



## 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).

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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

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