Online maternity information seeking among lesbian, bisexual, and queer women

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ABSTRACT

Objective: recent research has concluded that barriers to maternity health care exist for lesbian, bisexual, and queer women. This mixed methods study aims to understand patterns in seeking and sharing online health information for LBQ women attempting conception.

Design: researchers performed a qualitative content analysis of 400 discussions in lesbian-oriented Facebook groups, containing 1764 total instances of text. 400 discussions from heterosexual-oriented conception and parenting Facebook groups were examined for comparison purposes, though they will not be the focus of this analysis. This paper also presents descriptive statistics on posts observed.

Setting: posts were drawn from a representative sample of lesbian-oriented conception, pregnancy, and parenting Facebook groups. Posts examined for comparison purposes were drawn from groups that appeared to primarily serve heterosexual women.

Measurements and findings: many participants in lesbian-oriented Facebook groups sought and provided medical information. Their queries focused on the insemination process, and frequently related to posters' specific situations, while heterosexual women tended to seek general advice about the conception and pregnancy process. The accuracy of the content of responses varied, and group members seemed to view the prevalence of contradictory information as positive evidence of diverse perspectives. Even when information was technically correct, posters did not always apply it properly to the question at hand.

Key conclusions: barriers to maternity care, or a lack of education and initiative among primary care providers, may drive lesbian, bisexual, and queer women to seek health information from peers on the Internet when trying to become pregnant. These exchanges may contribute to misinformation, which may negatively affect lesbian, bisexual, and queer women's fertility outcomes and overall health.

Implications for practice: clinicians should be conscious of online health information seeking as both a symptom of and cause of sexuality-based disparities.

Introduction

Lesbian, bisexual and queer-identified (LBQ) women seeking medical care face major obstacles, including direct and indirect discrimination from health care systems and providers, lack of provider education about their specific needs, legal barriers, and increased financial barriers to care (Fields and Scout, 2001; McManus et al., 2006; Ross et al., 2006; McNair et al., 2008; Rondahl et al., 2009; Dahl et al., 2013; Hayman et al., 2013). Hayman et al. identify four types of homophobia LBQ women seeking health care may experience: lack of recognition for lesbian relationships, the assumption of heterosexuality, inappropriate questions, and direct refusal of services (2013, p. 122). As their findings suggest, homophobia does not have to be explicit to alienate lesbian and bisexual women (Fields and Scout, 2001; McNair et al., 2008; Rondahl et al., 2009; Hayman et al., 2013). Women who experience discriminatory treatment when seeking care are less likely to access traditional medicine in the future (Fields and Scout, 2001).
Many LBQ women cope with these issues by remaining closeted to their medical providers, but when seeking maternity care, the need to disclose relevant medical information challenges this strategy (McManus et al., 2006; Ross et al., 2006; McNair et al., 2008; Dahl et al., 2013; Hayman et al., 2013). Irrespective of whether they cope with documented barriers by seeking information from alternative sources or by avoiding care entirely, research suggests that LBQ women perceive these barriers as negatively affecting their reproductive health (Johnson et al., 1981). When women do seek maternity care, providers are typically ignorant of LBQ-specific issues; therefore, they may be unaware of conception options available to lesbian and bisexual women, and thus unable to provide adequate support (McManus et al., 2006).

Those who have difficulty accessing traditional medical care often seek medical information online (Cline and Haynes, 2001; Eysenbach and Jadad, 2001; Korp, 2006; Bhandari et al., 2014; Mano, 2014; O’Higgins et al., 2014). Though the amount of medical information available online is difficult to quantify, millions of people seek health information on the Internet, either in addition to or in place of traditional medical care (Bhandari et al., 2014; Cline and Haynes, 2001; Korp, 2006; Mano, 2014). These resources take many forms, from informational sites such as WebMD to discussion and support groups, and are often extremely interactive (Korp, 2006). Pregnant women in particular seek online maternity advice at extremely high rates (O’Higgins et al., 2014), though no studies have examined how sexual orientation may moderate this trend.

When a group is prevented from accessing traditional medical resources, an information vacuum forms; the quality of the material that fills it is difficult to regulate. A few scholars have lauded online health information as a great equalizer, arguing that the ease and low cost with which patients may access it will eradicate inequalities in health care access (Korp, 2006; Mano, 2014). Other scholars emphasize the interactive nature of online resources and their potential to even out asymmetric power relations between doctors and patients (Korp, 2006; Loane and D’Alessandro, 2014). These positive perspectives suggest that online resources may empower LBQ women, who would otherwise receive limited support, to make healthy decisions about conception and maternity care. On the other hand, some scholars argue that the wide availability of online medical resources provides patients with a surfeit of material to sift through, reducing its usefulness by overwhelming them with sheer mass (Cline and Haynes, 2001). Perhaps more significantly, online health information comes with no guarantee of quality, and misinformation is rife (Cline and Haynes, 2001; Eysenbach and Jadad, 2001; Korp, 2006). No research has addressed the quality of maternity resources shared among lesbian and bisexual women, so the potential impact of this information sharing is unclear. When women seek information from peers, rather than from peer-reviewed online forums such as WebMD or MayoClinic, risks may be more pronounced (Cline and Haynes, 2001).

When online information is used in place of or in addition to direct provider interaction, the effects of online medical information may disproportionately impact marginalized populations, including LBQ women seeking information about conception and pregnancy. The extent to which this occurs, the kinds of information sought, and the accuracy of information provided remain unknown. From a provider perspective, a better understanding of common questions and the reliability of data obtained by patients online can guide clinical conversations and encourage providers to support patients’ health literacy as patients navigate conflicting data. Given existing research on sexual orientation-based health disparities, in this study we describe LBQ women’s online information seeking and disseminating behavior in order to 1.) Identify knowledge gaps that LBQ women seek to fill by engaging with their peers in online forums, 2.) Examine the quality of peer provided medical advice provided in such forums, and 3.) Identify common misconceptions or myths perpetuated in such forums that may contribute to health disparities.

### Methods

LBQ populations engage heavily in peer communication in online environments because of the perceived safety of disclosing LBQ identity in these forums (Suler, 2004). Social networking sites receive specific attention for public health activities and discussions, with Facebook recognized as a leading forum among these sites (Gold et al., 2011). When we examined several well-established online parenting communities (e.g., Babycenter.com), we discovered that the most active LBQ-identified communities around family planning for women were not on these forums, but on Facebook. Facebook is currently the most frequently used social networking site, and most who use the site use it daily (Duggan et al., 2014). Other public health researchers have focused on Facebook for this reason (Lagu et al., 2016). The research team identified and targeted the most active LBQ conception and parenting groups on Facebook with the most membership (n=661 and n=663) for observation in this study. We also examined two conception and parenting Facebook groups that primarily advertised themselves to heterosexual individuals (n=5964 and n=4651). However, comparing these groups will not be the focus of our analysis; we are primarily interested in qualitative information about LBQ women’s online information-seeking patterns.

The Smith College Institutional Review Board approved IRB Project #1415-076 on 01/22/15. For each group, we contacted the group administrators for permission to monitor the group for research purposes. Only the groups that consented were monitored, and administrators chose whether or not to alert group members. Data collection occurred during July 2015. To establish our codebook, we collected the 100 most recent posts and responses in each of the groups and performed a qualitative content analysis (Prior, 2014) drawing on methodology from similar medical studies (Lagu et al., 2010; Goff et al., 2011; Lagu et al., 2013). Three members of the research team and an academic and clinical obstetrician/gynecologist made up the coding team. Each member of the team independently coded the sample of posts using emergent coding, and refined their codes using an iterative process. The team then conferred to create a single codebook via a consensus process. We selected an additional sample of 50 screen captures and used these captures to test and refine our codebook. Finally, we drew a chronological sample of 200 exchanges from each of the four parenting and conception groups for a total of 1764 posts from the LBQ-oriented groups and 2368 posts from the heterosexual-oriented groups. We coded these data for reporting in this analysis, and will present both statistics on code use frequency and qualitative analysis of themes. Quotes have been lightly edited for readability, as some posters communicated using online shorthand, limited capitalization, or atypical spelling and grammar.

### Findings

**Overview**

Researchers divided the maternity process into five stages (Table 1), though many posts in the groups (e.g. discussion of same-sex marriage laws) did not fit within these categories. In LBQ-oriented groups, Facebook activity was highest during the conception process, and particularly during the two-week wait between insemination and confirmation of pregnancy status, with a subsequent decline for women with confirmed pregnancies. 14.9% of posts in the LBQ groups discussed insemination, while only 1.3% of posts in heterosexual groups discussed this phase, making this the most notable disparity in frequencies.

The lesbian conception, pregnancy, and parenting Facebook groups provided two primary services to their members: medical advice and emotional support. These two broad themes of support sharing and information sharing were present across all stages of conception, and the provision of emotional support will be discussed in a different
Frequency of posts about different phases of the conception, pregnancy, and childbirth processes in LBQ- and straight-oriented groups. Some posts referred to multiple periods and not all posts referred to a specific phase. In LBQ groups, \( n = 1764 \); in heterosexual groups, \( n = 2368 \).

<table>
<thead>
<tr>
<th>Phase</th>
<th>Frequency in LBQ groups (in instances)</th>
<th>Frequency in LBQ groups (in per cent of posts)</th>
<th>Frequency in heterosexual groups (in instances)</th>
<th>Frequency in heterosexual groups (in per cent of posts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-insemination</td>
<td>350</td>
<td>19.8%</td>
<td>558</td>
<td>23.6%</td>
</tr>
<tr>
<td>Insemination</td>
<td>263</td>
<td>14.9%</td>
<td>31</td>
<td>1.3%</td>
</tr>
<tr>
<td>Period between insemination and a pregnancy result</td>
<td>405</td>
<td>23.0%</td>
<td>720</td>
<td>30.4%</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>186</td>
<td>10.5%</td>
<td>309</td>
<td>13.0%</td>
</tr>
<tr>
<td>Postpartum period</td>
<td>59</td>
<td>3.3%</td>
<td>95</td>
<td>4.0%</td>
</tr>
</tbody>
</table>

Table 2 presents the researchers’ most commonly used codes in the LBQ-oriented groups and the frequency of their use in the heterosexual-oriented groups. 28.2% of posts and comments in the LBQ-oriented Facebook groups sought or provided medical advice, compared to 19.5% in the heterosexual-oriented groups.

### Seeking medical advice

As this study aims to understand maternity advice-seeking patterns among LBQ women, we do not review qualitative patterns in heterosexual-oriented Facebook groups in depth, noting only their significant differences from the patterns in LBQ-oriented groups. Posters in the LBQ-oriented groups solicited medical information in 130 of the 1764 posts observed. Medical information seeking covered general information about the conception and pregnancy process (7.7% of information-seeking posts), advice related to fertility and conception products, services, and medications (20.8% of posts), and advice about specific health concerns, including concerns about miscarriage (50.1% of posts). Medical information seeking in the 131 such exchanges in the LBQ-oriented groups focused on general information (32.1% of posts) and products and supplements (28.2% of posts), and 40.4% of posts referenced specific situations. We also categorized medical information seeking by phase of the conception, pregnancy, and childbirth process. Table 3 delineates the frequency of questions within each phase in LBQ-oriented groups versus heterosexual-oriented groups.

Within each phase, several themes emerged in the LBQ-oriented groups. 17 posts asked for advice using specific products. Products most frequently mentioned were ovulation predictor kits, cervical cups, syringes, collection containers for sperm and pregnancy tests. Many posters on the groups used or considered using cervical cups to hold the semen against the cervix during insemination, such as one woman who asked, 'Has anyone used a soft cup to conceive? Because I am very nervous using it and in only in few hours it is gonna be inside of me... I’m very scared that is gonna get lost up there.' Product questions were implicit in other queries, such as one comment that asked simply 'How are you doing the insemination?' Participants often provided photographs of ovulation or pregnancy tests and asked for help interpreting the results.

Other posts (\( n = 10 \)) asked for specific advice about what medications to take or how to take their fertility medication. One group member asked, 'So which is better to do, [what is] the difference between taking Clomid on cycle day 3 or 5?' Many posts referenced fertility drugs or fertility supplements even during initial insemination attempts and before any infertility diagnosis. One poster stated, 'Taking Vitex for attempt number two. Anyone else use Vitex? Thoughts?' After being told it would prevent ovulation, a woman trying to conceive while being told it would prevent ovulation, a woman trying to conceive while...'

Researchers distinguished between queries for general information or instructions and posts seeking consultation on a specific medical situation. We identified 37 information-seeking posts and 66 consulta-
tion posts in the LBQ-oriented groups. Several consultation posts were related to miscarriage. One woman who feared her wife was miscarrying wrote, ‘My wife is 13 weeks 2 days pregnant and has been getting cramping on her lower left side since about 4 pm. [I] was just wondering what it could be. Online [it] just says rest’. Another poster suggested that her early ovulation had caused her two miscarriages and asked group members for their perspectives. As mentioned previously, consultation posts were more common in the LBQ-oriented groups than in the heterosexual-oriented groups. Furthermore, these posts often dealt with more critical situations (e.g. miscarriage, medication dosage, and other questions with serious health ramifications) than consultation posts in the heterosexual-oriented groups, which addressed more benign situations.

Providing medical advice

Many queries for medical advice in LBQ-oriented groups received several responses, and some commenters provided advice unsolicited. Posters and commenters provided medical information and advice in 367 instances. It was often unclear from what authority they provided this information. While some women referenced research in a vague way, sources were never provided and the information given was often inaccurate. A few commenters cited their medical providers as sources. Even so, information that did not cite a source or cited only personal experience was far more common, comprising 47.1% and 42.2% of posts respectively. Table 4 states source frequencies for the LBQ-oriented groups.

The accuracy of information varied widely depending on topics discussed. In one exchange, a commenter conflated having an anterior placenta with having a placenta previa, potentially causing undue stress for the recipient of the information. In another exchange, a woman was advised against doing more than one insemination during her cycle, as sperm would ‘fight and kill each other off’. Another comment urged against swimming in open water during any part of the pregnancy.

Information exchanged around breastfeeding support was accurate and supportive, suggesting good health literacy around this topic. Sample recommendations include:

Make sure you’re comfy and have a bottle of water on hand as it’s thirsty work. We bought the expensive breastfeeding pillows but found a U-shaped pillow worked better. Don’t put too much pressure on yourself and if breastfeeding in public don’t let anyone make you feel like you’re doing something wrong.

Another thread offered reasonable and reassuring advice regarding cramping at 13 weeks. One commenter writes, ‘Tell her to have a warm (not hot) bath, take two paracetamol, and relax. Sounds like ligament pain. If they get severe with any kind of spotting, contact midwives’.

While some information offered was technically correct, the people offering it had limited information on the specifics of the recipient’s health, and were rarely trained in adapting data to an individual situation. During one discussion, a poster listed fertility medications and dosages that her partner had tried, and commenters suggested what they would recommend trying in a future cycle based on their own experiences. This advice was given without consideration for varying causes of infertility, or an understanding of the risks and benefits of different treatment options. Much of the most concerning advice responded to consultation posts, which comprised 50.8% of medical information-seeking posts in the LBQ-oriented groups. The prevalence of these posts in LBQ-oriented groups, combined with qualitative differences between LBQ women’s consultation posts and heterosexual women’s consultation posts, suggests that LBQ women who seek information online may be receiving poor advice more frequently and with more serious ramifications than straight women who seek maternity information.

On several occasions, posters disagreed about the correct medical protocol for a situation. For example, at one point, two posters disagreed about the length of time that sperm could survive post-insemination after a commenter recommended leaving a soft cup in for 10–12 hours post-insemination:

Poster 1: The vagina is such a hostile environment for sperm that there’s no need to use a softcup for that long...It’s personal preference but it’s really not necessary...

Poster 2: I don’t agree with [Poster 1’s] comment because I have used a microscope and saw moving/swimming sperm from the instead cup after taking out 10 hours after sex. They can live a LONG time in the vagina.

Poster 1: The pH of the vagina makes it hostile to sperm. It’s the body’s natural defense system. Look it up. All of the medical journals and research will tell you the same...

Poster 2: Pre-seed and healthy fertile vaginal mucus can keep swimmers alive and I’m also a midwife...your post above stated they will be dead in an hour which is not accurate. As a midwife I don’t go off of research only, I go off what I see in the past 13 years of my work and most of that is not in books. All I’m saying is, you are giving a definitive on sperm being dead, and I’m saying that is NOT true and anything is possible. These ladies need all the info.

Not just what a journal says. Sperm do not all travel thru a cervix in seconds. Be a little more open.

Poster 1: Ok. Medical research suggests that sperm in the vagina lasts about 1–2 hours at most due to the pH of the vaginal fluid. From my years of studying conception and fertility specifically I personally have found this to be true...You have a different opinion to myself and the medical experts. That doesn’t make either one of us wrong. It means our opinions differ.

In another exchange, posters disagreed about whether or not using taking cough syrup prior to insemination could help one conceive. After one woman stated that it had thinned out her mucus, a poster who had previously advocated against Robitussin as a fertility aid bowed out of the argument, stating, ‘It doesn’t hurt to try.’ Though emotions occasionally ran high, most disputes resolved when posters agreed to disagree rather than when views consolidated around a particular position.

Group administrators actively encouraged this type of resolution, intervening in threads where they perceived potential for conflict. The rules of one group we observed stated, ‘Never judge anyone’s choice of method, if you disagree with someone’s choice of method just ignore and don’t comment.’ Administrative positions and commenter behavior generated a widespread sense that all perspectives should be treated as equally valid. Note Poster 2’s statement in the excerpt above that ‘anything is possible,’ and Poster 1’s final statement: ‘[The medical consensus] doesn’t make either one of us wrong. It means our opinions differ.’ This lens could be at the root of posters’ reliance on personal experience over established resources. More significantly, since many medical questions do have both correct and incorrect answers, the perception that all posters’ medical opinions were equally worthwhile could be potentially dangerous.

Table 4
Source of authority for posts providing medical advice in LBQ groups. Note that some posts cited multiple sources. n=367.

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency (in instances)</th>
<th>Frequency (in per cent of interactions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal experience</td>
<td>155</td>
<td>42.2%</td>
</tr>
<tr>
<td>Source given</td>
<td>38</td>
<td>10.4%</td>
</tr>
<tr>
<td>No source given</td>
<td>173</td>
<td>47.1%</td>
</tr>
</tbody>
</table>
Discussion

This study suggests that in LBQ women’s online conception and pregnancy groups, which are ostensibly created for social support, nearly 30% of interactions involve seeking or providing medical advice, and over a quarter of these relate to the process of artificial insemination. These proportions are substantially higher than those in conception and pregnancy groups with largely heterosexual memberships. By definition, LBQ women face a more complex conception process than their heterosexual counterparts, so quantitative differences between their queries and heterosexual women’s queries do not prove the existence of access barriers. However, the complexity of the insemination process suggests that LBQ women may need more medical information than heterosexual women at the outset. Furthermore, LBQ women frequently consult with group members about specific medical situations, while heterosexual women more often seek general advice about conception and pregnancy. These data suggest that LBQ women are uncomfortable with accessing or unable to access key information from medical providers. The lack of curated online information for LBQ women interested in conceiving further exacerbates this issue, as it leaves LBQ women to seek information from peers, rather than from sites that have at least been reviewed by medical professionals. Disparities in needs, coupled with potential disparities in available information, suggest that LBQ women seeking support for conception may face challenges.

This study’s significance is limited by its sample size, the potential for selection bias, and the lack of detailed demographic information about our participants. Posters’ sexual orientations were not declared (meaning, for instance, that there were likely some LBQ women in the heterosexual-oriented groups), and as such, we were only able to make inferences based on groups’ apparent focuses. We also lack information about race/ethnicity, socioeconomic status, age, and other variables that may shape women’s health care experiences. Furthermore, since we sampled from four groups within one social media website, it is possible that the women were not representative of all women seeking conception and pregnancy information. However, given that we intentionally identified the most active online communities, our study still has important implications for patients, health care providers, researchers concerned with reproductive care disparities, and health informatics researchers.

Our findings echo the link found in previous research between barriers to care and online information seeking. Most of this research focuses on financial and transportation barriers (Eysenbach and Jadad, 2001; Bhandari et al., 2014; Mano, 2014; O’Higgins et al., 2014). However, Cline and Haynes (2001) suggest that patients with stigmatized identities who are uncomfortable with traditional care may turn to Internet resources instead. Given the frequency with which LBQ women appear to come to Facebook groups for medical advice, and the readiness with which other women share this advice, our data support further investigation of this hypothesis. Future research might address how the phenomenon plays out in other identity groups.

Our findings LBQ women’s online information-seeking behaviors have particularly concerning implications for the conception process. Consistent with prior literature on lesbian perceptions of maternity care by phase of conception and pregnancy (van Dam, 2004; McNair et al., 2008) and insurance coverage during conception (Rank, 2010), which finds greater inequities during the conception process than post-conception, our study found that women’s online advice seeking decreases once they conceive, suggesting they may be more likely to engage with the formal healthcare system once they are pregnant. This may lead to reduced fertility outcomes, as by nature of the process, cisgender LBQ women partnered with other cisgender LBQ women will require information to successfully conceive regardless of the presence of specific difficulty. The health care system should thus seek innovative ways to provide information about conception to LBQ women. Instead of relying on women’s identification of specific problems, obstetricians and gynecologists might consider assessing their patients’ interest in and questions about conception during regular visits. While many providers assume that they have no need to discuss fertility with LBQ patients, our findings suggest that these conversations may in fact be more important to have with LBQ women, since they face a more complex conception process than their heterosexual counterparts.

Marrazzo and Stine (2004) suggest that family planning clinics must engage women in discussions about family planning regardless of sexual orientation, an assertion our findings support. However, since LBQ women aiming to conceive may not access obstetric or gynecological care until they are already pregnant, primary care providers should actively engage their LBQ patients in family planning discussions and encourage them to access an appropriate provider at all stages in the family planning process. Preparation to discuss the process of conducting artificial insemination at home would be particularly valuable, as information about this process was highly sought after online. The medical interview process for LBQ women should include questions about fertility and providers should be prepared to provide detailed instructions for accessing sperm and engaging in at home insemination, or offer appropriate referrals to qualified obstetrician gynecologists. Furthermore, primary care providers should be conscious of gendered language and other discriminatory practices that may dissuade LBQ women from discussing fertility and conception (e.g. the assumption that a woman’s sexual partner is male).

Women who seek advice about artificial insemination from peers in place of their formal health care providers may be at high risk for poor fertility outcomes if they receive misleading or incorrect advice. The tools that women may employ in their home environments (for instance, soft cups) appear to be of particular interest. Online communities may have generated collective knowledge about these approaches that is not currently reflected in the medical literature, or their ‘anything is possible’ lenses may be perpetuating myths that others should dispel with evidence. Furthermore, discussions of sperm sources (9.9% of posts) may have significant medical implications. LBQ women may face particular health risks during the conception process, especially if they are using known donor sperm. In this case, women who do not speak with medical providers may be unaware of the risk of sexually transmitted infections, including HIV/AIDS, which occurs with use of a known donor. They may also be unaware of standards and options for donor testing prior to insemination. In addition, common myths observed in online communities (e.g., that cough syrup aids in conception) could have potential implications for fetuses.

The lack of institutional recognition and support for LBQ women may contribute to limited access to evidence-based maternity health information tailored to their needs. As a result, patients turn to informal online support groups for health information regarding conception and pregnancy. Following research on the uses of online resources to increase health care access (Cline and Haynes, 2001; Korp, 2006) development of evidence-based online resources could supplement these websites and address some of the concerns this paper raises. Providing evidence-based information via the Internet may support LBQ women in decision-making during their care and limit the potential proliferation of misinformation. It therefore has the potential to address the disparities that presently exist for LBQ women seeking health care during conception and pregnancy.

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