Article

Improving the Accuracy of Identifying Lesbians for Telephone Surveys About Health

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Abstract Knowledge about the health status and health care needs of lesbians is limited by the lack of population-based studies, although recent survey methods research offers suggestions that may be relevant to involving lesbians in more rigorous studies. To explore the transferability of findings about the general population to research on lesbian health, focus groups were conducted in 1997–1998 with self-identified lesbians in five U.S. urban areas. Videotaped telephone interviews stimulated discussion about methods for enhancing participation of lesbians in random digit dial telephone surveys. Results are useful for developing improved practices for conducting health surveys with lesbians.

Researchers who study lesbians are challenged by ways to identify lesbian participants in a general population sample. Lesbians differ in how "out" or openly identified they are about their sexual orientation. They may fear social stigma or legal sanctions if they disclose their sexual orientation, particularly to an anonymous interviewer. For

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this reason, most research on lesbian health has contacted lesbian participants through convenience samples, such as distributing surveys at lesbian events or organizations, or through ads in lesbian periodicals.[1] Other studies have used a "snowball" method, where respondents are asked to give additional surveys to their friends and acquaintances.[2,3] Such methods of data collection are nonrepresentative or nonrandom because they focus on lesbians who are out enough to attend lesbian events or known to other women in the lesbian communities. Health status and health services data collected through these methods may underrepresent certain subgroups of lesbians of special concern to health planners and care providers.[4]

Although a recent study in New York City found no significant differences between samples of gay men created by random digit dial (RDD) and community sampling,[5] a 1996 RDD survey of the U.S. general population indicated that different results may be obtained with women.[6] Among 520 women respondents in the 1996 sample, preferred modes of data collection varied on the basis of age, race/ethnic minority status, education, income, geographic region, and sexual orientation. The most substantial differences between respondents who identified their sexual orientation and those who did not were found in their answers about interviewer sexual orientation and study sponsorship. Study results indicated that tailoring survey methods to subpopulation characteristics can be expected to increase the willingness of women to honestly report sexual orientation. Similar findings have been reported about the impact of race and age on the effectiveness of data collection methods. Nonrandom measurement error has been shown to occur through the influence of interviewer's race in surveys of African Americans,[7] and in a study of middle-aged and older lesbians, researchers noted that respondents' skepticism about traditional health care systems and fear of disclosure about sexual orientation were substantial barriers to study participation from this subpopulation.[8]

A recent report from the Institute of Medicine (Committee on Lesbian Health Research Priorities) concluded that ideally, lesbians should be recruited through probability sampling in the general community, and identified three reasons why lesbians are difficult to recruit for such studies.[9] First, lesbians are a hidden population and are hesitant to disclose their sexual orientation to avoid negative repercussions. Second, lesbians are not evenly distributed in the United States geographically. Third, lesbians represent a very small percentage of women in the general population, so extremely large sample sizes are necessary to recruit an adequate subsample of lesbians. This report recommended strengthening the methods used in research about lesbians and emphasized the need for methodologic studies, concluding that research on lesbians could lead to more sophisticated methodology for research on women's health in general, as well as that of other rare or hard-to-reach population subgroups. Both probability and nonprobability methods warranted further development.

Lesbians are a hidden population

Results from a recent national survey using probability sampling illustrate the challenges in conducting and interpreting data about sexual orientation, even from rigorous approaches.[10] The percentages of lesbians among this sample of the general population of U.S. adult women varied dramatically based on demographic characteristics and how sexual orientation was measured. Within this national sample, 7.5% of women reported same-sex desire and 4.3% same-sex behavior since puberty, yet only 1.4% self-identified as homosexual or bisexual. Whereas 2.6% of women in 12 central cities self-identified as homosexual or bisexual, none who lived in rural areas did so. Similar variations were found based on age, education, race/ethnicity, marital status, and religion. These variations may reflect true differences in the population of lesbians, but they may also be reflective of the differential

willingness of lesbians to disclose sexual orientation in phone surveys, based on a variety of other personal, cultural, and societal characteristics.[6] Patterns of difference in reporting sexual orientation are found throughout all sexual minority subgroups of the population and are not limited to women. Other recent national studies that have estimated the percentages of U.S. adult men and women based on the three dimensions of attraction, behavior, and identity produced ranges from 1% to 4% who identify as gay or lesbian, 2% to 6% who report same-sex behavior within the previous 5 years, and as high as 21% who report same-sex attraction at least once in adulthood.[10]

Although the need to discover the most effective research methods for learning about sexual minority subgroups has been identified and a fairly large number of studies has been conducted about gay men, little published research has provided answers specific to lesbians.[11] Recent survey research findings about methods to enhance participation in studies about sensitive topics with the general population reflect concerns raised in the limited number of studies about lesbians. Respondent engagement is of considerable importance to the collection of valid data. Eligible individuals who are less interested in participating are likely to give more missing data and may differ from other respondents in specific ways that raise concern for generalizing results.[12] Data collection mode also has a significant impact on response to sensitive questions. In a randomly selected general population sample, respondents were offered computerized and noncomputerized options for completing a survey through self administration or with interviewer involvement.[13] Results indicated that self-administered modes fostered a greater sense of privacy, whereas interviewer availability facilitated understanding of study questions and increased confidence of participants. The degree of privacy, extent of cognitive burden, and sense of legitimacy afforded to respondents were key variables in mediating the major effects of data collection mode on data quality. Although the positive effect of monetary incentives on response rates has been documented,[14] the role of incentives has not been explored in the lesbian population.

The purpose of the present study was to examine ways to improve telephone surveys to increase the likelihood that lesbians would honestly self-identify, by using "lesbian" to describe themselves and/or by providing information about their same-sex behavior or desire. The specific methodologic questions we explored in this study fit within a broader methodologic exploration of how best to enroll lesbians in health surveys.

METHODS

Data Collection Technique

Focus group methodology was chosen to facilitate in-depth discussion among lesbians about effective methods for recruiting individuals from their communities into health survey research. A recent review describes this method as naturalistic, interactive, and well-suited for exploratory and qualitative research (Table 1).[15] Although there are no formal procedures to assess the validity of focus group results, researchers can increase the relevance of their findings by conducting several groups on the same topic and checking for consistency as a partial test of generalizability.[16] In keeping with this principle, we conducted multiple focus groups in various parts of the country and with diverse members to enhance the value of study results.

Focus groups are particularly useful for learning about opinions of underrepresented groups

Focus groups are particularly useful for learning about the opinions of underrepresented groups.[17] They may be the method of choice when there is a power differential between research participants and decision makers and/or professionals (such as health care providers and academics) who will use the

Table 1. FOCUS GROUP METHODOLOGY

Careful recruitment of participants
Systematic procedures
Similar types of people
5–10 people/group
Proper meeting environment
Neutral setting
Circle seating
Tape recorded
Skillful moderator (facilitator)
Trained and experienced
Used predetermined questions
Established a permissive environment
Worked with assistant moderator to handle logistics
Appropriate analysis and reporting
Systematic analysis
Verifiable procedures
Appropriate reporting

data, when the investigation is about complex behaviors, when there is a need to learn more about the degree of consensus on a topic of interest, and/or when there is a desire for a "friendly research method" that is respectful and not condescending.[18] Focus groups may be most appropriate when research studies involve the collection of data about sensitive topics from particular subpopulations. In the personal context that focus groups can create, lesbians may be more able to disclose information about sexual behaviors and/or to disclose their sexual orientation without specific reference to sexual behaviors.[19] Within the private sphere that can be created in the discussion format of focus groups, the predictably human barriers to sharing information about one's sexual life with nonintimates (as required in more typical health surveys), may be set aside.

Recruitment of Focus Group Participants

Self-identified lesbians were recruited through local community coordinators in five urban areas of the United States: Chicago; Dallas; Richmond (African American lesbians); Portland, Oregon (with a focus on Asian/Pacific Islander lesbians); and Seattle. An incentive of $20 was offered, which three fourths of all participants accepted. Each focus group was audiotaped and transcribed for qualitative analysis, using the software package HyperResearch. In addition, focus group leaders took field notes and made written observations. The study design was determined to meet the requirements for protection of human subjects by the Internal Review Board of Virginia Commonwealth University. Characteristics of focus group participants are shown in Table 2.

Conduct of Focus Groups

Focus group participants were asked to watch a videotaped simulation of the first 6 minutes of an RDD telephone survey with a female respondent. The survey was described as a "national women's health survey." Two versions were prepared, one with an African American respondent and one with a white respondent. The first minute of the tape was shot in an actual telephone survey lab, showing an experienced interviewer placing the call. The scene then shifted to a facsimile of someone's living room, showing a ringing

Table 2. PARTICIPANT CHARACTERISTICS

Total participants (All groups)	*(N = 46)*
Race/ethnicity	
African American	11 (24%)
White	27 (59%)
Asian Pacific Islander	8 (17%)
Age 18–58	
Earned income $0–75,000	

telephone and a woman coming into the room to answer the call. After a brief description of the purpose of the call and request for permission to continue, the interviewer presented two modules of questions, a screening module and an abbreviated set of health status questions.

Screening module questions included the number of women in the respondent's household over age 18; whether there were men in the household; whether there were children; whether the respondents had pets; whether her friends were male or female; whether she was in a relationship, and if so, the gender of her partner; and whether she considered herself heterosexual, bisexual, lesbian, or "something else." In this way, the interview led up to more sensitive questions. The interviewer also asked about leisure and social life activities that might indicate community involvement for some lesbians, such as watching and participating in women's sports, attending a women's music festival, and frequenting women's bookstores. Such questions were embedded in more general questions, such as, "In the past month, have you gone to a wine store? A computer store? A women's bookstore?"

The screening module was followed by a brief series of questions commonly used to assess health status. These included general health status, usual source of care, any major health conditions, substance abuse, and so forth. About a minute and a half into the second series of questions, the camera began to fade away from the respondent, and the video ended. After a brief period of 2–3 minutes to unwind, focus group members were asked by semistructured interview for their reactions to the video. With the video fresh in their minds, they were asked to share their opinions about the most effective methods for conducting health surveys with lesbians, emphasizing the advantages and disadvantages of using the telephone.

RESULTS

A number of themes emerged about ways to improve telephone surveys to increase identification of lesbians, including inviting participation of lesbians, the importance of trust, role and characteristics of the interviewer, design and placement of sensitive questions, acknowledging the totality of lesbians' lives, and confronting diversity among lesbians. A summary of the focus group themes with associated methodologic implications is presented in Table 3. These themes and methodologic comments are consistent with recommended areas for additional research identified in the IOM Report—how techniques for sampling hard-to-identify population subgroups might be applied to probability sampling of lesbians, what the technologies are for eliciting disclosure and how demographic factors affect the use of such technologies, and how the use of qualitative methods can better inform other research.

Table 3. FOCUS GROUP THEMES WITH METHODOLOGIC SUGGESTIONS

Lesbians (particularly "closeted" lesbians) are often overlooked in research, yet would like to participate in research on women's health and lesbian issues if convinced that it is safe to do so.

- Appeals to altruism (eg, recognition of the contribution of lesbians to the study of women's health) may be particularly effective with lesbians.
- Sample altruism wording: "We are particularly interested in talking to women who for various reasons have some difficulties in obtaining care, for example, those who do not have health insurance, lesbians, etc.")

Potential respondents must be convinced that the survey is being conducted by a trustworthy organization for a legitimate purpose.

- Allowing the respondent to verify the legitimacy of the contact would increase the level of trust (eg, provide a phone number the respondent could check before conducting the survey).
- Sponsorship by an organization recognized for impartiality (eg, university) or an organization familiar to the lesbian community would increase the level of trust. Sponsorship by lesbian organizations would be more effective with "out" than "closeted" lesbians.
- Provide a mechanism for respondents to give feedback to the survey and sponsoring organization(s) on their experiences.
- Place strong stress on anonymity/confidentiality in the survey introduction.
- Insert comments empathizing with the difficulty of answering sensitive questions

In telephone or face-to-face interview surveys, attention should be paid to the interviewers' skill in conducting interviews on sensitive topics and their demographic characteristics.

- Interviewers must be capable of generating trust in the process. Preferably, only interviewers with experience in interviewing on sensitive topics should be selected.
- Interviewers should be female. If possible, also match the age and ethnicity of respondents.
- Interviewers should convey a nonjudgmental attitude.

Special care should be taken with the design and placement of sensitive questions.

- If researchers wish to screen large populations to narrow down to women with a higher proportion of lesbians (a screening module), care must be taken to ensure that respondents perceive the module as a natural part of the survey process and not as questions designed to trick them into revealing their sexual orientation. Extensive pretesting should be done with as many kinds of lesbians as possible.
- A screening module should avoid stereotypical questions and address how lesbians' lives are different from those of heterosexual women.
- In addition to sexuality, lesbians may perceive other kinds of questions to be sensitive (eg, substance abuse and mental health conditions/treatments).

The totality of lesbians' lives should be acknowledged in the survey process.

- If using a screening module, consider asking about the numerous ways lesbians' lives differ from those of heterosexual women—eg, social lives, experiences in the health care system.
- Allowing open-ended responses to some questions about sexuality would enable respondents to convey the richness of their lives.
- Offering an incentive for participation might be helpful in reaching the more general lesbian population. Also, incentives can convey a sense of respect for participation and need not be monetary (eg, a list of lesbian-friendly health care providers).

Diversity among lesbians (eg, by virtue of disclosure of sexual orientation, age, race/ethnicity, language, physical abilities, urban/rural place of residence) should be addressed in the survey methodology.

- Researchers should be familiar with the particular characteristics of the lesbian population before a survey. Qualitative studies can identify important subgroups, and sampling and data collection methods tailored to the best modes for reaching them.
- Recruitment of "closeted" lesbians is particularly problematic. Snowball sampling may be effective for some "closeted" lesbians who are known to "out" lesbians in a community, who could be recruited into the study through a trusted contact. Others may be recruited into probability samples if they can be convinced of the legitimacy and anonymity/confidentiality of the survey.
- Leading up gradually to questions addressing sexuality (what our focus group participants called an "indirect approach") may be particularly useful with more "closeted" lesbians. By contrast, lesbians who are "out" would respond to questions about sexuality early in the survey. If both "closeted" and "out" lesbians are potential respondents, we suggest adapting techniques to maximize response from "closeted" lesbians.
- If possible, allow the respondent to choose which method of data collection (eg, face-to-face, telephone, questionnaire) would be most comfortable for her.

Inviting Participation of Lesbians

Some participants spontaneously mentioned that lesbians (particularly closeted lesbians) are often overlooked in research yet would like to participate in research on women's health and lesbian issues if convinced that it was safe to do so. Participants joined the focus groups for altruistic reasons and felt that health research about lesbians was needed:

> "I was interested in it because it was for gay women, and I had a chance to give some input."

> "Well, I really debated my commitment, because the sun was shining this morning, and it's the weekend, and I thought, 'Why did I say I would do this?' And then I thought, because I am really committed to women and women's health."

Inviting participation from many different kinds of women, particularly those whose opinions are often overlooked, places the lesbian respondent in a larger social context. However, appeals to altruism will be effective only if lesbians feel they can trust those conducting the survey.

The Importance of Trust

In all of the focus groups, participants mentioned their concerns that the survey was being conducted by a trustworthy organization for a legitimate purpose. Some expressed concerns that phone interviews were not truly anonymous. A high level of trust is particularly important for closeted lesbians.

> "Especially women, the ones I'm really concerned about are ones who, maybe they're in a divorce and they've just come out and they're worried about child custody stuff. And I think they're really important to include in the study, those women. Especially if we're looking at cervical cancer issues and that kind of stuff. But there is no way they're going to say over the phone, 'Yes, I'm lesbian,' because it could be some slimy lawyer calling on their husband's behalf that's going to wreck their whole custody battle."

One approach participants suggested that might increase respondents' belief in the legitimacy of the survey was to contact sample members in advance to provide information on the sponsorship and purpose of the survey. Giving potential respondents a phone number to call before the conduct of the survey to check on its legitimacy would be helpful. Participants also mentioned the desirability of providing a mechanism for respondents to give feedback about their experiences to the survey and sponsoring organizations and placing extra stress in the introduction on the anonymity or confidentiality of responses.

> "That would also give the participants a route, if they had complaints about what occurred in the intervention, in the discussion, they could go back to one of those organizations and give feedback about that."

In general, participants were more optimistic about getting lesbians to participate in nonprobability than in probability sample surveys. Some participants expressed comfort with snowball sampling. A personal contact from a trusted friend may reach "closeted" lesbians, as well as those who are more "out."

Advertising the survey by way of the local lesbian media or events and allowing for call-ins may increase the number of lesbian respondents.

> "What about the local media? Say a week or two weeks in advance of the survey, like in our community it's *The Voice* and *Dallas Morning News*, a small article, saying about your organization and in the next two weeks you may receive a phone call regarding women's health issues that might be personal,

the identification of possible lesbians. Many focus group participants considered this an indirect approach to the questions asking for sexual orientation. Although this was not the intent of the screening module, focus group participants offered interesting comments on whether sensitive questions ought to be introduced in an indirect manner, such as we did in the video, or directly and forthrightly near the front of the interview. The indirect approach seemed to make some of these "out" lesbians suspicious of the investigators' motives, and these participants would have preferred a direct approach. However, others thought that a more indirect approach acknowledged the wholeness of lesbians' lives, made them more comfortable, and would be more successful with "closeted" lesbians and in less supportive regions of the country.

Other suggested approaches to sensitive questions included inserting comments empathizing with the difficulty of answering sensitive questions, starting with a module of health questions before addressing sexuality, and allowing open-ended responses to questions about sexuality. Focus group participants also suggested basing screening module items on ways in which lesbians probably differ from heterosexual women according to demographic variables, their experiences in the health care system, and aspects of their social lives.

> "The questions themselves were very good questions. I thought they tied one into the other. They gradually brought you up to "Are you a lesbian or not?'"

> "That I really did like a lot. It made you comfortable. It talked about you as a human being as opposed to everything being centered around your lesbianism. In other words, people think that because you're a lesbian, it's a sexual thing, and it's not. Your life is a whole lot more than a partner. So I thought that the questions as they led up were very good. They made you comfortable. They prepared you, I thought, for the big questions."

> "And to kind of piggy-back on what you're saying, I think if there could be like a little training initially of the interviewers to talk about tone, and delivery, and maybe just a few empathic comments interspersed throughout the interview, like "I know this might be really difficult to talk about, or I know these are very personal questions. . .' Just some way to kind of get away from that rote, interview style."

Acknowledging the Totality of Lesbians' Lives

By acknowledging that lesbians' lives are not confined to sexuality, researchers can convey a sense of respect for the contribution of lesbian respondents. In a screening module, for example, survey instruments can explore the many ways that lesbians' lives differ from those of heterosexual women and not be confined to a focus on sexual behavior. Allowing open-ended responses to questions about sexuality, as suggested by some of our participants, respects the desire of some respondents to avoid narrow labels.

Offering an incentive for participation can also be an acknowledgment of the value of a respondent's contribution. Some participants thought that although appeals to altruism might be sufficient to encourage participation among out lesbians, an offer of money for participation might be helpful in reaching the more general lesbian population. Others were concerned that an offer might make the motivation of the respondent suspect. One participant suggested giving a nonmonetary benefit, such as a list of lesbian-friendly health care providers.

Confronting Diversity Among Lesbians

Many participants made the point that survey methods appropriate for "out" lesbians will not work with those who are more "closeted." Other important differences include those of age, race, language, physical abilities, culture, and (related to social acceptance of lesbians) place of residence (urban versus rural).

> (Cultural diversity)
> "I spent a lot of time working in the Latino culture, and I would think you would find very few women that would be comfortable with the direct approach in that particular culture. The indirect would be so much more effective."

> (Place of residence)
> "My only concern is if you're calling and you get somebody in a small town, let's say you call (a small town in central Virginia), none of these buzzwords are going to work."

Participants' opinions were quite diverse about the desirability of various survey data collection methods. Some participants felt more comfortable and in greater control of the interview circumstances with a face-to-face interview in their homes. Others were more concerned about loss of confidentiality in a face-to-face interview or had concerns about inviting an interviewer into their homes, and these respondents preferred a more neutral location, such as a professional office or a women's health center. The idea of having the respondent fill out sensitive information on a questionnaire by herself and put it in an envelope in the presence of the interviewer received support in each of the focus groups. However, some noted that this does not ensure confidentiality. When asked about using a laptop computer, some felt that the computer would be an interesting toy and would work well with lesbians who enjoyed computers, but others noted that some respondents would be uncomfortable using computers. In addition, some were concerned about the confidentiality of computer files. Participants in each of the focus groups mentioned the desirability of offering potential respondents different options for providing data (such as responding verbally or in writing, interviewing participants at home versus at a central location). Ideally, potential respondents would be able to choose the technique with which they were most comfortable.

In general, if the researcher is interested in reaching both "out" and "closeted" lesbians, we believe that research techniques should be developed to maximize response from "closeted" lesbians. For example, response from "out" lesbians would probably not be substantially compromised by adopting an indirect question series leading up to the disclosure of sexual orientation, but response from "closeted" lesbians probably would be diminished by taking a very direct and forthright approach near the beginning of a survey.

Researchers should gain as much familiarity with the particular characteristics of the lesbian population they are studying before a survey. Qualitative studies can identify important subgroups, as well as sampling and data collection methods tailored to the best modes for reaching them.

DISCUSSION

Study results confirm suggestions from survey methods research in the general population, although these other studies have not targeted lesbians. Focus group participants demonstrated through their comments that they recognized the importance of engaging respondents in the research effort and providing a sense of reciprocity. They believed that motivated respondents would value the opportunity to expand knowledge that could be used to

improve the quality of health care and access for women in general, and lesbians in particular. Similar to respondents in general population surveys, participants thought that the offer of appropriate monetary incentives could demonstrate awareness of respondents' critical role, and most emphasized the value of an opportunity to contribute toward a social good.

There was general agreement that a carefully worded and executed telephone screening module may identify more lesbians than including only a few questions on sexual orientation. Some themes indicated, however, that such a screening module needs to avoid stereotypes and be tailored for sociodemographic diversity and place of residence, with multiple response options and question wording. Only participants who were clearly "out" felt that such a module would be a waste of time. As patterns of outness have been shown to reflect regional attitudes about the rights of sexual minorities, so did focus group responses reflect suggestions about whether a screening module was appropriate and how it should be configured. In areas where sexual minorities are safer to be "out," a screening module would be less relevant than in areas where these individuals would be understandably reluctant to disclose their sexual orientation.

Trust and confidentiality are particularly important issues

Trust and confidentiality are particularly important issues for members of minority groups in general, and in this study lesbian participants underlined the need to emphasize these concerns when conducting research in their communities. Their comments indicated that no one method will ensure a feeling of safety. Marketing the survey in advance with a lesbian or other sponsor may facilitate this process and get the word out to many (but not all) lesbians. A female interviewer would help to build rapport, particularly if she is trained to have an empathic style. Matching interviewer and respondent characteristics such as age and ethnicity would facilitate participation, as would the offer of incentives. As much as possible, researchers should understand the dimensions of diversity in the particular population of lesbians they wish to study and match methodologies to these qualitative characteristics.

Being "closeted" was discussed as a barrier to participation in all focus groups. It is easier to reach lesbians who are "out," because they have less to fear in being interviewed and because they are more likely to know lesbian sponsors and/or to have heard about the survey beforehand. Strategies which may increase the willingness of "closeted" lesbians to honestly disclose sexual orientation information when reached through random digit dialing include allowing a choice of survey modality for all or a portion of the survey, contacting potential respondents in advance and providing a phone number for checking on the legitimacy of the survey, strongly stressing anonymity or confidentiality in the introduction, and using interviewers skilled in the conduct of sensitive surveys.

For the most part, themes identified in this study paralleled identified gaps in the methods literature later reviewed by the IOM study committee.[9] Study results thus expand our understanding of an emerging best practices approach to conducting health research with lesbians. Researchers seeking to develop reliable and valid data sets for promoting knowledge about lesbian health status and health care needs can use the findings from relevant survey research experiments with the general population to build a foundation for targeted studies of lesbians. Artful packaging of strategies shown to increase response in probability samples, enhanced by knowledge about lesbian communities from nonprobability and qualitative research, can achieve a better fit with the estimated sociodemographic characteristics of lesbians in various geographic regions. Innovative integration of experimental research findings with community awareness and sensitivity toward the known characteristics

of lesbians provides a useful framework for identification and further development of the most effective methods to conduct lesbian health surveys.

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