

Information Sources Survey

Women's Health Information Communities

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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 seek out health information in order to manage their own health and the health of their families (Wathen & Harris, 2007). They search for health information as a way to take an active role in their health, seeking information both before and after visiting medical professionals in order to supplement or better understand the information provided by doctors (Warner & Procaccino, 2004, 2007). They tend to use anonymous sources, such as the internet or print materials, when they are concerned about privacy or when searching for information about stigmatized conditions (Wathen & Harris, 2007, Rowlands, Loxton, Dobson, & Mishra, 2015).

Women's health information communities take many forms including advocacy organizations such as National Women's Health Network, health care providers such as Planned Parenthood, and online message boards such as Vagina Pagina. These communities serve women of different ages, ethnicities, locations, sexualities, socio-economic statuses, and other variables. 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 women's health information communities to consider the diversity of their users when creating resources.

RESEARCH BASED RESOURCE:

Boston Women's Health Book Collective. (2011). *Our bodies, ourselves*. New York: Simon & Schuster.

Our Bodies, Ourselves (OBOS) is a consumer health guide focusing on women's reproductive health and sexuality. First published as a photocopied booklet written by a small grassroots collective in 1970, it has transitioned from a community based resource to a research based one and is currently in its ninth commercial edition. Because of the infrequency of updates and the amount of review that occurs before publication, OBOS fall under the years category in the information cycle (University of Washington, 2012). Significant updates between the 2004 and 2011 editions include the addition of information about Health Care Reform Law, and an updated and expanded section on transgender health which abandoned outdated rhetoric included in the 2004 edition suggesting that medical transition would not be necessary in a world that allowed for broader range of gender expressions.

Although not subject to the same peer-review process as an academic journal, OBOS is a research based resource. During the editorial process, each chapter is reviewed by 15 to 20 health and topic experts to make sure the information is current and accurate. Each chapter has extensive notes and recommended resources for readers who wish to fact-check or delve deeper into a subject. *Library Journal* named OBOS as a "Best Book: Consumer Health" in both 2008 and 2011.

At just under one thousand pages, OBOS covers an impressive range of health topics. In addition to sections on anatomy, reproduction, identity and selected medical problems, the book concludes with a section titled “Major Forces Affecting Women’s Sexuality and Reproductive Health.” This section contains chapters on violence against women, environmental and occupational health, politics, and activism. The presence of these chapters illustrate the feminist lens that the guide is written through.

OBOS serves as a valuable resource to women health information communities because it provides accurate medical information in accessible terms. Interspersed in the chapters are personal quotes and stories from women discussing how they’ve dealt with various health issues. Interpersonal resources are favored by women in everyday life information seeking contexts (Savolanein, 2009); these narratives may give readers a sense of connection to the print resource.

COMMUNITY BASED RESOURCE:

Vagina Pagina [website] (n.d.). Retrieved October 19, 2015 from: <http://vaginapagina.com>

The information community Vagina Pagina (VP) 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. Unlike sites such as Wikipedia.com where editing is open to all users, content creation on the Vulvapedia is restricted to a small group of moderators.

As on online forum, VP straddles more than one position in the information cycle. Users post in the LiveJournal community on a near daily basis, primarily to ask and answer health questions. This positions it in the hours/day of the event category. The site also hosts original content produced by users over a longer time period, such as the Vulvapedia, which falls under the months/years category.

The information of VP is not formally reviewed or fact checked. While users often provide links to outside sources when answering questions, the community describes itself as a place for networking and support, not as a substitute for medical advice or care.

Although VP uses the terms *female sexual and reproductive health and wellness* and *women's sexual health* in its mission statement, community guidelines require that users use gender inclusive language when posting in VP to create a welcoming environment for trans and gender nonconforming individuals. This results in discussions using anatomy-based terms such as *vagina-owners* rather than identity based terms such as *women*.

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.

COMPARISON

Both OBOS and VP provide information about reproductive health and sexuality using language aimed at health information consumers rather than at doctors or researchers. Both resources couch this information in a feminist framework that considers the social and political contexts in which health occurs. OBOS has a greater degree of authority than VP, as it is created and reviewed by experts in the field, whereas the anonymous users of VP frequently rely on anecdotes and personal experience when advising others. The two resources are complementary, with OBOS providing accurate information, and VP providing emotional support and opportunity for discussion.

CONCLUSION

A study by Warner and Procaccino (2007) about the differences between women who used the web to search for health information and those who did not showed that 63% of web users were aware of OBOS in comparison to only 16% of non-web users. Since OBOS is a print resource, I found the low awareness among non-web users initially surprising, but this pattern of greater awareness by web users than non-web users followed for awareness of all print resources included in the survey. Warner and Procaccino found that web users “are likely to use multiple channels to locate health information, and do not exclusively use the Web for this purpose,”

reaffirming the value of both print and online resources for women's health information communities in an increasingly digital age.

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