



## Keeping Things Private

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### Description

When a sociologist conducting a qualitative study about social support and ovarian cancer, she interviews a participant who says she does not feel supported in the group because of her social orientation. The sociologist had promised all participants that their responses would be confidential, but would like to share this woman's experience with hospital staff to try and help improve the support received by gay patients.

### Body

Professor Kathleen Kline, a sociologist, is conducting a qualitative study about social support and ovarian cancer. She contacted an oncologist at the hospital in the small town where she lives to request his help in recruiting cancer patients for her study. With his help, she was introduced to Mary, who manages the cancer patient database for the hospital. Mary agreed to create a list of current ovarian cancer patients and then send a letter to each woman on behalf of Kathleen. Women interested in the study would then contact Kathleen to set up an in-depth interview with her. Mary asked Kathleen if she would be willing to share her findings with the oncologists and others who work with cancer patients at the hospital. Mary was particularly interested in findings related to the hospital's ovarian cancer support group, which she runs. Kathleen readily agreed to share her findings with Mary and the doctors and nurses at the hospital at the end of the study.

Kathleen completed in-depth interviews with 25 women recruited from the hospital. Before each interview, she assured each woman that information shared in the interview would be kept confidential. The informed consent form stated that pseudonyms would be used in place of the women's real names and all precautions would be taken to disguise individuals' identities in any research reports resulting from the study. In addition to ensuring confidentiality, the consent form also stated that the health care the women receive would not be affected by their participation (or non-participation) in the study.

In general, the women she interviewed had very positive things to say about their experiences with the support group. However, one respondent, Sara, told Kathleen that she went to the support group once, but did not feel comfortable at the support group because she is a lesbian. Sara felt that the support group had a heterosexual focus and she felt like she "didn't belong" there. Because of these feelings, Sara hasn't been back to the support group, even though she often feels quite lonely and in need of advice.

Kathleen is now preparing her findings in order to give a presentation before Mary and the rest of the hospital personnel. Kathleen wants to mention Sara's views about the support group because she feels that this information could help the hospital and the support group to make their services more inviting for other lesbian women. However, she worries that the hospital staff will immediately know that anything she reports about lesbians came from Sara since Sara was open with all of her physicians about her sexuality and even brought her girlfriend with her to doctor's appointments. Because the hospital is in a small community, Kathleen feels that it is highly unlikely that another lesbian woman was receiving treatment for ovarian cancer during the time of her study. Thus, Kathleen worries that the doctors will know that any data or findings she presents about the experiences of lesbians will have come from Sara. She worries that she will be revealing to them what Sara had to say and breaking her promise of confidentiality to Sara.

## Questions

1. Kathleen doesn't know for sure that Sara is the only lesbian the physicians treated during the study time frame. Should she even worry about the possibility that they would be able to link any information about lesbian experiences back to Sara?

2. Kathleen is following IRB guidelines by changing Sara's name in her interview transcript and in any research reports written about the study. If Kathleen is following IRB guidelines, need she worry about the possibility that someone may still guess the identity of a respondent?
3. In writing qualitative research reports, some characteristics of individuals (e.g., job title and place of employment) must be changed in order to ensure confidentiality. Is sexual orientation the type of characteristic that one should change in research reports in order to ensure confidentiality?
4. Does Kathleen have more of a responsibility to ensure absolute confidentiality for her respondents or more of a responsibility to share useful information with the hospital?
5. How should she handle the upcoming presentation at the hospital?
  - a. Should Kathleen discuss the fact that a lesbian woman felt uncomfortable at the support group? What are the possible consequences of this decision?
  - b. Should Kathleen simply say that one woman felt uncomfortable at the support group, but not mention that the discomfort was a result of sexual orientation?
  - c. Should Kathleen contact Sara and ask her if it's okay to share her experiences with the hospital staff? Is it fair to put Sara in this position?
  - d. If Kathleen contacts Sara, and Sara says she does not want to be identified to the hospital staff, what should Kathleen do?
6. Kathleen sensed that Sara needed support and advice. Should Kathleen try to find a cancer support group for lesbians and provide Sara with information about the group? (Keep in mind that Kathleen has not provided support group information to any of the other women she spoke with, she's only asked them questions about support groups they already attend.)
7. Suppose that Sara was not a lesbian, but was an African American woman who did not feel comfortable in the support group because of her race (the other women there were all white, as is the vast majority of the patients seen at this hospital). If this situation dealt with race instead of sexuality, would you handle it any differently? Why or why not?

## **Contributor(s)**

Brian Schrag

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