Disclosing Sexual Orientation and Gender Identity in Healthcare Settings: Lessons for the Healthcare Providers and Policy Makers from LGBTQ Patients
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Background and Significance

Literature suggests that lesbian, gay, bisexual, transgender and queer (LGBTQ) patients experience health disparities, which are the avoidable and unjust differences in health outcomes associated with social disadvantage. As a result, many healthcare advocates and accrediting bodies such as The Joint Commission (2011) highlight the importance of collecting sexual orientation and gender identity data as a way to increase healthcare organizations’ capacity to identify and eliminate the disparities in healthcare outcomes, which contribute to health disparities (Bradford et al., 2012). However, LGBTQ patients have many reasons for not disclosing their sexual orientation or gender identity in healthcare settings, including homophobic reactions, confidentiality and privacy concerns, past negative experiences with healthcare providers, and fear of being stigmatized (Bradford et al., 2012; Mayer et al., 2008). This is why some of the leading LGBTQ advocates oppose the current focus on issues of disclosure and emphasize the need for healthcare provider education needed to create a safe environment for patients to discuss their sexual orientation and gender identity. The issue is further complicated by limited research studies to assist with understanding challenges related to disclosure from the LGBTQ patients’ perspective.

To address this knowledge gap, we designed a mixed methods study to learn about LGBTQ patients’ lived experiences and perspectives in healthcare settings related to disclosing sexual orientation and gender identity to their providers, which is important for designing inclusive, patient-centered, high-quality and safe healthcare. This research project prioritizes LGBTQ patients’ voices and experiences needed to inform structural changes, unlike much of the current literature, which is primarily based on expert opinions and recommendations.

Theoretical Framework and Research Questions

Health disparities and stigma affect disclosure efficacy for LGB people (Durso & Meyer, 2013). Communication influences patient navigation through these inequalities, much as it influences health predictors, health experiences, and health outcomes. Gershman (1983) described the twin anxieties of revealing or concealing one's sexual minority status as a "Catch 22." Individuals have reasons for and against disclosure that reflect their multiple goals in a given situation (Greene, Derlega, Yep, & Petronio, 2003). Learning about LGBTQ patients' lived experiences
and perspectives with sexual orientation and gender identity in healthcare settings is important for designing patient-centered healthcare policies. Additionally, improving the assessment process can remove one of the barriers related to LGBTQ patients' healthcare services utilization. It is possible that making a small, yet innovative structural change regarding "coming out" disclosures in healthcare settings could contribute to increased access, improved care, lowered healthcare costs, and more effective prevention for this vulnerable population. This research project ensures that LGBTQ patients' voices and experiences inform these structural changes.

This project aims to improve the quality of healthcare for LGBTQ individuals in the United States by investigating communicative needs related to gender identity and sexual orientation disclosure in healthcare settings. Our overarching research questions are:

**RQ1:** What are LGBTQ patients' beliefs about the importance of disclosing sexual orientation and gender identity to their health care providers?

**RQ2:** What factors influence LGBTQ patients' decisions to disclose their sexual orientation and gender identity in healthcare settings?

While this study includes multiple healthcare inpatient and outpatient settings, in this paper we focus only on our primary care setting findings.

**Methods and Analysis**

We received IRB approval to conduct this mixed methods study in January 2015, and we are in the process of collecting data. We are recruiting a convenience sample of approximately 400 participants, from anywhere in the United States, who identify as LGBTQ, are over the age of 18, and saw a healthcare provider in the United States in the past 12 months. Those who complete the survey can volunteer to participate in individual interviews about their lived experiences as patients who are LGBTQ. Preliminary descriptive findings and thematic qualitative survey data analysis are based on 63% of our planned survey sample.

**Projected Results**

Out of 267 participants who completed the anonymous online survey, 46% identified as women, 29% as men, 6% as genderqueer, and 8% chose to self-identify (e.g. transgender, agender, two spirit). In terms of sexual orientation, approximately 23% identified as bisexual, 27% as gay, 24% as lesbian, and 34% as queer. The race demographics are as follows: 4% of the sample identified as Black, 10% as Latino, and 77% as White. In total, 77% completed college, and 49% were in a committed relationship, with 16% being married. The average age was 32.6, ranging from 19 to 68 years of age. About one-third (33%) of the sample were involved or very involved in LGBTQ activism, and 30% were involved or very involved specifically with LGBTQ issues in health and healthcare.

Only 10% of the sample reported fair or poor health. Approximately 96% had healthcare coverage at the time of the survey, with 72.3% having constant coverage for the past five years. Despite the healthcare coverage, 46% of the sample did not have a general physical exam in the
past 12 months, with 26% not having one in more than two years. Additionally, 40% of the sample did not have a primary healthcare provider.

Out of those who did have a primary healthcare provider (n = 159), approximately 53% believed that it was very important for their primary healthcare provider to know that they were LGBTQ, 33% believed that it was somewhat important, and 14% believe that it was not very important or not important at all. Among those who had a primary care provider approximately 18% did not disclose their sexual orientation or gender identity, and an additional 12% did not know if their primary healthcare provider knew if they were LGBTQ. Only 5% of the participants had their primary healthcare provider bring up the topic of sexual orientation or gender identity. Only 1% of participants believed that their care was somewhat worse as a result of disclosure and 36% believed that their care was somewhat or a lot better because their provider knew they were LGBTQ.

Just over half (52%) of the participants worried that they would receive lower quality of care than heterosexual patients, and 57% worried that they would be treated poorly by healthcare providers because they were LGBTQ. Additionally, 44% of the participants worried that their support person would be excluded from their healthcare, and 84% of the participants agreed that there were not enough healthcare providers adequately trained to care for LGBTQ patients. While the majority of the survey participants did not experience forms of discrimination in the healthcare settings we inquired about, many have heard about others in the LGBTQ community experiencing them. For example, 91% have never been refused care because they were LGBTQ, but 49% have heard at least once of other LGBTQ individuals having the experience; 80% have never had a provider use harsh or abusive language, but 50% have heard of other LGBTQ individuals having the experience.

The majority of participants believed that questions about gender identity and sexual orientation should be asked in standard healthcare assessment but the response should be optional (71% and 72%, respectively). Additionally, approximately 9% believed that the questions should be asked but not recorded in the medical chart. When asked about the concerns related to disclosing sexual orientation and gender identity to the healthcare provider, the thematic analysis of 100 qualitative responses revealed that the survey participants were primarily concerned about experiencing discrimination and receiving low quality of care as a result of disclosure.

Sixty-three percent of the participants believed that the providers should leave it up to the patients to tell them they are LGBTQ. The following actions would make it easier to disclose sexual orientation or gender identity to a new healthcare provider: posting a nondiscrimination sign (71%), asking on a paper assessment (i.e., patient intake) form and then following up in person (61%), asking on a paper assessment form (58%), putting LGBTQ materials in waiting rooms and exam areas (57%), asking in person (40%), and providing assurance that the information would not be written in the patient’s chart (29%). The following healthcare providers should inquire about gender identity and sexual orientation: doctors (64%), specialists (50%), nurses (40%), inpatient care doctors, nurses, and specialists (39%), emergency rooms doctors and nurses (37%), no one (13%), and registrar or front office staff (5.6%). Additionally 60% of participants believed that questions about sexual orientation and gender identity should be included on the paper intake forms.
Conclusion
This is a nonrepresentative sample, and the results should be interpreted with caution. Our findings are consistent with several recent studies, suggesting that a majority of LGBTQ patients believed that it was important for their healthcare provider to inquire about sexual orientation and gender identity. However, nearly a third of participants in our sample reported that not recording sexual orientation and gender identity data would facilitate disclosure. Additionally, less than 6% believed that the registrar or the front office staff should be asking about SOGI. These responses contradict the current best practices for SOGI data collection. Our findings have important implications for healthcare policy and practice. While sexual orientation and gender identity data collection is critical for eliminating LGBTQ health disparities, these current efforts must be accompanied by a simultaneous strong focus on LGBTQ healthcare provider training, changing healthcare policy and practice based on the LGBTQ patient recommendations, and LGBTQ community engagement focused on increasing knowledge related to the LGBTQ health disparities and ways to eliminate them. A broad comprehensive strategy with patients’ voices always at the center of it is crucial for elimination of LGBTQ healthcare and health disparities.

References


