

Seeking Autonomy: Women’s Search for Reproductive Health Information

Alannah Vanderburgh-Oakley
Faculty of Information, University of Toronto
alannah.vanderburgh.oakley@mail.utoronto.ca

Abstract

The purpose of this study is to elucidate the information behaviour of women in regards to their reproductive health. This study builds on preceding literature on women’s health information behaviour, and contributes qualitative research to concepts of independence and agency within women’s information seeking. Sonnenwald’s (2005) Information Horizon Interview method was used to conduct semi-structured interviews and information horizon maps with three female participants, and the findings were analyzed using both narrative and inductive thematic analysis strategies. The women in this study all preferred and trusted online sources due to convenience and their ability to facilitate agency, and felt that being able to conduct their own independent research was a critical part of their information seeking process. Independent searches also allowed women to process and ‘dress’ the information, providing the confidence necessary to make decisions about their reproductive health; however, physicians were information barriers as they could potentially obstruct what information the women were able to use to care for their reproductive health. Possible implications include educating young women about conducting independent research to facilitate confidence, and have physicians provide patients with literature so they can inform themselves prior to making health decisions.

INTRODUCTION

A woman’s right to access information and services related to her female reproductive health has and continues to be a contentious debate within political and social arenas. As Lynn P. Freedman (1995) argues, the female reproductive system teeters between being “a key to women’s empowerment” and a potential point “of women’s vulnerability” (p. 29); the ability, or inability, to find and utilize information can potentially tip the scale either way. Consequently, the information behaviours associated with reproductive health are integral to understanding how to facilitate the former, and avoid the latter. While previous studies have examined the information behaviours associated with women concerning their general health, or specific demographics of women concerning particular reproductive events or diseases, this research study seeks to answer the question: What is the information behaviour of women in regards to their reproductive health?

Through qualitative analysis of data obtained from three women’s information seeking experiences, this study contributes to preceding literature, exploring what sources women rely on for their reproductive health, the specific sequence or stages that encompass their searching process, and the obstacles they perceive as impeding their access to and use of information.

Due to the confines of time and space, this study will only examine the active information seeking behaviours of women. As such, the findings and discussion will not

examine the information encountering or information monitoring activities that the participants discussed in their interviews, or illustrated in their graphic representations.

LITERATURE REVIEW

Within the field of health-related information behaviour, studies have documented and identified the unique practices of women in their search for information regarding their health. Although these studies do not specifically examine women’s reproductive health, but rather offer a broad look at women’s health, their findings reveal general trends and themes from which this study will build on.

In a quantitative study, surveying 471 participants—including 256 women—Rowley, Johnson and Scaffi (2017), found that women generally tend to undertake information seeking in regards to their health more often than men. Specifically, women reported searching for information before health issues became serious or chronic, engaging sources as a means of ongoing “health monitoring” (Rowley, Johnson, & Scaffi, 2017, p. 43). Correspondingly, Harris and Wathen (2007) noted that their study participants expressed a “desire to take responsibility for their own health” (p. 73), and demonstrated independence when it came to procuring and administering treatments. Throughout this ongoing and independent process of information seeking, previous studies have found that women use a variety of diverse sources, combining information from web-based sources, their peers, as well as health authorities or experts (Rowley, Johnson, & Scaffi, 2017; Harris & Wathen, 2007; Warner &

Procaccino, 2004). In particular, literature on the health information behaviour of women reports that the personal relationships and other non-institutional sources are preferred because of the emotional support they may offer (Harris & Wathen, 2007), and the Internet is a prevalent source, despite women's uncertainty about the reliability of the information contained therein (Warner & Procaccino, 2004).

Accordingly, given the frequency of—and personal responsibility associated with—women's search for health information, an examination of how women find and use information related to female-specific health issues, is warranted. This study is particularly interested in investigating women who do not rely on personal or informal exchanges of information, but rather prefer formal and online sources, and their specific search process. Additionally, this study aims to further explore the idea of independence and agency, and how this affects or contributes to multiple information behaviour activities.

RESEARCH METHODS

This study gathered results during three separate audio-recorded interviews and drawing exercises. Prior to each interview, the interviewer read participants a consent statement provided by Dr. Jenna Hartel, Associate Professor at the University of Toronto's Faculty of Information, to address ethical considerations, and guarantee confidentiality.

The interviews were semi-structured, and guided by Diane Sonnenwald's (2005) Information Horizon Interview Method. Each interview followed a predetermined interview guide, which outlined specific topics to discuss, while allowing participants to explore ideas they thought were pertinent (see Appendix 1). The interviews began by asking participants context questions to establish a brief history of their experience with information regarding female reproductive health. The interviewer then asked participants to discuss recent and/or past information searches, focusing on their process and preferred sources, disclosing as much detail as they felt comfortable. Each interview concluded with participants drawing an information horizon map to illustrate their information search, while simultaneously describing their drawing. The interviewer then transcribed each recording, removed all identifying information, and scanned each map as a digital file, for later qualitative analysis.

The three individuals who consented to participate in this study are all cisgender women who reside within the Greater Toronto Area. All three women are Caucasian, and are either currently pursuing undergraduate studies, have completed a postsecondary education, or are in a graduate program. Each

woman lives in close proximity* to a public library, and has internet access within her home. The participants' names and ages are as follows: Emily**, 20; Anne, 25; and Charlotte, 55.

FINDINGS

This study employs both narrative and inductive thematic strategies of analysis to trace each participants' information search process, and report persistent themes. Given the personal and continuing nature of reproductive health, a narrative analysis allows for an examination of the practical and emotional motivations behind these women's information behaviours.

Information Sources

Each participant listed the Internet as their first source of information, and had their own trusted and preferred sites, including WebMD, Mayo Clinic, or government-run sites (see Figures 1 and 2).

For Emily, the two online sources she prefers are Youtube and WebMD, due to their convenience and accessibility: "For me, it's about how accessible it is—in an instant. [. . .] WebMD I would use more for looking up PMS symptoms or missed periods. For Youtube, I'm just on it anyways, all the time."

Similarly, Charlotte noted the Internet was "the fastest way to get information now," and while she relied on pamphlets provided by her doctor in her twenties, "information technology has changed how [she] does everything," so her favourite sources are authoritative websites affiliated with a hospital, the government, or a health association.

Anne was also particular about her online sources, and explained that she prefers medical journals, because of the peer-review process, but also consults popular sites such as WebMD and Wikipedia to "gather enough bits and pieces from different sources to form an answer."

Interpersonal relationships only appeared as a direct source in Emily's process. For Anne and Charlotte, friends and family existed within the search environment to provide emotional support, but were not active contributors. As Anne reported, discussions with her peers were casual and conversational rather than informative: "It's not like I'm seeking definitive answers from them. It's more that I'm sharing experiences."

Information Processes

When describing their information search process, each woman spoke about the importance of their independent

* Within 1 kilometre.

** All names have been changed.

online searches, especially as a precursor to seeing a physician.

As Emily noted, an online search gives her time to look at various sources, evaluate the information, and make decisions autonomously, without external pressure: “More independent is preferred because I can think about things by myself—there’s more agency in what I do online. With a doctor, it’s kind of more what the doctor says you have to do.”

In Anne’s process, her online research allows her to decipher what is happening with her body, and determine her own course of treatment: “Generally I feel like I’m pretty self-reliant. I would do a bit of my own research first and make sure it’s not something transient or benign that I could wait out at home, before I seek medical attention.”

For Charlotte, an exploratory online search is a necessary step for her to feel confident, and construct “a frame of reference” for when she does see a physician, which prepares her to receive the physician’s information: “Initial research is big for me. I like to have a basic knowledge of whatever issue before I see the doctor so that I will have at least some frame of knowledge about what they’re telling me.”

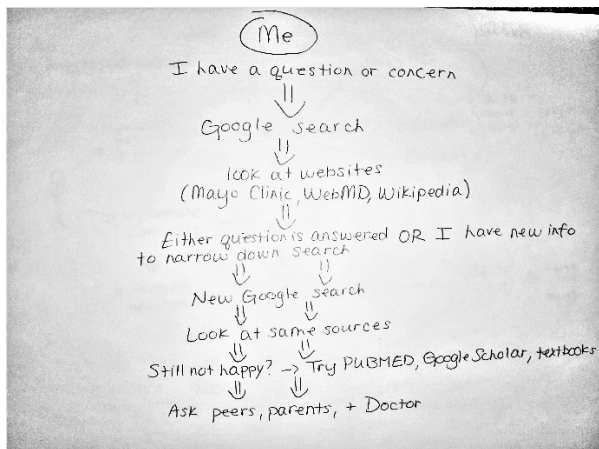


Figure 1. Anne’s Linear Path

Information Barriers

While all three participants reported satisfaction in finding relevant and helpful sources online, each woman reported information barriers when consulting a physician.

Emily reported that “going to a general physician would be a good option,” as a doctor could equip patients with “good knowledge,” but was personally hesitant to go, believing that her physician would give her biased information:

When I was on the pill I became very skeptical, but I felt that if I did go to see my physician, she

would only give me a biased, Western-medicine answer. [. . .] I’m willing to try anything but the pill, so I feel a little bit stuck in that way—if I want other options.

Similarly, Anne encountered a barrier when her doctor gave her a casual diagnosis, and felt that she had not been given sufficient information: “She just kind of said, ‘Oh, you have a heart-shaped uterus,’ just like that. Then I went home and researched, and found all of the health problems that she didn’t bring up.”

In Charlotte’s case, she experienced an impediment during an immediate health problem when a physician disregarded her knowledge of her own body, and did not answer her information need:

I went to a clinic because I was losing so much blood I was going to faint, and the doctor treated me as if I didn’t know what was going on. He didn’t give me any reason for the massive bleeding. [. . .] He was very dismissive, and I was very unhappy.

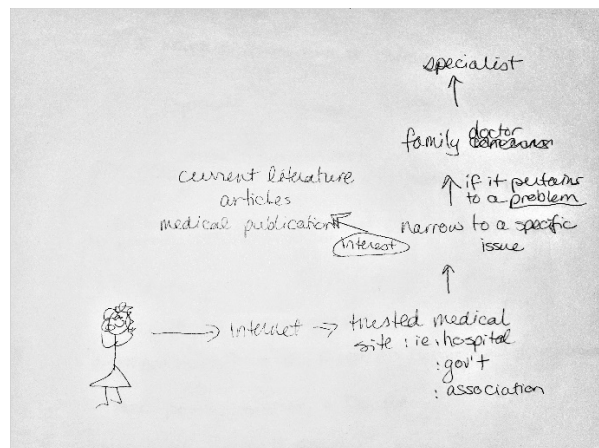


Figure 2. Charlotte’s Sequential Search

DISCUSSION

The findings of this study confirm previous research reporting the internet as a preferred source of health information for women. Unlike friends, family, or even a medical professional, the Internet allows women to ask questions freely, access information at any time, and go straight to their favourite site within seconds. However, unlike Warner and Procaccino’s (2004) study, which found that women were wary of trusting online sources, Emily, Anne and Charlotte were all comfortable using and relying upon the Internet for their health. This disparity in comfort levels may be attributed to the thirteen-year gap between the studies, and the ubiquity of the Internet in everyday life at

present. As Savolainen (2009) posits, “people tend to favor a limited number of easily accessible sources, which have been found useful in previous use contexts” (p. 1786). In this sense, the women of this study were already using the Internet in various capacities, so going to web-based sources for information about their reproductive health was a comfortable step.

The women’s preference for online information also suggests that the Internet may be a liberating force. Complementary to previous literature (Harris & Wathen, 2007), the women in this study all asserted that their independence in the search process was a vital aspect for them to feel comfortable making choices for their body, confident in taking the appropriate course of action, and knowledgeable enough to proceed in the search. This independence not only relates to finding sources, but to the time spent processing and evaluating their information. This process aligns with Hektor’s (2003) “dressing” information activity, wherein “information is framed” (p. 129), but in this case the women are performing the “dressing” for themselves. In this sense, women’s information needs are not just to find information about their bodies to lead to diagnosis or treatment, but to find information that they can independently process, wield as they see fit, and use to control their own health.

One of the main findings of this study is that doctors are serious sites of contention within women’s searches. Even though doctors are medical experts—and often necessary at some juncture—they are also often the last source to exhaust. This is apparent in the information horizon maps (Figure 1 and 2), as the women place themselves at one end, with a physician appearing as the final destination at the opposite end, if and when other sources do not prove helpful. Though women may favour and trust online resources written by physicians, a face-to-face exchange of information may lead to emotionally distressing barriers. In this respect, it is the unfolding activity—which Hektor (2003) defines as the communication of information—that leads to obstacles in the search. For the women in this study, these obstacles came in the form of feeling that their doctor was providing partial, incomplete, or unexplained information, inhibiting their use of said information. These barriers are not solely about access, but about limiting women’s choices and options of information, subsequently impeding how they will apply information to their reproductive health.

METHODOLOGICAL REFLECTIONS

This study employed Sonnenwald’s (2005) Information Horizon Interview technique, including semi-structured interviews and a drawing exercise in order to examine the information sources and behaviours of participants. The semi-structured interviews allowed participants to fully explain their reasoning and the emotional factors behind their information behaviours, and gave them time to

personally reflect on what they look for, what they like, and how they feel about their information seeking. In this sense, the methodology inspired a great deal of introspection, and elicited rich data for qualitative analysis. However, this method of data collection may not be as conducive to quantitative data due to the narrative—and potentially tangential—responses that the method evokes.

CONCLUSION

Throughout the course of gathering the qualitative data and analyzing the results, this study has attempted to gain insight into the information behaviour of women in regards to their personal reproductive health. By conducting three individual face-to-face interviews and information horizon maps, the women who participated in this study have revealed insights into this original query. Firstly, all three women cited the Internet as their favourite resource due to its prevalence in their lives, and its ability to grant them agency. Secondly, conducting independent research was a crucial part of the search process, contributing to women’s confidence and sense of control over their bodies. Thirdly, the ability to evaluate and ‘dress’ information autonomously was just as much a part of the information need as the ability to find information. Lastly, the truly obstructive barriers were those that posed a threat to women’s choice and subsequent use of information about their reproductive health. Possible implications of these results then include teaching young women how to conduct online research so that they feel comfortable finding valuable information independently, and having physicians provide patients with relevant literature or sources about their health, so they may process their options and make informed decisions. As Freedman (1995) suggests in her discussion of women’s right to information about reproductive health, “the abstract right to make a decision is meaningless if the conditions needed to carry it out do not exist” (p. 6); therefore, LIS professionals must continue to research and strive to ensure that women’s right to care for their bodies is never meaningless.

REFERENCES

- Freedman, L. P. (1995). Censorship and manipulation of reproductive health information: An issue of human rights and women’s health. In Article 19 (Ed.), *The right to know: Human rights and access to reproductive health information* (pp. 1–37). Philadelphia, PA: University of Pennsylvania Press.
- Harris, R., & Wathen, N. (2007). “If my mother was alive I’d probably have called her”: Women’s search for health information in rural Canada. *Reference & User Services Quarterly*, 47(1), 67–79.

- Hektor, A. (2003). Information activities on the Internet in everyday life. *The New Review of Information Behaviour Research*, 4(1), 127–138.
- Rowley, J., Johnson, F., & Sbaffi, L. (2017). Gender as an influencer of online health information-seeking evaluation behavior. *Journal of the Association for Information Science and Technology*, 68(1), 36–47.
- Savolainen, R. (2009). Everyday life information seeking. In M. J. Bates & M. N. Maack (Eds.), *Encyclopedia of Library and Information Sciences* (3rd ed., pp. 1780–1789). Washington: Taylor & Francis.
- Sonnenwald, D. H. (2005). Information horizons. In K. E. Fisher, S. Erdelez, & L. McKechnie (Eds.), *Theories of information behavior: A researcher's guide* (pp. 191–197). Medford, NJ: Information Today.
- Warner, D., & Procaccino, J. D. (2004). Toward wellness: Women seeking health information. *Journal of the American Society of Information Science and Technology*, 55(8), 709–730.

AUTHOR'S BIO

Alannah Vanderburgh-Oakley
alannah.vanderburgh.oakley@mail.utoronto.ca is a current graduate student at the University of Toronto's Faculty of Information, in the second year of her Master of Information studies. She is a Subject Specialist at Studiosity, providing writing feedback services to international secondary and postsecondary students. Her research interests include critical feminist perspectives of LIS issues.

APPENDIX 1

Interview Guide:

1. Can you describe to me how you first learned or accessed information about your reproductive health?
2. Was your first experience with this information instructional, or did you specifically seek it out?
3. If you have a health concern or question about an aspect of your reproductive health, how do you go about finding answers and information? Please walk me through your process.
4. Can you describe to me the last time you needed information about your reproductive health?
 - a. What type of information did you need?
 - b. How did you find your sources?
 - c. Were you satisfied with the outcomes? If not, what would you do differently?

5. Can you think of a time when it was particularly difficult to obtain information?
 - a. What were the obstacles that you faced in your search process?
6. Are there any particular sources that you always consult?
 - a. Do you like to follow a specific sequence of these sources?
 - b. How did you find these sources?
7. Is there anyone that you go to as a source of information, or to help you find a source?
8. Have your sources changed, or has your process changed, as you've gotten older?

APPENDIX 2

Memorable quotes from interviews:

Interviewer: So do you think that online sources help in that way, in that you don't have to be embarrassed, and you can ask things openly?

Emily: Yeah, it's less embarrassing. And I feel like I can better evaluate the information. If I were to go to a doctor, and she were to tell me one thing, and I didn't necessarily agree, it's more awkward and confrontational. Whereas if I'm consulting a bunch of different sources online, I have time to think about it. On Youtube for example, I was listening to this story of this girl who was coerced into getting a birth control shot, and she said, "If I had time to go in and think about it first, I would have made a different decision, but because my doctor was so adamant about it, I felt pressured to make a decision right there." So I feel like doing it from a distance online, there's not this pressure.

Interviewer: So if you have a concern about your reproductive health, how do you go about finding answers and information? Where do you go, what do you look for?

Emily: I personally go online, but I definitely feel like going to a general physician would be a good option too. I feel confident in getting good knowledge from them, although I am a slight conspiracy theorist, so I am against sort of more conventional birth controls like the pill. So I wouldn't trust that so much. I would personally just go online, and look things up. For example, if I miss a period, or something, I immediately go online and see if that's okay.

Interviewer: Would you ever search for or look at more anecdotal information?

Anne: Not so much. I mean if I had an issue when I found a forum online where people were posting their experiences, I

would probably read it and be interested, and probably take that into account, but I wouldn't base it solely on those responses from other people. I would base it on hard science.

Interviewer: Is it important for you to feel that you have agency in your search for information about your reproductive health?

Anne: I feel that it's very important to have the ability to make my own decisions regarding my health, specifically my reproductive health. Who else is going to advocate for me but me? I want options to seek out info from all kinds of resources.

Interviewer: Is there anyone that you would go to as another source, other than a physician?

Charlotte: I don't know that I have another friend in my peer group that I would go to for information. A discussion, of something that was common to all of us at a time of life, sure. But it certainly wouldn't be to find information.

Interviewer: Do you go into your doctor's appointment with specific questions?

Charlotte: Yeah, my questions tend to be pretty specific, and not really general. I tend to have broad strokes in my head before I go, and if I'm wrong I'll correct them. But my questions about my reproductive health tend to be pretty specific. And I try not to leave without an answer or at least an idea of where to find an answer. Whether that be a specialist, or another doctor, or literature.

APPENDIX 3

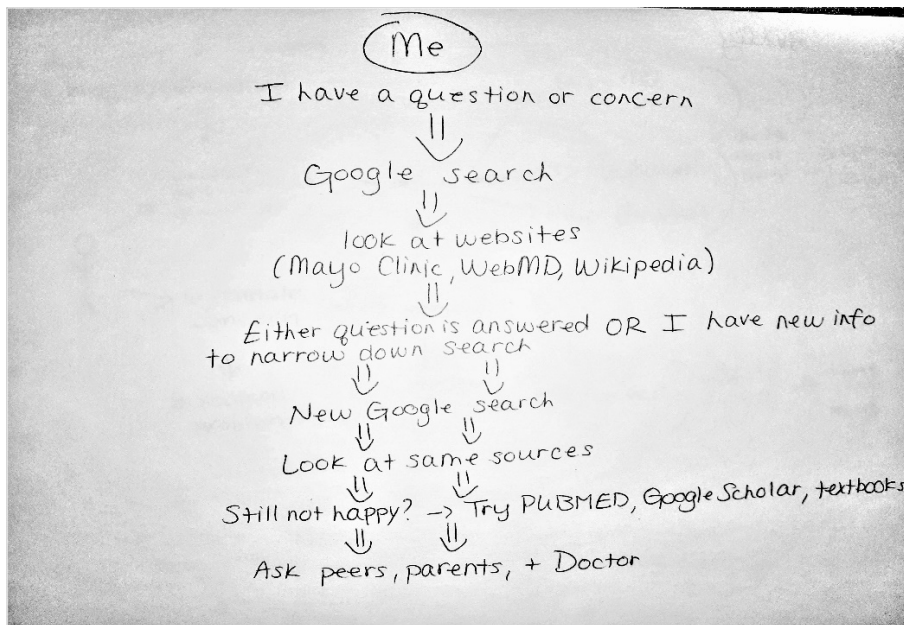


Figure 1. Anne's Information Horizon Map

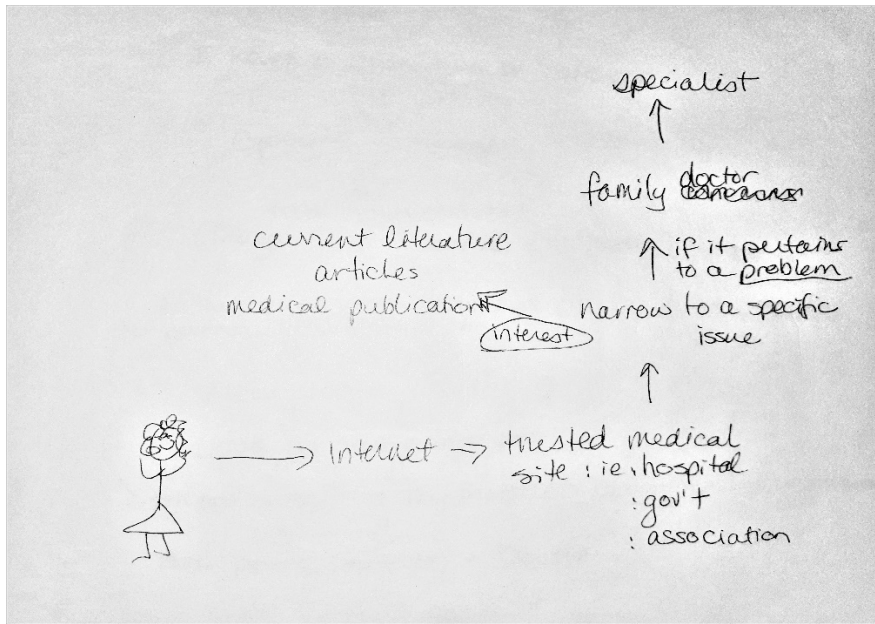


Figure 2. Charlotte's Information Horizon Map

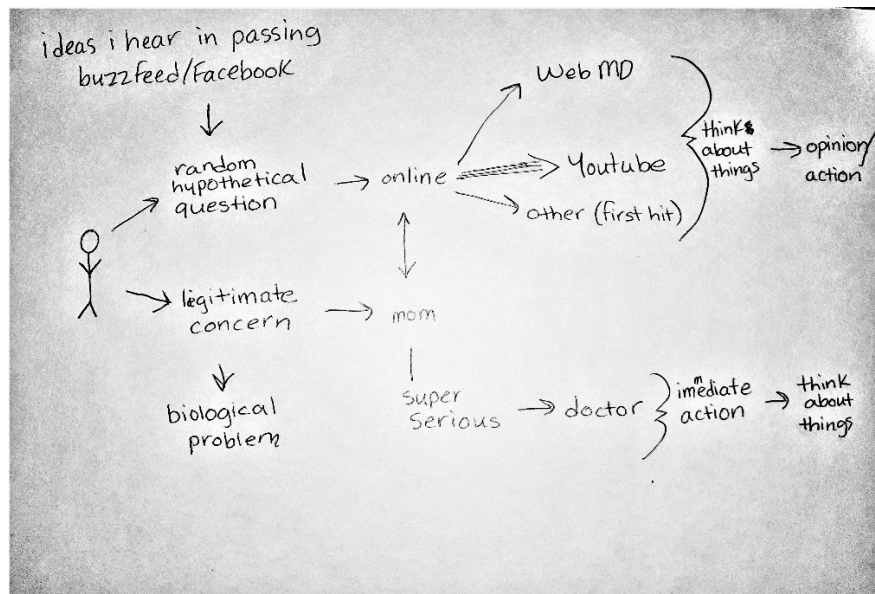


Figure 3. Emily's Information Horizon Map