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Do Ask, Tell, and Show: Contextual Factors Affecting Sexual Orientation and Gender Identity Disclosure for Sexual and Gender Minority People

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Abstract

Purpose: Sexual and gender minority (SGM) people—including members of lesbian, gay, bisexual, transgender, and queer communities—remain underrepresented in health research due to poor collection of sexual orientation and gender identity (SOGI) data. We sought to understand the contextual factors affecting how SGM research participants interact with SOGI questions to enhance participant experience and increase the accuracy and sensitivity of research findings.

Methods: We recruited SGM adults for in-person semi-structured focus groups or online cognitive interviews from 2016 to 2018. During focus groups and cognitive interviews, we asked participants to respond to SOGI question sets. We employed template analysis to describe the contextual factors that affected SGM participants' responses to SOGI questions.

Results: We had a total of 74 participants, including 55 participants organized into nine focus groups and 19 participants in cognitive interviews. Most self-identified as a sexual minority person (88%), and 51% identified as a gender minority person. Two main themes were: (1) the need to know the relevance (of why SOGI questions are asked) and (2) the importance of environmental and contextual cues (communicating physical safety and freedom from discrimination that influenced SOGI disclosure).

Conclusions: Contextualizing the relevance of SOGI data sought could help improve the accuracy and sensitivity of data collection efforts. Environmental cues that communicate acceptance and safety for SGM individuals in research settings may support disclosure. Researchers should consider these contextual factors when designing future studies to improve research experiences for SGM individuals and increase the likelihood of future participation.

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Introduction

SEXUAL AND GENDER MINORITY (SGM) people—including members of lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities—represent an increasingly visible portion of the United States (U.S.) population and have unique health and health care needs.^{1–4} Despite carrying a larger health disparities burden, SGM people remain underrepresented in health research studies.^{5–8}

This invisibility is, in part, due to the lack of accurate and systematic collection of sexual orientation and gender identity (SOGI) data.^{3,9–11} Even as health systems and surveys are increasingly collecting SOGI data, insufficient attention is paid toward developing best practices.¹²

The needs of SGM communities participating in research studies differ from those of non-SGM populations.^{12–14} SGM participants report experiences of stigma and discrimination in health and research settings, reducing participation.^{15–18} Without critically examining how SOGI questions can be improved, researchers may inadvertently reinforce cisnormative and heteronormative structures that exclude SGM communities. Analysis of Behavioral Risk Factor Surveillance System data, the nation's largest survey on health-related behaviors, found that almost 30% of transgender individuals' sex assigned at birth data were misclassified due to lack of validated SOGI questions.¹⁹

How studies conceptualize SOGI has significant implications in applications and interpretations of research findings.²⁰ Careful attention to developing accurate SOGI measurement, especially for health studies, is critical to reducing SGM health disparities.

Significant gaps exist in understanding how to optimize accurate SOGI data collection within research. Prior work has focused on best practices for wording and phrasing of SOGI questions.^{13,21–25} Few studies have examined contextual factors. The context in which questions are asked affects SGM participant comfort and willingness to respond, and contextual factors may also affect selection of response choices.^{26–28} SGM people vary in their disclosure of SGM status from context to context.²⁹

Understanding and enhancing contextual factors that affect SOGI response could improve SGM people's participation in research and increase the accuracy of research methodology, dissemination, and implementation. We conducted a qualitative analysis to determine the contextual factors that influence how SGM people relate to SOGI questions within research studies and how these factors could be enhanced to make research participation more inclusive and inviting.

Methods

Recruitment and enrollment

We previously described the methods for study procedures.²³ Briefly, we recruited participants from The Population Research in Identity and Disparities for Equality (PRIDE) Study (a national online cohort of SGM adults), social media advertisements, community fliers, and/or referrals from LGBTQ community center staff from January 2016 to March 2018.

Participants aged 18 years or older, fluent in English, residing in the U.S., and self-identifying as a sexual minority

person (someone who is not exclusively straight/heterosexual) and/or as a gender minority person (someone whose current gender identity differs from that commonly associated with their sex assigned at birth) were eligible. Cognitive interviews also required phone and Internet access. Prospective participants completed a 22-item screening survey.

We used convenience and purposive sampling with the goal of diversity in gender identity, sexual orientation, age, race/ethnicity, income, and (for cognitive interviews) geographic location. Participants were not geographically representative, although they did represent all census regions with 88% from the West, 7% from the Midwest, 1.4% from the Northeast, and 4% from Southern regions. All participants provided written informed consent on enrollment and reconfirmed verbal consent during focus groups and cognitive interviews. The Institutional Review Board at the University of California, San Francisco (IRB #15-16116) approved this study.

Focus groups

We conducted nine 2-hour in-person focus groups from January to September 2016. Seven groups clustered around SGM identities: two groups of sexual minority men irrespective of sex assigned at birth, two groups of sexual minority women irrespective of sex assigned at birth, and three groups of gender minority people (gender minority women, gender minority men, and participants with nonbinary, genderfluid, or other nonbinary identities). Two groups had multiple SGM identities represented.²³ During focus groups, we displayed SOGI questions (from prior national surveys or best practice recommendations endorsed by SGM health experts and researchers) to elicit reactions.

Cognitive interviews

We conducted 19 cognitive interviews from October 2017 to May 2018. Participants were emailed a survey displaying new sets of SOGI questions developed based on focus group findings. Using a semi-structured interview guide, interviewers probed for emotional and cognitive responses, eliciting views of any factors that could affect question response. Two participants completed interviews by phone, and 17 completed interviews using BlueJeans videoconferencing software (BlueJeans Network, San Jose, CA).²³

Data analysis

We audio-recorded, transcribed, and coded transcripts by using Dedoose (SocioCultural Research Consultants, LLC, Manhattan Beach, CA). We used template analysis with themes centered on sexual orientation, gender identity, and sex assigned at birth.³⁰ We iteratively analyzed results until thematic agreement was reached. In this article, we present findings related to contextual factors. We paired quotes with self-identified characteristics, using the participant's own words for identification.

Results

Participant characteristics

The demographics of participants were previously described.²³ Of the 74 participants in the study, 55 participated in one of nine focus groups and 19 participated in cognitive

TABLE 1. EXEMPLAR QUOTES DESCRIBING THEMES RELATED TO HOW CONTEXTUAL FACTORS AFFECT SEXUAL ORIENTATION AND GENDER IDENTITY DISCLOSURE AMONG SEXUAL AND GENDER MINORITY PARTICIPANTS IN RESEARCH

<i>Major theme</i>	<i>Exemplar quotes</i>
Relevance: the importance of knowing why questions are being asked and how information is relevant.	<p>“So if I’m receiving a treatment, if it’s necessary for me to tell my doctor my sex, then I would totally do it because it’s my health. But on the other hand, if it’s, like, not related, I’m going to a doctor to get some medication for a flu, then why are you asking for my sex? I think it’s a very, very tricky question that requires a justification to ask.” (31, Asian/Pacific Islander, woman/transgender woman, assigned male at birth, straight, gender minority women focus group)</p> <p>“Am I in a physician’s office or a psychiatrist’s office or am I signing up for the gym membership? [...] It depends on when you would have asked me” (37, White, man/transgender man/currently questioning/detransitioner/regretter, assigned male at birth, queer/de-sexed, genderqueer/gender nonbinary focus group)</p> <p>“I think it depends on the type of office because [...] thinking like a primary care or something that is a direct health issue that directly stems from your sexual orientation.” (26, White, woman, assigned female at birth, lesbian/gay, sexual minority women focus group)</p> <p>“Like medically if, you know, I’m going for any surgery and this is on my [intake form], I wouldn’t mind that question because it’s a question. You know what I mean? But if somebody randomly walks down the street and sees me and questions me that, it’s going to strike a nerve.” (Declined to provide age, Black/African American, transgender woman, assigned male at birth, declined to provide sexual orientation, gender minority women focus group)</p> <p>“I think for me it mainly depends on the intention and why I’m being asked [“What’s your sexual orientation?”]. Like with a survey, presumably, I’m filling out a study of something, or like if I saw my doctor or whatever. I would feel pretty comfortable with that. [...] Presumably there’s a specific reason behind that question.” (20, American Indian or Alaskan Native and White, woman, assigned female at birth, bisexual/queer, cognitive interview)</p>
Environmental and relational contextual cues: these communicated physical safety and freedom from discrimination, influencing likelihood and comfort with SOGI disclosure.	<p>“I would do a lot of those internal scans as you look at the other person and go, ‘Why do they want to know and what are they gonna do with that information?’ I mean like, what’s the context? Is this person a friend? Is this someone I already know? Is it someone I’m walking up to on the street? Does this person look gay and do they think I look gay? [...] Do they seem like the sort of person who would lash out if they are not happy with my answer?” (20, White and American Indian or Alaskan Native, woman, assigned female at birth, bisexual/queer, cognitive interview)</p> <p>“To know that a healthcare provider had enough awareness to think about the trans people is a huge deal. It’s telling me all sorts of things. It’s telling me, wow, this may be a safe space. Wow, they will actually listen to me and take what I say seriously and not challenge me, not gate keep or anything like that. So, so, my emotional reaction to this is very positive, whatever the packaging is, whether it’s perfect or not. It doesn’t matter, because just asking it is a big deal. [...] Even today, no one asking me this stuff. I have to tell them.” (56, White, woman/transgender woman, assigned male at birth, pansexual, cognitive interview)</p> <p>“I’m wondering if that’s also a way to segregate, how do you feel when you’re talking with your doctor or your family? Because that’s one of the issues I see with medical professionals. It’s very personal and private, so you need to feel that level of comfort that.” (61, White, man, assigned male at birth, gay, sexual minority men focus group)</p> <p>“For me, none of these questions make sense in the doctor’s office because all they really want to know about is my behavior. Unless they care, if they want to care. If it’s a psychologist or that kind of doctor’s office, then okay.” (24, White, woman, assigned female at birth, lesbian/queer, sexual minority women focus group)</p> <p>“Anything you can do to validate [a participant’s] experience is going to help [researchers] and make [participants] more inclined to take another survey from the same source that maybe asks different questions, but make sure that everyone, and as many voices as possible, [are] being included and are being asked really important questions, especially when you get into things like healthcare and access to healthcare and the way you’re treated.” (27, White, woman, assigned female at birth, pansexual, cognitive interview)</p>

SOGI, sexual orientation and gender identity.

interviews. The median age was 34 years old (interquartile range 28–50); 24.3% identified as Asian/Pacific Islander, 13.5% as Black/African American, 8.1% as Hispanic/Latinx, and 56.8% as White. Half (51.3%) were gender minority people, and 43.2% had multiple gender identities.

For sexual orientation, 87.8% were sexual minority people, and 35.1% had multiple sexual orientations.²³ We found two major themes: (1) the need to know the relevance (of why SOGI questions are asked) and (2) the importance of environmental and contextual cues (communicating physical safety and freedom from discrimination that influenced SOGI disclosure) (Table 1).

The importance of relevance

Participants emphasized the importance of understanding why SOGI questions were being asked and how the information was relevant to the context at hand. Participants reflected on their experiences answering SOGI questions in health care and research settings and seldom distinguished between the two. They described prior experiences when asked SOGI questions in contexts where reasons for SOGI data collection were not apparent. They desired reassurance that information would not be used in discriminatory ways.

When asked about answering SOGI questions in the context of a health survey, one focus group participant responded:

“Part of me also wants to question why do you—like, you don’t need to know my gender identity. Why? Why are you asking? What business is it of yours?” (37, White, man/transgender man/currently questioning/detransitioner/regretter, assigned male at birth, queer/de-sexed, genderqueer/gender nonbinary focus group)

Participants remarked on being more likely to respond if questions were asked for health studies or within other health contexts, as it was generally understood how SGM status might affect health. By contrast, administrative contexts (e.g., forms for the post office), or strangers asking out of curiosity, were considered more intrusive and voyeuristic since the relevance of SOGI information was not obvious.

“I’m trying to think of the situations where this is going to be used. I’m thinking why do they need to know this information and how is it pertinent? If it’s a healthcare situation, then, yes, they probably need to know to ask questions about general health.” (56, Asian/Pacific Islander, man, assigned male at birth, gay, sexual minority men focus group)

However, even within health contexts, participants still wanted to understand why SOGI information was being collected.

“[Some of the SOGI questions] depend on the context of what kind of care is being provided and what sort of research is being done. Again, if they’re treating a broken arm, does it even matter what sex you are at all? Whereas, if you’re talking about research about a herpes vaccine, well, yes, actually, a lot of those details matter.” (38, White, genderqueer/gender non-conforming/indifferent to gender, assigned male at birth, bisexual/pansexual, genderqueer/gender nonbinary focus group)

Participants also used context to decide which SGM identity they would use to describe themselves:

“I was going to comment that it’s interesting. Normally in most contexts, including the medical context, gay would be the prime word being used, but in a political context, I’m more comfortable with queer.” (61, White, man, assigned male at birth, gay, sexual minority men focus group)

Many gender minority participants emphasized how they used the transgender label as a qualifier in some contexts and not others. Examples included seeking gender-affirming medical care, wanting to increase visibility and resources for transgender communities, and communicating transgender experiences to providers when medically relevant. Understanding why information was being asked helped gender minority participants determine whether to apply the transgender label.

“I think of myself internally as a woman. I say ‘trans woman’ to medical care providers because they need to know that I have a history where my body may not be in alignment with my gender identity. So, I want to speak in their language something they will understand. But many health care decisions have to do with how we live our lives. And how we describe ourselves in day-to-day living is really important.” (56, White, woman/transgender woman, assigned male at birth, pansexual, cognitive interview)

Understanding the relevance of and reasons for SOGI data collection factored significantly in how the participants responded to SOGI questions and their decisions about whether and how to disclose SOGI information.

Importance of environmental and relational contextual cues

Despite the study’s emphasis on research settings, participants frequently drew upon their experiences interacting with SOGI questions across their lives, including social, health-related, and research-related contexts. When responding to SOGI questions, participants looked beyond SOGI question wording to environmental and relational contextual cues to find signs of safety and inclusion. When asked about the question, “What’s your sexual orientation?” one participant described looking for environmental and relational cues to determine safety:

“I sometimes go to the gay youth center, right? If someone there asked me, ‘Hey, what’s your sexual orientation?’ I’d be totally chill, because it’s a context where I feel safe and it’s with people who, presumably, are there seeking commonality through that. Versus, like at work. Before I figured out how many queer people work here, I might have felt way less comfortable and thought maybe it had something to do with discrimination and homophobia. ‘Does this person look friendly? [...] Do they seem like the sort of person who would lash out if they are not happy with my answer.’” (20, American Indian or Alaskan Native and White, woman, assigned female at birth, bisexual/queer, cognitive interview)

Participants spoke of health and research settings interchangeably, describing how researchers and clinicians could attend to these cues. Environmental cues, such as seeing SGM-identified staff or welcoming signs, were significant. Seeing evidence in the physical space of attempts to communicate acceptance meant that staff were intentional about creating a welcoming, inclusive, and safe environment. When asked whether SOGI question phrasing or environmental cues, for example in a clinic space serving queer

and nonbinary patients, had more of an impact in increasing comfort and perceptions of safety, one focus group participant answered:

“If anything, just saying it’s a queer safe space and seeing people like you behind the counter that puts you at ease to even be answering the questions with as much freedom as you want.” (26, Asian/Pacific Islander, transgender man, assigned female at birth, queer, sexual minority men focus group)

The mode of questioning was also important to enhance comfort, disclosure, and sense of autonomy. When asked about preferences for forms, tablet, or an online web-based platform compared with in-person interviews, participants emphasized how an in-person format was less desirable due to potential for stigma and/or discrimination. Other platforms offered more control and autonomy during participation:

“But I would be more comfortable with a video or web format than in person. And I think that’s just because there’s always going to be some hesitancy when somebody’s right across from you. But if you were asking me these questions and I felt uncomfortable or like, if you were going to judge me or something, I could seriously just slam my computer down and walk away from it.” (32, White, woman/genderqueer or gender non-conforming, assigned female at birth, lesbian/gay, cognitive interview)

This discomfort with being asked SOGI questions in-person could be offset if participants had existing relationships with the interviewer (e.g., their primary care provider):

“If I’m looking at something that’s just on a paper or a tablet or something, I’m focused pretty much on the reading or my interiority. Whereas, if I have to sort of keep like one eye on the person, it’s a little distracting [...] If it was something that like my doctor that I’ve been seeing for a number of years, and she was like, ‘Okay. We have this questionnaire. Can you answer?’ I’d be pretty comfortable talking to her, because she knows my history.” (24, Asian/Pacific Islander, genderfluid/nonbinary/cozy femme/agender/gender non-conforming, assigned female at birth, queer/aromantic asexual, cognitive interview)

Participants discussed how despite previously experiencing discrimination and stigma when responding to SOGI questions, it was still important to ask these questions and to continue doing so in intentional, thoughtful ways.

“It all depends on how you’re asking and your demeanor about going about asking it. If someone comes up to you and they’re like, ‘What are you?’ You’re going to get offended. Now, if somebody comes up to you privately and pull you away from whatever you’re doing and sparks a conversation then at the end asks you that, I think it’s nothing wrong with that.” (Declined to answer for age, Black/African American, transgender woman, assigned male at birth, declined to answer for sexual orientation, gender minority women focus group)

Overall, participants related the importance of environmental and relational contextual factors in affecting SOGI response, and how attention to these factors could create more welcoming and inclusive spaces for SGM people in health and research settings.

Discussion

In this qualitative analysis of SGM people discussing contextual factors that affect their responses to SOGI questions

in research studies, participants emphasized the importance of knowing why questions are being asked and how information is relevant. SGM people are significantly more likely to face discriminatory practices in health care and research settings, including being misgendered, having sexual behaviors and preferences assumed, or being subjected to inappropriate health service recommendations by providers (e.g., absent/diminished pap testing for cisgender women who have sex with women).^{16,18,31}

Many SGM participants also perceive voyeurism when asked about SOGI and other questions that seem irrelevant to the purpose of the visit and more to satisfy staff curiosity, exacerbating experiences of discrimination.^{31,32} Researchers and health care providers understanding and explaining the reasons for SOGI questions may improve experiences for SGM participants and, thus, enhance SOGI disclosure.^{32,33}

Participants also drew on their experiences in other contexts to inform how research settings can become inclusive. Attention toward environmental and relational cues within the context can convey safety, provide reassurance, and help SGM participants decide what identity labels to use. Prior studies have emphasized the role that minority stress can play for SGM people, especially in affecting disclosure versus the concealment of SGM status in varying contexts.^{34–37}

Minority stress is the physiological and psychological cumulative toll from stress related to discrimination, stigmatization, and violence due to one’s SGM status.^{34–37} Identity concealment is one aspect of minority stress and provides a method for coping with discrimination, although it is also associated with deleterious long-term health outcomes for some SGM community members.^{29,33,35–37} SGM individuals vary in how much they disclose their SGM identities depending on the context, and few SGM people are fully “out” in all contexts of their lives.^{29,37}

Literature from Self-Determination Theory has highlighted how environments that support identity expression and autonomy are associated with higher levels of SGM identity disclosure, whereas controlling environments, with less autonomy and community support, are associated with more SGM identity concealment.^{29,38–40} Our study also builds upon this work by emphasizing how participants use environmental and relational cues to interpret environments as more or less supporting of their autonomy, which, in turn, could have affected their response to SOGI questions.

Implications

These findings have several implications. Researchers can consider sharing reasons for SOGI data collection to increase the perceptions of safety and discretion during studies. We recommend including SOGI questions as general demographic questions and using introductory statement(s) describing reasons for data collection and how data will be used at the beginning of demographic sections to avoid drawing attention to and inadvertently stigmatizing SOGI questions.^{23,41} The use of introductory statements is often implemented in qualitative studies, especially with sensitive topics,⁴² although it is seldom practiced in quantitative studies.

Environments should also display cues to communicate acceptance of participants regardless of SGM status. Potential

practices include partnering with LGBTQ-identified organizations; ensuring recruitment materials feature SGM people of various backgrounds and use inclusive language; hiring and valuing SGM staff; and normalizing pronoun sharing. Attention to these practices could improve research experiences for SGM people and enhance the likelihood of future participation, while improving the accuracy and sensitivity of research methodologies.

Strengths and limitations

Study strengths include using multiple qualitative methodologies and inclusion of participants diverse in age, race/ethnicity, geographic location, and SGM background. Limitations include cognitive interviews requiring Internet access, which may limit generalizability, and restricting the study to English-speaking participants only. We lack information on whether participants had prior research experience. Thus, the recommendations of participants without known research experience may be hypothetical. However, their contributions are still invaluable to understanding barriers to participation.

Participant age skewed younger, and applicability to older SGM populations is unclear. Finally, the results may be reflective of only one point in time. Language has continued to evolve since these data were collected. Recent improvements in SOGI question development include deploying patient-centered terminology in survey design and increasing the recognition of differences between gender and sex assigned at birth.^{13,43} Despite advances, attention toward contextual factors is still applicable to SOGI question design, especially as these topics are being explored by the National Institutes of Health and National Academies of Sciences, Engineering, and Medicine.^{44,45}

Conclusion

Reasons for SOGI data collection and relevance to context were important and influenced responses. Participants looked for environmental and relational cues that communicated inclusion and safety. Researchers should consider these factors when designing studies to improve research experiences for SGM individuals and increase the likelihood of participation.

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Authors' Contributions

L.W.S., J.O.-M., J.M.S., and M.R.L. conceived and designed the study. S.W., L.W.S., J.O.-M., and M.R.L. conducted the focus groups. L.W.S. conducted the cognitive interviews. J.O.-M. and M.R.L. obtained funding for the study. All authors contributed to data analysis and interpretation. L.W.S. and J.O.-M. drafted the initial article, and all authors contributed significantly to article revisions. All co-authors reviewed and approved the article before submission.

Disclaimer

The statements in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute, its Board of Governors or Methodology Committee, or the National Institutes of Health.

Author Disclosure Statement

M.R.L. has consulted for Hims, Inc. (2019-present) and Folx, Inc. (2020). J.O.-M. has consulted for Sage Therapeutics (5/2017) in a 1-day advisory board, Ibis Reproductive Health (a not-for-profit research group, 2017-present), Hims, Inc. (2019-present), and Folx, Inc. (2020-present). A.F. consulted for HopeLab, a nonprofit research group (2020). S.W. is a contractor with Gilead Sciences Corporate Giving. None of these roles presents a conflict of interest with this work as described herein. All other authors report no conflict of interest.

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