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Medical Law

CAN YOU ASK THAT OVER THE TELEPHONE? CONDUCTING SENSITIVE OR CONTROVERSIAL RESEARCH USING RANDOM-DIGIT DIALING

H. Bell, * N. Bridget Busch, ** and D. DiNitto ***

Abstract: Social science, medical, and legal researchers often study sensitive or controversial topics and behaviors. This research raises methodological and ethical issues. Using examples from the literature and a recent statewide telephone prevalence survey on sexual assault, we focus on the relative merits of various survey methods, especially those employing new technologies; developing instrumentation that includes explicit behavioral questions; obtaining an appropriate sample in a cost efficient way; gaining informed consent and inquiring about sensitive topics while protecting participants from harm or retraumatization; presenting findings in a way that does not further stigmatize participants; and responding to the media.

Keywords: Research; sexual assault; ethics

INTRODUCTION

Myths and misconceptions surround social problems such as sexual assault, illicit drug use, and other criminal activities. Conducting research to increase knowledge about these sensitive and controversial subjects and improve practice can be difficult. Researchers must ask behaviorally-specific questions that raise both methodological and ethical challenges requiring additional safeguards for protecting human subjects. Much of our interest in conducting research on sensitive topics grew out of our experience conducting a statewide sexual assault prevalence study in a southwestern state in the United States. The study was initiated because of the wide discrepancy between sexual assault

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statistics for states reported in the Uniform Crime Report (UCR) and estimates provided by the National Crime Victims Research and Treatment Group (NCVRTG, 2001). The NCVRTG figures are based on statistical modeling. The UCR reflects only sexual assaults reported to law enforcement and fails to represent the full extent of this problem since as few as one in six cases are reported (NCVRTG, 2001). Given limitations of existing reports, more accurate prevalence information derived from an epidemiological study using a representative sample of this state population was needed.

Based on our experience conducting this sexual assault prevalence survey, we focus on how to obtain information about sensitive or controversial topics while minimizing retraumatization or other risks to participants. First, we address the relative merits of different types of surveys as well as new technologies for obtaining data. Second, we examine how to develop instruments that provide an accurate picture of sensitive or controversial issues. Third, we discuss sampling in order to gain participation of members of hidden or stigmatized groups. Fourth, we address human subjects protection, including introducing sensitive topics and encouraging research participation, ensuring participants' anonymity or confidentiality, and identifying and responding to participants who become upset by answering questions about their experiences and behavior. Finally, we discuss how to present research findings in research reports and the media in ways that do not further stigmatize participants or unnecessarily sensationalize the topic.

Methodological Issues

Among the first issues to be addressed in conducting sensitive or controversial research is selecting the appropriate methodology. As new technologies for conducting research continue to be developed, researchers have more options to weigh and more decisions to make.

Using Interviews to Obtain Data

Controversial or sensitive subjects are sometimes studied using unobtrusive means such as a review of records. These methods eliminate the need for obtaining new samples and reduce or eliminate the chance of retraumatizing victims. However, interview methodologies are often employed because arrest records and other existing materials are often inadequate for the task (e.g., they lack sufficient detail or a standardized method for collecting data needed by researchers). Qualitative interviews in particular, in which respondents

are asked open-ended questions, can elicit in-depth information and help to obtain information about topics about which little is known. Unfortunately, this approach is expensive, rarely utilizes samples representative of the population of interest, and increases the emotional impact on participants as well as researchers (Ortiz, 1985).

Whether the researcher is seeking depth or breadth of information from participants, another methodological concern is the efficacy of telephone versus face-to-face interviews. While in-person interviews can increase response rates, telephone surveys are less expensive and less time consuming. Random digit-dial procedures make the job of obtaining larger samples less prohibitive than in-person interviews. They allow access to the many people with unlisted numbers, also increasing the representativeness of samples obtained by telephone (Salahu-Din, 2003). At least in the U.S. and cultures with similar access to technology, telephone surveys may also more adequately assure participants' confidentiality and sense of privacy and safety in revealing personal and sensitive experiences because (1) participants may feel safer talking with someone on the telephone than in their home, and (2) participants may feel more comfortable terminating a telephone conversation than a face-to-face conversation (Rubin & Babbie, 1997). Lau, Thomas, and Liu (2001) found that participants answering questions about risky sexual behavior reported a higher frequency of risk behaviors over the telephone than did participants answering either mailed surveys or in-person interviews.

Using Technology

We also considered whether newer technological approaches might be suited to our task. Some of these technologies offer research participants increased anonymity, such as Audio Computer Assisted Self Interview (ACASI) where participants listen to questions through headphones and type their answers into a computer (e.g., Jones, 2003). Metzger et al. (2000) found that ACASI elicited more reports of risk behaviors associated with the human immunodeficiency virus (HIV) than did face-to-face interviews. On the other hand, Jennings, Lucenko, Malow, and Devieux (2002), however, found that incarcerated adolescents awaiting criminal adjudication reported fewer incidents of HIV risk or illegal behaviors via ACASI. Another innovative methodology is touch-tone data entry (TTDE) where telephone interviewers ask questions and participants use their telephone keypad to indicate their response thereby keeping their answers confidential from people who might

be listening in (Blumberg, Cynamon, Osborn, & Olson, 2003). Methods like these also allow data to be uploaded directly into computer programs for analysis, reducing data entry errors and costs. TTDE led to increased reports of some types of behaviors that put participants at high risk for HIV (Blumberg et al., 2003, Lau & Wang, 2003), but limits respondents to forced choice answers and does not permit participants to elaborate on their responses. In another example of the innovative use of technology in research, Minnis and Padian (2001) reported on the use of written versus telephone diaries in reporting sexual behavior by teenage girls. In the telephone diary, participants were asked to call a 24-hour toll free number and respond to an automated recorded interview schedule using the telephone keypad for their responses. Participants preferred the telephone diary because it was novel and fun and provided more privacy. Data obtained via the two methods were essentially comparable, although telephone interviews at the end of the one-month data collection period revealed that neither method was very reliable. These new computer technologies are of interest, though most are not practical for large population surveys without a substantial investment of time and resources.

The World Wide Web (Internet) holds promise for conducting research because of its ability to reach formerly inaccessible groups, its speed, ability to upload survey data into analysis programs, and the anonymity it provides. However, Rhodes, Bowie, and Hergenrather (2003) point out disadvantages of Internet surveys such as the possibility of hackers identifying participants and gaining access to the data, inability to calculate response rates in many cases or identify multiple submissions, challenges of obtaining informed consent (e.g., participants' inability to ask questions without revealing their identity), protecting or excluding minors, and questionable self-report data. In addition, many individuals still lack access to a computer or are not comfortable using one.

Random digit-dial telephone surveys have been employed in the major national sexual assault prevalence studies conducted in the United States including the National College Women Victimization Study (NCWVS) (Fisher, Cullen, & Turner, 2002); the National Violence Against Women (NVAW) Survey (Tjaden & Thoennes, 1998); and the National Crime Victim Survey (NCVS) (U.S. Department of Justice, Bureau of Justice Statistics, n.d.). Given that participants in these studies disclosed sensitive information about sexual assault experiences over the telephone, we had evidence that this method could result in credible response rates in our study. A telephone survey also best suited some realities

of our work - the need to conduct the study with a modest budget in a relatively short amount of time in a state with a population of more than 22 million covering nearly 262,000 square miles.

One limitation of telephone interviews for our sexual assault prevalence study was that we were unable to survey some people at risk for sexual assault, such as people with low-income, people without telephones, prisoners and other persons residing in institutions, and individuals with physical and mental disabilities that prevent them from using the telephone or providing informed consent. We were also unable to survey individuals who had only cell phone service. Researchers are only beginning to gain access to cell phones. In weighing the costs, benefits, and limitations of the various data collection methods, we decided that detailed questions about sexual assault could be asked over the telephone. Thus, we selected a random digit-dial methodology as the most viable method to obtain statewide prevalence data.

Instrument Selection and Development

When researching sensitive and controversial topics, researchers often look to experts, such as noted researchers and state and community professionals for guidance with instrumentation and other aspects of methodology. In our experience, these experts are generous in helping, and researchers are encouraged to talk with them in the course of planning their work. We contacted other researchers who had previously conducted research on sexual assault both by email and telephone to ask about the barriers that they encountered in their studies. In studying topics like sexual assault, victims¹ provide another source of experience and expertise.

Researchers who conducted the NVAW (Tjaden & Thoennes, 1998), NCVS (U.S. Department of Justice, n.d.), and the NCWSV (Fisher *et al.*, 2002) employed a two-step methodology in the instrumentation for their telephone surveys. First they asked a series of behaviorally-specific screening questions that included the definition of sexual assault used in their study. In these studies and ours, sexual assault was considered any unwanted oral, vaginal, or anal sex and unwanted sexual contact. Since victims often do not define their

1. We are sensitive to the fact that the term "victim" in reference to someone who has experienced sexual assault may generate strong feelings among advocates and those who have experienced sexual assault. Whenever possible, we have tried to use the term "survivor of sexual assault" but sometimes use the term "victim" for clarity.

experiences as sexual assault, we used the same explicit and behaviorally-specific questions as in the NVAW survey to ascertain if participants had ever been sexually assaulted. An example of one of the behaviorally-specific questions was:

Since you've been 18, has anyone, male or female, ever made you have oral sex by using force or threat of harm? Just so there is no mistake, by oral sex we mean that a man or boy put his penis in your mouth or someone, male or female, penetrated your vagina or anus with his or her mouth or tongue (see Tjaden & Thoennes, 1998, for a full discussion.)

Second, previous researchers asked each respondent who screened positively for sexual assault a series of follow-up questions about their victimization. We followed suit, inquiring about details such as the victim's relationship to the perpetrator, location of the assault, and victim and perpetrator's use of alcohol and drugs at the time of the assault. The behaviorally-specific questions were also intended to address memory decay that typically occurs when asking retrospective questions (Bernard, Killworth, Kronefeld, and Sailer, 1984).

Relying on the instrumentation used in previous studies can be very useful. It is also necessary to ensure that existing instrumentation is appropriate for the context (time and place) of the study at hand as well as the population of interest. For example, culture, language, and age often influence participants' responses. Ford and Norris (1991) discussed these issues in the context of research on sexual behavior with urban African-American and Hispanic youth. Most participants understood the terms the interviewers used, but some Hispanic females did not understand the words "anus" or "vagina." Hispanic males preferred to be asked directly if they were homosexual, rather than asking about their lifetime partners. Sensitive topics for the young women included oral sex and, for Hispanic women, in particular, menstruation was especially sensitive.

To assist in our sexual assault prevalence study, we assembled a nine-person community expert panel, made up of men and women who represented professionals and survivors working in the sexual assault field in the state, to advise us on modifying the NVAW instrument. The panel members were from diverse ethnic groups and various geographical locations throughout the state. The research team met with them twice. Based on their recommendations, questions were added about U.S. residency status (legally residing in the U.S. or undocumented), as this may affect vulnerability to sexual assault and

willingness to report victimization. Some questions were omitted, and some were reworded for added clarity, particularly questions about drug use at the time of the sexual assault. Given the large number of individuals residing in the state who speak Spanish (primarily or solely), the instrument was also translated into Spanish and evaluated by an expert for accuracy and cultural appropriateness. Spanish-speaking respondents were asked if they preferred to participate in English or Spanish.

When developing a survey instrument or interview protocol, researchers generally place less sensitive topics before more sensitive topics. For example, Edin and Lein (1997) typically began their series of interviews with low-income women by asking them for a topical life history. In later interviews they focused on how participants "made ends meet," the actual focus of the research, which sometimes involved illegal activity such as prostitution, working "under the table," or welfare fraud. Following this lead, participants in our study were asked 41 questions about perceptions of their health status and history of injuries and illnesses before proceeding to the topics of alcohol and other drug problems and sexual assault. A brief (four item) and widely used instrument with good psychometric properties called the CAGE (Mayfield, McLeod, & Hall, 1974) was incorporated into our interview protocol to determine whether participants screened positively for alcohol problems. We also replaced the word "alcohol" with "drugs" in each of the four items as a screening tool for drug problems. Participants who revealed that they had been sexually assaulted were asked whether they and/or the perpetrator were using alcohol or drugs at the time of the assault. The interviewers were instructed to ask questions about alcohol and drugs in the same nonjudgmental way as questions about sexual assault victimization.

Sampling

Often there is a low incidence of experiences or behaviors in sensitive or controversial research. Though 20% of women in our study reported at least one incident of sexual assault, only 5% of men reported ever being sexually assaulted. With low-incidence events, researchers are forced to either contact a large representative sample or concentrate on those who have had the experience. It can be difficult to find people who have experienced the event of interest. Even more challenging is encouraging them to talk about their experiences. With some behaviors such as welfare receipt or illicit drug use, snowball sampling, where one participant identifies or refers another, may be

an effective way to locate participants. Snowball sampling is also a way of gaining participants' trust so they will talk about the sensitive issue. Edin and Lein (1997) used snowball sampling to gain entrée to low-income women via gatekeepers whom they trusted, such as representatives of churches, community organizations, and charities. Once identified, people who are willing to talk about their behavior may be very different from those who are not (Paavilainen, Astedt-Kurki, & Paunonen, 1998). Snowball sampling was not a viable option for our study, given, for example, men's reluctance to discuss this experience with their peers and the use of the telephone as our data collection methodology.

Probability sampling, which is necessary for obtaining a group of respondents representative of the population of interest, is a technical issue. Obtaining samples sufficiently large to reflect the target population and reduce sampling error generally requires contracting with an expert in order to assure representativeness and to calculate study costs as accurately as possible before proceeding. For the sexual assault prevalence survey, we purchased a sampling frame and used standard computer-generated random digit dial procedures to contact potential participants.² Interviewers made approximately 21,000 telephone calls to reach 1,200 participants. Twenty-seven percent of calls resulted in "bad numbers" and there was a persistent "no answer" for 31% of the calls. Seventeen percent of callers declined participation and approximately 7% were excluded because the caller did not meet the study requirements (e.g., was too young to participate). Telephone calls were made during day and evening hours to increase sample representativeness.

Sampling itself can become controversial. Hurley and Pinder (1992) described the political fallout of conducting studies of HIV prevalence in three U.S. cities. The researchers had planned to conduct stratified sampling and oversample African Americans. In one city, information about the study and the proposed design was leaked to the press and the public perceived the oversampling of African Americans as targeting of this racial group. The study had to be moved elsewhere, and the sampling strategy changed for the other two cities. The reluctance of African Americans to participate in research is often attributed to historical factors—research control by Whites and research like the Tuskegee syphilis study in which African American men were denied

2. Additional information on the sampling frame can be obtained from [www.surveysampling.com/ssi.x2o\\$ssi_gen.product?id=119](http://www.surveysampling.com/ssi.x2o$ssi_gen.product?id=119)

treatment of syphilis.³ In our sexual assault prevalence study we oversampled Hispanics and African Americans to obtain sub-group samples large enough to make comparisons across racial/ethnic groups. We encountered no such backlash.

The Institutional Review Board and Human Subjects Protection

Over time, Institutional Review Boards (IRBs) at universities and research institutes in the U.S. have increased their scrutiny of research projects, often in response to federal law and accompanying rules and regulation found in the Code of Federal Regulations (45 CFR 46). Especially due to the graphic nature of the questions we were asking, our sexual assault prevalence study raised a number of ethical concerns for our own Departmental (human subjects) Review Committee (DRC) and the University IRB.

To facilitate the human subjects review process, we discussed the study with members of our DRC and attended IRB meetings to elicit their suggestions about the best way to protect participants and answer questions regarding the study. These exchanges significantly improved our strategies for protecting study participants. We provided the DRC and IRB with evidence that our methodology reflected the standard for conducting national sexual assault research and justified why the approach was appropriate to *our* study. This is especially necessary when conducting research in an area where there is little or no prior research and no clear precedent. It required several revisions before we and members of our DRC and the IRBs at our university and the survey research center felt that adequate measures for the protection of human subjects were in place.

Introducing the Study

Since potential participants can easily hang up the telephone, the manner of introducing the study was critical. Immediately providing participants with our university affiliation, as is required, helped assure them of the research's legitimacy. Interviewers described procedures to protect participant anonymity by stating that interviewers had no records of the number that the computer was dialing. In addition, interviewers gave participants a telephone number to verify the legitimacy of the research. Participants were informed that they

3. Information on the Tuskegee syphilis study can be found at <http://www.gpc.edu/~shale/humanities/composition/assignments/experiment/tuskegee.html>

would be part of a group of 1,200 participants and that their information would be reported in aggregate, not individual, form. Participants were assured that their involvement was voluntary and that they could end the call at any time and they were reminded of this before beginning the interview questions. In the event of a callback (if for example, the participant wanted to think about it first, or wanted to participate, but at a later time) the interviewer was instructed to tell the participant:

I will have to take your telephone number, although I will still not have any other information about you such as your name or address. When I call back I will announce that I am with the survey and ask for a [male or female, depending on the participant] member of the household.

Researchers must weigh the issues of how much to tell participants about the study in order to gain informed consent, but without providing so much detail of potential risk that it might discourage participation (Paavilainen et al., 1998). Our sexual assault prevalence study was framed in the context of health concerns to generate initial interest but avoid alarming participants. In order to be honest and forthright about our purposes, we also indicated that questions about sexual assault were a part of the study. Thus, our study was titled *A Health Survey of State Residents⁴: A Focus on Sexual Assault*. In this way, we hoped to introduce the survey to participants in a way that was honest, but not too threatening. Since sexual assault is a major public health concern and has implications for victims' physical and emotional well-being, the survey included a series of questions about health- and mental health-related experiences. In order to assure participants that we were indeed conducting a health survey these questions preceded questions about sexual assault.

Whether or not potential participants will answer questions may be influenced by interviewer characteristics, such as race or gender. Fowler and Mangione (1990) in their review of research on the impact of interviewer characteristics, such as race, gender, social status and education, religion and ethnicity, on data collection conclude that, despite considerable research, there are relatively few instances where such associations emerge, and these effects are often subtle. For example, in the Campanelli and O'Muircheartaigh (1999) study of interviewer effects on the British Household Panel Survey, bivariate analysis revealed that characteristics such as age, gender, experience and grade level (supervisor versus worker) and area (including population density, percentage

4. This research was carried out in the state of Texas.

of non-white residents) were important predictors of non-response. However, these effects disappeared in the multiple regression analysis and reappeared in the cross-classified multilevel analysis in which they were treated as random effects. Similarly, Pickery and Loosveldt (1998) found a significant interviewer effect on "no opinion" answers, but were not able to explain this in terms of interviewer variables such as age, sex, education, number of interviews completed, or the number of "no answers" obtained.

Interviewer effects are more likely to emerge when a characteristic is directly related to the survey topic (Campanelli & O'Muircheartaigh, 1999; Fowler & Mangione, 1990; Marin & Marin, 1991). Padfield and Proctor (1996) found interviewer gender effects in only one area of questioning: female participants' willingness to volunteer that they had had an abortion. In a study with Latino couples, Wilson, Brown, Mejia, & Lavori, (2002) found no significant gender or age effects for the majority of their questions on high-risk sexual behavior. However, Latino men reported 30% fewer lifetime partners to female interviewers and were only 63% as likely to report sex with a stranger to a female interviewer and were significantly more likely to report having had sex with a prostitute or having had sex with another man to older interviewers. Female participants were only half as likely to report having had oral sex with their current partner to an older than to a younger interviewer. In contrast to the independent effects of age and gender, men were significantly more likely to report having had sex with an injection drug user to younger female interviewers.

Interviewer effects may operate differently in different types of surveys. Morton-Williams (1993) suggests the way the interviewer approached the prospective respondent, by allowing the respondent to ask questions about the survey, and by not pushing or making the respondent feel guilty about nonparticipation, was more important than interviewer demographic characteristics in door-to-door surveys. Fowler and Mangione (1990) point out that interviewer race, age, social status and education are less discernable in a telephone interview, but gender is discernable and so may have an effect.

Considering that participants might feel more or less comfortable speaking about sexual assault experiences with someone of their same gender, all participants in our study who screened positively for sexual victimization were given the option of choosing a male or female interviewer to continue the survey. Although most of the interviewers were female, no one asked for an interviewer of another gender.

Obtaining Informed Consent Over the Telephone

The use of a random-digit dial survey, which allows researchers to obtain sensitive information without access to any personal data, requires participants to provide verbal rather than written informed consent. Obtaining verbal consent over the telephone may require extra care to ensure that participants clearly understand the research subject and procedures before agreeing to participate. Since interviewers other than the principal investigators often collect study data, they must be carefully trained to obtain verbal consent using a script. In our study, interviewers documented each participant's consent by using a newly created identification code for each participant and indicating that they consented to participate.

To further ensure human subjects protection, we carefully worded the introduction to the sexual assault screening questions so that participants understood what they were about to discuss. Prior to asking the screening questions, the interviewer read the following statement:

One issue that can affect physical and emotional health is being a victim of a crime, including unwanted sexual experiences. I'm going to ask you six questions about unwanted sexual experiences you may or may not have experienced either as an adult or as a child. We will be using medical language to describe private body parts. Sometimes this kind of language can make people uncomfortable, but we are using it so that there will be no mistake about the kinds of experiences we are talking about. Please let me know if this makes you uncomfortable. Remember that the information you are providing is confidential and that your responses will help us understand the extent of unwanted sexual experiences and sexual assaults⁵. You are free to skip a question or stop the interview at any time.

Fontes (2004) suggests that, in addition to providing initial consent, participants in highly sensitive research should be asked at multiple points in the interview if they want to continue. Our university IRB required our interviewers to stop the sexual assault questions at several points and check on the participants' comfort level. The following statement was inserted five times into the 54 follow-up questions for each sexual assault experience a participant reported:

Please let me know if this makes you uncomfortable. Remember that

5. This research was carried out in the state of Texas.

the information you are providing is confidential and that your responses will help us understand the extent of unwanted sexual experiences and sexual assaults⁶. You are free to skip a question or stop the interview at any time. At any time, I can connect you with or provide you with contact information for community resources.

These reminders provided participants with the opportunity to gracefully terminate the interview and reinforced the voluntary nature of their participation.

Children and Research Participation

Due to issues such as children's ability to assent to be research participants, a good case can be made that *any* research involving children is sensitive. Children's research participation generally requires their parents' or guardian's consent as well as the child's assent. The age of the child is an important factor in whether they can give true assent, as are developmental maturity, the child's emotional state, role constraints (the impact of family or other authority figures) on the child's willingness to disclose information, as well as the person seeking consent/assent (Meaux & Bell, 2001). Research on sexual behavior with children and adolescents may expose them to sexual material of which they were not previously aware (Ringheim, 1995). Such research may be justified if there is evidence that their behavior is placing them at risk of pregnancy or disease and the information needed cannot be obtained from adults. It may be possible to pose questions in a way that does not provide explicit information. However, locating parents or guardians and obtaining consent for their child to participate can be difficult. There are also increasingly stiff federal and university safeguards for children's research participation. As a result, researchers may avoid including minors as subjects and instead rely on proxies such as parents' reports of their children's behaviors.

Given the difficulties of obtaining parents' or guardian's consent and children's assent via telephone and the adult nature of the questions, we excluded children and adolescents (those under age 18) from our study. When the individual answering the telephone said he or she was younger than age 18 our interviewer thanked them and terminated the call. Since young people might have been curious about the study topic, we asked to speak to someone 18 years or older before stating the study topic. However, a major goal of the project was to

6. This research was carried out in the state of Texas

collect data about sexual assault experiences occurring over the lifespan. To accomplish this, adult participants were asked retrospective questions about lifetime sexual assault experiences during three mutually-exclusive time periods—under the age of 14, between ages 14 and 17 and after the age of 18. This procedure allowed us to obtain information about rates of sexual victimization at each time period without having to interview minors. In the NVAW survey (Tjaden & Thoennes, 1998), of women who reported a completed or attempted rape at some point in their lives, 22% were under 12 years of age and 32% were 12-17 years old. In our statewide study, 46% reported being sexually assaulted before the age of 14 and 36% between ages 14 and 17; some participants reported being assaulted during both time periods.

Addressing Risks and Benefits to Participants

Sensitive or controversial research demands rigorous mechanisms for protecting participants' privacy during data collection, as exposure could be very damaging. Once collected, maintaining confidentiality of the data is also critical. This poses particular challenges when methodologies such as focus groups are used. Even with clear instructions about the need to protect others' confidentiality and promises to do so, violations may occur because focus group participants are not subject to the same penalties for breaching confidentiality as researchers may be. Whatever the study methodology, researchers must have a plan for dealing with the risks associated with participation. Data safety and monitoring plans (DSMPs) must be clearly spelled out in the IRB application. Where participants' identities are retained for a period of time and the research topic is sensitive or the participants may be especially vulnerable (e.g., prisoners), extra safeguards must be implemented. In some cases, a small committee or board must be appointed to oversee data safety and monitoring. In addition to monitoring data security, including safeguards for participants' identities and protections against data loss, the board may also monitor whether the anticipated numbers of participants are being enrolled in the study. In the United States, researchers and universities must now also meet federal requirements set forth by the Health Insurance Portability and Accountability Act (HIPAA) of 1996 which requires additional safeguards for health-related information.

Among the ethical challenges in conducting research on sexually-oriented topics is the necessity for benefits to outweigh the risks (Ringheim, 1995). The U.S. National Institutes of Health and IRBs are demanding that researchers

spell out in advance procedures for responding to adverse events (AEs). In conducting research on violence against women, Fontes (2004) suggests developing the equivalent of safety plans for participants who might become distressed as a result of their research participation. In our study, the primary type of adverse event we anticipated was posttraumatic responses by participants to the sexual assault questions. In the event that a participant should become upset as a result of the questions we asked, we developed procedures for identifying and reporting AEs. Interviewers were instructed to pay attention to signals that a participant might be in distress, such as becoming withdrawn or quiet, taking long pauses after a question to provide his or her answer, his or her voice quivering, or she/he making statements that indicated they wanted to end the call. In situations where a participant became emotionally upset during the interview, our interviewers were trained to use the following protocol: (1) Ask participant if he/she would like to terminate the interview; (2) Reassure participant that strong feelings are normal when reliving a traumatic experience like sexual assault; (3) Tell the participant that many people feel better about themselves after talking with a professional about the experience; (4) Inform the participant about the local rape crisis hotline; (5) Ask the participant if he/she wishes to be directly connected to the hotline. If he/she says yes, interviewers were instructed to do so. We developed a procedure that allowed interviewers to directly connect participant to a rape crisis hotline. If the participant did not wish to be connected to the hotline, the interviewer was to offer the hotline number and talk about options for getting support (for example, suggest they call a friend). All participants in our study were given the number of the national rape crisis hotline, whether or not they identified themselves as victims of sexual assault.

Only one adverse event was identified and reported to the university IRB. In this case, the survivor became emotionally upset and cried as she recalled her victimization although the AE protocol from the interviewer indicated she was also grateful for the opportunity to tell her story. Upon review of the AE report, the IRB concluded that the interviewer had followed the appropriate procedures. In the other three cases, the interviewers felt that rape crisis hotline staff were better qualified to answer participants' questions so they gave the rape crisis number to these participants again.

Although researchers have to protect against possible adverse effects of research participation, there can be positive benefits. While Fontes (2004) points out that there has been insufficient study to draw firm conclusions about the

psychological impact of research on participants, Shamai (2003) argues that talking to an interested listener can give participants a venue to tell their stories, help them attain new insights, empower them to choose how to tell their stories, voice frustration or other feelings about the event, promote healing, and improve self-worth. Since a great deal of research focuses on negative events, we might also ask participants about any good that came from the adversity they faced. In keeping with this research, and our experience as social workers working with sexual assault survivors, we believed that survivors would find the experience cathartic and would welcome the opportunity to tell their stories to a nonjudgmental listener.

Even when there is not an immediate personal benefit, research participants often feel that they are making contributions to the greater good, and rightfully so. Our study report, for example, was made widely available in hard copy and via the Internet to state policymakers and community officials throughout the state. The report was intended to increase knowledge and more importantly to promote better treatment of sexual assault victims. Moreover, the study was successful in providing information about important community resources to participants because we found that about half of participants did not know that rape crisis advocacy agencies existed in their community.

Impact On The Research Staff

In addition to impacts on participants, conducting sensitive or controversial research can affect research staff, particularly interviewers, in ways that other types of research may not. These feelings may include discomfort with the level of intimacy required, guilt about evoking painful material for participants, inability to reciprocate, uncertainty about how far to push potential participants to participate, fear that participants might be identified from details of their reports, and pressure from referral agencies to disclose confidential information about participants (Johnson & Clark, 2003). Listening to stories of sexual victimization can be emotionally draining for interviewers. The potential impact on interviewers in our study was reflected in the time it took to complete interviews with those who had been sexually assaulted: the average was 57 minutes and the longest was 2.6 hours.

Researchers who are trained helpers (e.g., social workers or psychologists) may experience conflict between their role as interviewer and counselor (Johnson & Clark, 2003; Paavilainen *et al.*, 1985). This conflict raises the issue of who is best to conduct such interviews—clinicians or more objective

survey interviewers employed by survey companies or offices at universities. Researchers studying sensitive and controversial research topics may also be susceptible to countertransference and secondary trauma through the cumulative impact of interviewing multiple trauma survivors (Campbell, 2002; Fontes, 2004; Urquiza, Wyatt, & Goodlin-Jones, 1997). Carefully selecting and training interviewers, providing them with emotional support, debriefings, and meetings to discuss issues in interviewing may reduce this risk. Safety precautions for interviewers working in the community or otherwise meeting face-to-face with study participants are also necessary to prevent physical harm and the psychological trauma that may follow it (Fontes, 2004).

The university students employed by the survey research center that conducted interviews for our study were asked to carefully consider whether they felt comfortable asking questions about sexual assault. They were assured that their continued employment did not rest on their willingness to participate in this study. Those who decided to take this assignment completed a three-hour training provided by a local rape crisis center in addition to the usual training they received for conducting the survey. The specialized training included an overview of sexual assault, information on the impact of sexual assault victimization, and a description of posttraumatic stress symptomology. The training format included lecture, small group exercises, and role-playing so that interviewers would be prepared to address the potential range of responses of sexual assault survivors. Specifically, interviewers were trained to recognize when a sexual assault victim participating in the study might be experiencing posttraumatic symptoms, instructed in procedures for immediately referring the individual to a rape crisis hotline, as well as providing community referral information for the future.

Reporting Study Results

Fontes (2004) argues that the topics selected and the way questions are asked are ethical and social justice issues because of their potential impact on public policy and program funding. It is important to consider how to report study findings, who will report findings, and how they will be used to promote the public interest. How findings are reported may threaten participants. In their studies of child abusing families, Paavilainen et al. (1998) found that participants' circumstances were often sufficiently unusual as to make them identifiable. Particularly in qualitative studies, researchers may have to forego close and accurate reporting to protect participants' identities. Ortiz (1985),

in reporting his research on Cuban refugees, chose to change names, dates and details, because of participants fears about possible retribution toward family members still living in Cuba. Further, researchers need to present data carefully so that victims are not further stigmatized. For example, we were concerned that our findings that victims were using alcohol and/or other drugs at the time of the assault could lead to victim blaming. In reporting these findings, we stressed that regardless of victims' alcohol or other drug use, the assault was not invited, justified, or the victim's fault. While the focus of our research was on victimization as a result of sexual assault, we did not want to further stigmatize participants by focusing on them solely as victims and made a note in the report discussing our use of the word "victim" rather than "survivor" to describe them. Dealing upfront with the question of who releases findings, who "owns" data, and whether raw data will be made available to others can prevent conflict later on. Experience indicates the importance of working with stakeholders, such as funders and other participating agencies, establishing whether funders want their names mentioned to the media, and when it is necessary to get permission to release findings, publish articles, and editorials, and share the limelight—though most of our studies do not receive any interest from the public media.

As mentioned earlier, Hurley and Pinder's (1992) HIV prevalence study was nearly derailed when negative publicity about plans to oversample African Americans caused the study to be moved to another city. At another site, a gay rights group challenged the need for the survey and opposed it. Despite opposition, data were collected in that city. However, as a result of public perception, some of the methods (such as oversampling, and follow-up with non-responders) had to be abandoned.

Our study received statewide media attention due largely to the university's media relations staff member assigned to our school. She worked with our research team to develop a newsworthy press release and warned us to be prepared for calls. The calls came quickly. Members of our research team were interviewed in print, radio, and television. We found media exposure a mixed blessing. As it happened, the release of our study coincided with the arrest of a national celebrity on sexual assault charges. To our dismay, the focus of these interviews was often on this story, rather than on our study. Reporters from the popular media seek to humanize and often sensationalize stories while researchers generally prefer to focus media interviews on important research findings. When researchers want to avoid commenting on

extraneous subjects posed to them, they should redirect the interviewer back to the points of the research. It helps to have a few talking points that you can keep referring to if the interview strays from a discussion of research findings.

If your findings differ from previous studies, researchers may need to clarify for the media why and how they differ. Did previous researchers use different samples, define key variables differently, or use different time periods (annual vs. lifetime)? Though researchers often feel compelled to describe the nuances, limitations, and caveats of their work, information should be provided to the media as clearly and succinctly as possible (in “soundbytes”) to avoid the common occurrence of misunderstandings and misquotation.

A short news cycle might also mean responding immediately to media calls for a couple of days. Researchers should weigh the costs and benefits of the effort required to court media attention, for example, whether it is worth getting up at 4:00 a.m. to give a five- or ten-minute interview on an early morning talk show. When the results of our study received only cursory mention in major city newspapers, we wrote a short opinion-editorial article for public consumption describing the study’s major findings and it was picked up by only one major newspaper.

CONCLUSION

Conducting research on sensitive and controversial subjects requires careful attention to methodological issues and the ethics of human subjects protection. Based on our experience conducting a sexual assault prevalence study, we suggest that researchers utilize practitioners and members of the affected group as well as research experts in developing the study methodology. Establishing a good working relationship with one’s university or other human subjects review committee is critical to develop a protocol that meets strict standards of protecting human subjects while allowing for accurate data collection. Finally, researchers should carefully consider the broader implications of research on those studied, especially when reporting the findings and responding to media. Even with the sensitive subject of sexual assault victimization we have determined that with thoughtful consideration of methodology, instrumentation, human subjects protection, and media constraints, that yes, you can ask that over the telephone.

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