Ullica Segerstrale's Commentary on "Keeping Things Private"

Commentary On
Keeping Things Private

This is an interesting case which illustrates the complications that may arise even in studies designed to protect identities of participants. This case may encourage researchers to use their imagination well before they begin the research to think about potential problems that may arise and how to best handle them. Researchers need to assess what they perceive to be their relative duties to their research subjects (who are promised confidentiality) and their scientific peers (who expect to be able to build on the results) vs. other, unforeseen, but on the face of it "deserving" parties who also want to share the results of the study.

In this case Professor Kathleen Kline may in fact have made a strategic mistake when she so readily responded positively to Mary's request that she share her findings with the doctors and nurses at the hospital. This means that when Kathleen initially assured each of the 25 women about the confidentiality of their interviews with her, she may actually not have been in the position to grant it.

One question here is what kind of "confidentiality" is supposed to be involved. There appears to exist many kinds of confidentiality: "scientific" confidentiality (anonymity in regard to scientific publications and reports); "immediate environment" confidentiality (in this case confidentiality in regard to the hospital staff); "study sample" confidentiality (confidentiality in regard to other members of the selected sample); and, finally, perhaps "local" confidentiality (in this case in regard to people in the small town of the hospital). Martin Tolich (2004) presented useful distinctions between "internal" — study sample — confidentiality and "external" — scientific publication — confidentiality, but sometimes it is important to consider even more categories. See also my commentary on "Ethical Issues in Incorporating Online Information with Interview-Based Research" in section 1 of this volume).

Another question is whether Kathleen saw it as necessary or as optional to agree to Mary's invitation to present the findings to the hospital. As the case is written, Mary's request comes *after* she has already agreed to provide the names of cancer patients to Kathleen. From Kathleen's point of view, was some implicit exchange with Marie involved, or did she foresee complications in her research if she did not agree? (If so, why? After all, obtaining a list of patients from a database seems a rather routine request by a researcher).

In a presentation by Kathleen to the doctors and nurses, potentially confidential information about persons who are not patients of a particular doctor or nurse may be revealed unwittingly. But the problem may be equally serious in regard to doctors and nurses actually involved with the patient. Kathleen may not, despite her good intentions, be able effectively to disguise the identity of her interviewees, because she may not be aware of subtle identifying details in her subjects' statements, which on the other hand the subject's attending doctors and nurses are able to recognize. In turn, such knowledge may affect the relationship between doctor/nurse and patient. There might well be a positive feedback loop (Kathleen found the subjects' comments about the support group to be "generally good"), but there may not. The doctors and nurses may be interpreting patient statements about the support group, or self-assessments, say, about their health and psychological well-being differently from Kathleen.

Initially the particular situation with Sara appears to be less of a problem, since in this case her sexual preference is well-known to doctors and nurses and she is quite open about it. In fact, Sara may not care about being identified (either in the hospital or outside), because it may be more important to her that the particular problems for lesbians in women's support groups become known. If so, does this circumstance solve Kathleen's problem in relationship to protecting Sara's identity from the doctors and nurses? It seems to me it may not.

Sara gets singled out in this case because of her self-description and her opinions, which were not known to Kathleen before her study. This is an interesting case, because if Sara were one of, say, very few non-white women in the hospital, and were she asked about the experience of being non-white, an IRB would probably consider her to be too easily identifiable. As it was, Kathleen's sample simply consisted of women with ovarian cancer willing to speak to her. We assume that her research plan had passed the IRB and that she had already taken care of any typical problems that might arise with easily identifiable minorities (this is, however, not

discussed in the case). Could and should Kathleen have used some additional criterion for patient inclusion in her study to prevent a situation where later “emerging” minorities (that is, minorities who themselves establish their minority status) might be easily identified? What kind of criterion might that have been?

One thing that may be complicating matters in this case is that Mary, the leader of the support group, is also in charge of the hospital’s database. Perhaps we should know more about the role of the leader of the support group and whether having access to data about each patient is in fact important or necessary for her to run the group. If not, then this double role should probably be discussed. We also have no information as to whether Kathleen plans to have in-depth discussions with Mary (perhaps the hope of future access to Mary affected Kathleen’s readiness to promise to make a presentation to the hospital staff).

References

Tolich, Martin (2004). “Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants.” *Qualitative Sociology* 27 (1): 101-106.