livejournal community on a near daily basis, primarily

to ask and answer health questions. The site also hosts original content produced by users over a longer time period. One example is *The Everyday Bodies Project* which is a series of galleries of user submitted photos showing the diversity in appearance of different body parts. This project grew as a response to frequent variations of the questions "Am I normal?" by new users. Unable to find an online resource to refer the inquirers to, the community invited users to submit photos of themselves and compiled them into a resource for education and reassurance.

As an online community allowing for anonymity, VP provides a space for health information consumers who may be embarrassed to consult their interpersonal networks or medical professionals. Shifren, Johannes, Monz, Russo, Bennett, & Rosen (2009) found that 63.7% of women seeking anonymous sources of information for distressing sexual concerns expressed moderate to high levels of embarrassment in discussing such concerns with a doctor, compared to only 43% of women who sought formal care for similar issues, suggesting that embarrassment may act as a deterrent to consulting medical professionals. VP also functions as a site of connection and reassurance. Wathen and Harris (2007) note that the emotional context in which health information is received is often as important as the information itself. Supportive communities such as VP meet the emotional needs of health information consumers.

VP is focused on women's general reproductive health and sexuality, but the benefits created by web 2.0 in connecting users to interpersonal resources apply regardless of the health issue. The Pew Internet & American Life Project's report on peer-to-peer healthcare discusses the growing number of internet users who go online to find other individuals experiencing the same medical symptoms and conditions as themselves. According to their research, 28% of women have looked to others with their same health condition for advice, 26% of internet users

have followed someone else's health issues online, and 16% of internet users have gone online to look for others sharing their health conditions in the last year (Duggan & Fox, 2013). Savolainen (2009) reports that interpersonal resources are overwhelmingly favored in Everyday Life Information Seeking contexts, and that familiar sources such as friends and family are favored over organizational sources such as health centers. The Pew study confirms this, noting that although doctors are favored for diagnoses and information about prescription drugs, most patients find other patients, friends, and family members to be more helpful sources in finding quick fixes for everyday health issues, or for emotional support in dealing with health issues (Fox, 2011).

Opportunities for Libraries

Knowing that women turn to their friends, family, other patients, and the internet for their health information needs, how can library and information professionals help? Libraries remain a valuable resource in terms of access to both the internet and print materials. As more and more women go online for health answers, the library provides internet access to women who do not have internet at home or their work. Providing public computer use, free Wi-Fi, and even loaner laptops and circulating Wi-Fi hotspots can increase access to health information for patrons who do not have home access and can serve as one strategy to bridge the digital divide. Print resources are also still useful to women looking for health information. The library remains a site to access books, magazines, and newspapers. Warner and Procaccino (2007) report that when comparing women who look online for health information and women who do not utilize the internet for their health information searches, web users have greater awareness of nearly all the print resources in the survey. Furthermore, they found that web users "are likely to use multiple

channels to locate health information, and do not exclusively use the Web for this

purpose" (Warner & Procaccino, 2007, p. 801), reaffirming the value for both print and online

resources. I checked my local library catalog for the print resources asked about in Warner and

Procaccino's survey to see how well our collection stacks up. Thirteen of the fourteen resources

asked about were available in at least one of the 33 branches that form the library consortium

that operates throughout the county, seven were available within the city library system I am

employed by, and one was available at the neighborhood branch where I work. Five of the

resources were also available through the library as e-books, though some of those were historic,

rather than current, editions.

Libraries can also serve women health information consumers with health related

programming and digital literacy instruction. Bell (2015) explains that limited social networks

decrease the likelihood that women of low socioeconomic status have doctors or other medical

professionals among their family and friends. By collaborating with local health organizations to

host lectures or question and answer sessions on health topics, the library can connect medical

professionals and patrons in a setting with less rigid doctor/patient roles than a doctor's office or

clinic. Librarians also have an opportunity to provide digital literacy instruction. As discussed in

the literature review, the majority of online health information seekers start with search engines

(Eysenbach & Köhler, 2002; Fox, 2011; Warner & Procaccino, 2007), and do not take steps to

verify the credibility of the websites they visit. Library instruction can help users identify trusted

sources to start their search with, such as the Mayo Clinic or MEDLINEPlus, and teach them

how to evaluate the credibility of other sources they encounter. Digital search instruction can

also increase awareness of subscription databases that can be accessed through a user's local

library. Duggan and Fox (2013) found that 26% of internet users looking for health information online have hit a paywall. Only 2% of this group chose to pay for the information, with the rest looking to see if they could find the information elsewhere or giving up. It is unclear from the survey whether or not the paywalls were associated with journals and newspapers, but libraries commonly subscribe to databases that allow patrons to freely access newspaper, magazine, and journal articles that would otherwise require payment to view and are thus a possible solution to this problem.

Conclusion

Women health information consumers engage in proactive searching using a variety of sources. Although they tend to favor interpersonal resources, such as doctors, friends, and family, they also use print and online sources, including online sources that connect them to other patients and thus serve as an interpersonal resource. Libraries can fill a valuable role in connecting this community with resources, such as books, magazines, journal articles, and internet access, as well as facilitating connections between patrons and local health organizations. While some women health consumers use library as a resource, such as the woman quoted in Harris and Wathen's (2007) study of rural Canadian women's health information behaviors as saying "The library in town, if you can't find it they'll help you find it. Usually you get what you're looking for, If not, you'll get it if from a different library in the county" (p. 71), others are not aware of the scope of resources and services available to library patrons. Chobot (2010) notes that minority populations in particular may be unaware of free library services or reluctant to use them due to language barriers. Greater outreach efforts are indicated to reach these potential users, and also to inform current users of the availability of

digital literacy instruction that can help them find resources that do not turn up in a simple

Google search.

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