

CONFIDENTIALITY ISSUES IN VIDEOTAPED DATA COLLECTION

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Background

In 1988 NORC began data collection for the Non-Shared Environment in Adolescent Development study for a research team headed by David Reiss, M.D. of the George Washington University's Center for Family Research. This study sought to examine which factors, environmental or biological, would predict most accurately the presence or absence of conduct disorders and depression in families. To do this, the researchers designed a survey that used a combination of self-report measures completed by individual family members and videotaped interactions among various combinations of those same family members. This was accomplished by sending a team of two interviewers to a family's home for two, three-and-one-half hour sessions during which the family members filled out a battery of psycho-social measures and participated in discussions recorded on videotape. One interviewer set up the video equipment, seated the respondents in a manner conducive to capturing the discussion on camera, and introduced the task to the family members. Once this was accomplished the interviewer left the room and closed the door. She returned after ten minutes and knocked on the door to signal the respondents that the allotted time had elapsed.

The interactions were constructed based on a set of questions each of the four family members answered. The questions dealt with a variety of issues germane to families with adolescents: chores, curfew, school performance, dating, smoking, behavior towards family members, etc. Two topics were selected for the videotaped interaction task based on the amount and intensity of conflict each family member reported for a given issue. Nine groupings of the four family members were videotaped: Mother and Father; Mother and Child 1; Mother and Child 2; Father and Child 1; Father and Child 2; Child 1 and Child 2; Mother, Father, and Child 1; Mother, Father, and Child 2; Mother, Father, Child 1, and Child 2.

To measure the degree to which environmental or biological factors influenced outcomes, a sample of families consisting of various biological relationships was selected. These family types consisted of two general categories: intact and step. The intact families consisted of two parents who were the biological

parents of both children. The stepfamilies consisted of two parents either or both of whom had brought a child into the family from a previous marriage so that the biological relationships between the parents and children and between the children themselves varied.

In 1991 we returned to these families to conduct a follow-up survey. With a few exceptions, we followed the same protocol as the one employed in the original study. In the follow-up survey only one interviewer visited the family for one, three- to four-hour session. The amount of videotaping was reduced from nine, ten-minute interactions to six. The two triads of Mother, Father, Child 1 and Mother, Father, Child 2 were omitted. As might be expected, many of these families were no longer living within the same configuration as in the initial study mainly due to children leaving home to pursue careers or college educations, but also as a result of parents separating or the death of one of the family members. To enable the researchers to measure change, only those families whose household composition (as it related to the original four participating family members) had stayed the same from the first study were eligible to participate in the follow-up study.

The researchers, however, were very interested in collecting some data on those families no longer eligible to participate and therefore commissioned us to do a brief telephone survey of these families. This contact resulted in an unanticipated request which presented us with previously unheard of challenges to our confidentiality guidelines. This paper examines the unique demands of protecting respondents' confidentiality when using videotaped interactions as a method of data collection by presenting a case study of one family whose request to view their videotape at a later date tested the limits of our usual understanding of what it means to protect the confidentiality of our respondents.

Confidentiality Issues

Traditional confidentiality issues revolve around protecting a respondent's answers to questions by removing any information from the data set that could result in anyone linking a response or set of responses to any one individual. One of the guiding principles for the Panel on Confidentiality and Data Access, democratic accountability, states that government

statistical agencies are responsible for "protecting the interests of data subjects through procedures that ensure appropriate standards of privacy and confidentiality (Duncan, Jabine, and de Wolf, 1993)." Although NORC is not a government agency, our work is governed by these principles. It is this facet of our industry that permits us to guarantee anonymity to those we interview and thereby gain the cooperation of people who might otherwise feel uncomfortable or threatened by participating in socially significant research. The question we faced was how to do this when the data collected would contain not only respondents' voices, but a videotaped recording of the respondents themselves in the context of their own homes.

To address this challenge we at NORC worked with the principal investigators to devise an informed consent form that would address these concerns we knew would create reluctance on the part of the respondents to participate. In the consent form we explicitly stated that no one other than the researchers and the staff responsible for coding the videotaped data would view the videotapes. (It should be noted here that all members of the research team who had access to any identifying data - either questionnaire or videotape - were required to sign NORC's agreement to uphold the NORC Statement of Professional Ethics. This statement includes the promise not to divulge any identifying information about a respondent.) The research team also anticipated the effect of a third party coming into someone's home to ask extensive personal questions. Knowing that our interviewers were not professional clinicians but merely collectors of data who could neither advise nor make referrals to professionals equipped to deal with stresses to the family dynamics this interview was likely to illuminate, a statement was included in the consent form acknowledging this. Although, were we to conduct a similar survey in the future I would recommend preparing handouts with a list of local mental health resources that the interviewer could leave with the family (Appelbaum and Rosenbaum, 1989).

The researchers had anticipated, however, that other professionals and researchers would be very interested in the videotaped data. In accordance with Principle 9j of the Ethical Principles of Psychologists (American Psychological Association, 1989), we created a separate consent form called "A Release for Educational Purposes" for families to sign if they would be willing to allow their videotapes to be viewed by students in advanced stages of their graduate studies and other mental health and medical professionals. This form was not presented to every family. Instead, interviewers were instructed to request families to sign this only after the interview was completed and then

only if they seemed unlikely to object. We did not want to risk any family's cooperation over something that was not essential to the primary objective of the study itself.

The researchers, without having the experience of conducting a study of this nature on a national scale, and NORC, having no previous experience with videotaped data but with extensive contributions from our field staff regarding the questions respondents were most likely to raise, were assured that the ethical and confidentiality issues had been addressed. This confidence was bolstered by knowing that the researchers had been put through a full institutional review board, which also requires annual reports for the duration of the study, at George Washington University.

We even anticipated that some families might ask to view their videotape and, therefore, established a rule that no family could see any portion of the videotape that contained discussions in which that member was not a part. Furthermore, we made the stipulation that all family members involved in a particular videotaped portion would have to consent to releasing a copy of that videotape segment and then only for viewing by those members who had participated in that segment. Armed with these precautions, we were certain we had covered every contingency for protecting our respondents' confidentiality. And, in regard to the majority of families, this confidence was warranted. That was until we received a request from one family asking to have a copy of their videotape. What follows is a case study that illustrates a confidentiality issue, specific to videotaped data collection, for which neither the researchers nor NORC was prepared.

A Case Study

For one family the request to view their videotape became a critical issue. As mentioned earlier, NORC contacted all of the families who we had interviewed initially to determine if they would be eligible to participate in the follow-up study. This contact was then followed by brief telephone interviews of one of the parents and both of the children to gather some information concerning the family's current situation. It was during this interview with one mother that we discovered her husband had died shortly after they had been interviewed as part of the original study. She desperately wanted a copy of the videotaped interaction in which she, her husband, and their two children had participated. The interviewer, making no mention to the mother of whether this request could be filled, took the information and passed it along to me.

I conferred with one of the research staff to make sure it was still possible to release a copy of the one

videotaped interaction in which all four family members had participated even though one of these participants was deceased. In accordance with our agreement with all of the families it was decided that as long as the two children agreed to us releasing this one segment of the videotape to the mother then we would honor the request. I also raised the issue with our legal counsel to make certain we were not violating the father's right to confidentiality. Since we were not releasing any information to the three surviving family members to which they had not been privy, our legal counsel agreed to releasing the requested segment.

The next step was to contact the mother to tell her we could release a copy of the interaction with her husband and two children if both children consented. The children did agree so I asked the mother to send me a letter stating the request in writing with her and her children's signatures. Once I received this letter I contacted the researcher in charge of the videotaped data and asked that a copy be made of the one interaction and sent to the family. It was only when a copy of the interaction was being made that the researchers realized we had been wrong to approve its release. It was then that the decision, on the part of the researchers, to release the videotape moved from the realm of protecting respondent confidentiality into one of ethical consideration.

In viewing the tape the researchers saw that the family was extremely distressed throughout the entire ten-minute interaction. This raised a great deal of concern regarding the effect reliving this experience would have on the surviving family members. The researchers were especially worried about how the tape would affect the family given the fact they no longer could resolve these issues of conflict with the father. This now put us in the difficult position of having to inform the mother we could not release the videotape after already having told her we would. No one on the research team felt this was a decision to be made lightly so they consulted a clinician from the George Washington University Medical Center who is recognized as an expert in family processes. After viewing the tape, this specialist concurred with the researchers' decision not to release the tape.

Principle 9i of the American Psychological Association states, "Where research procedures result in undesirable consequences for the individual participant, the investigator has the responsibility to detect and remove or correct these consequences, including long-term effects (American Psychological Association, 1989)." Given the fact that many of the researchers are psychologists and members of the APA, the decision not to release the tape because of the potential psychological harm it could inflict on the

remaining family members was in accordance with their standard of ethics even though it could be argued that releasing the tape would not have violated the father's right to confidentiality. The difficulty of this decision, however, paled in comparison to the task of actually having to explain our decision to the mother. Because of the researchers' clinical expertise, the task of informing the mother of this decision fell to their project coordinator who is also a clinical psychologist, Danielle A. Bussell, Ph.D.

As part of notifying the mother of our decision, Dr. Bussell was faced with an additional challenge. The mother was in psychotherapy at the time she asked for a copy of the tape. So when Dr. Bussell relayed our decision to her, the mother consulted her therapist who recommended that we release the tape to the mother. The therapist, never having seen the tape, based her recommendation on the premise that viewing the tape would help the mother and children in the process of their grieving over the loss of the father. It was then up to Dr. Bussell to speak with the therapist to explain why it would not be in the family's best interest to view the tape. Dr. Bussell had to tread carefully because although the mother was a patient of the therapist's, the children were not. Therefore, Dr. Bussell had to convince the therapist why releasing the videotape could have detrimental psychological effects without compromising the confidentiality of those family members who were not patients of the therapist. Dr. Bussell's skill as a clinician and her commitment to the integrity of the study enabled her to explain our position to both the mother and the mother's therapist without causing harm to the family or breaching our promise of confidentiality while convincing both that all of us associated with the project were acting in the family's best interest.

Conclusion

This case forced us to rescind our earlier agreements with the family: the one we made at the start of the project when we told families they could see videotaped segments in which they had participated if the other participants in the interaction agreed; and our later initial understanding with the mother, detailed in the above case, to release a particular segment. Both of these agreements were changed in order to protect the family members from any psychological distress that might result from viewing the tape.

It is from this experience that we should learn it is impossible to anticipate the circumstances surrounding every conceivable request. And now knowing this we should strongly consider making a blanket statement at the outset, within the context of the informed consent, that no videotaped data will be available for viewing by

the respondent. The mother's evident disappointment over not obtaining a copy of the tape and the enormous difficulty encountered by the researchers in coming to this decision when it could have been avoided at the outset of the project supports this recommendation.

I would further recommend that we not even allow the family to view the tape immediately after the recording while the interviewer is still in the respondent's home as this could lead to biasing the sample by collecting videotaped data primarily from those respondents who are satisfied or pleased with the results of the videotape.

The value of videotaped data is becoming indispensable to family process research because it does "provide an accurate and complete record of human behavior, minimize[s] selective bias and memory limitations, and permit[s] a permanent record that can be checked for other research purposes and by other researchers (Grisso et al., 1991)." As a result, similar situations will become more prevalent. This endows us, as survey researchers, with the responsibility to our clients and our respondents to examine fully the implications inherent in this mode of data collection and to incorporate these lessons into our protocol for informed consent.

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