

# Ethical Considerations for Researching Violence Against Women\*

#### Topics covered in this chapter:

Respect for persons at all stages of the research process
Minimizing harm to respondents and research staff
Maximizing benefits to participants and communities (beneficence)
Justice: Balancing risks and benefits of research on violence against women

[The experience] that most affected me was with a girl my age, maybe 22 years old...She told me all about how her husband beat her while she was washing clothes in the back patio. Her mother-in-law would spy on her and tell her son things so that he would punish her. She was very afraid, and her voice trembled as she spoke, but she really wanted to tell me about her tragedy. She kept looking over to where her mother-in-law was watching us. She asked me for help and I told her about the Women's Police Station. When her mother-in-law got up to go to the latrine, I quickly gave her a copy of the pamphlet and she hid it. She thanked me when I left and I ended up crying in the street because I couldn't stand to see such a young girl being so mistreated... Nicaraguan interviewer. (Ellsberg et al, 2001.<sup>19</sup>)

n many ways, researching violence against women is similar to researching other sensitive topics. There are issues of confidentiality, problems of disclosure, and the need to ensure adequate and informed consent. As the previous quote from an interviewer illustrates, however, there are aspects of gender-based violence research

that transcend those in other areas because of the potentially threatening and traumatic nature of the subject matter. In the case of violence, the safety and even the lives of women respondents and interviewers may be at risk.<sup>1</sup>

In 1991, the Council for International Organization of Medical Sciences (CIOMS)

<sup>\*</sup> This chapter was adapted from Ellsberg and Heise, 2002.1

presented a set of International Guidelines for Ethical Review of Epidemiological Studies.<sup>3</sup> These guidelines apply the basic ethical principles of biomedical research involving human subjects to the field of epidemiology: respect for persons, nonmaleficence (minimizing harm), beneficence (maximizing benefits), and justice. In 1999, the World Health Organization (WHO) published guidelines for addressing ethical and safety issues in genderbased violence research.<sup>4</sup> The guidelines were based on the experiences of the International Research Network on Violence Against Women (IRNVAW) and were designed to inform the WHO Multi-country Study on Women's Health and Domestic Violence Against Women. (See Box 2.1 for a description of the main points.) The authors argue that these ethical guidelines are critical, not only to protecting the safety of respondents and researchers, but also to ensuring data quality.

This chapter examines each of the basic principles mentioned in the CIOMS

#### **BOX 2.1 ETHICAL AND SAFETY RECOMMENDATIONS** FOR DOMESTIC VIOLENCE RESEARCH

- The safety of respondents and the research team is paramount and should infuse all project decisions.
- Prevalence studies need to be methodologically sound and to build upon current research experience about how to minimize the underreporting of abuse.
- Protecting confidentiality is essential to ensure both women's safety and data
- All research team members should be carefully selected and receive specialized training and ongoing support.
- The study design must include a number of actions aimed at reducing any possible distress caused to the participants by the research.
- Fieldworkers should be trained to refer women requesting assistance to available sources of support. Where few resources exist, it may be necessary for the study to create short-term support mechanisms.
- Researchers and donors have an ethical obligation to help ensure that their findings are properly interpreted and used to advance policy and intervention
- Violence questions should be incorporated into surveys designed for other purposes only when ethical and methodological requirements can be met.

(From WHO, 1999.4)

guidelines in turn and explores the challenges of applying them to the special case of conducting research on domestic and sexual violence.

#### RESPECT FOR PERSONS AT ALL STAGES OF THE RESEARCH PROCESS

#### Informed consent for respondents

The principle of respect for persons incorporates two fundamental ethical principles: respect for autonomy and protection of vulnerable persons. These are commonly addressed by individual informed consent procedures that ensure that respondents understand the purpose of the research and that their participation is voluntary.

There is still no consensus on whether the informed consent process for VAW studies should explicitly acknowledge that the study will include questions on violence or whether it is sufficient to warn participants that sensitive topics will be raised. The WHO VAW study used an oral consent process that referred to the survey as a study on women's health and life experiences.5 Women were advised that, "Some of the topics discussed may be personal and difficult to talk about, but many women have found it useful to have the opportunity to talk." Women were told that they could end the interview at any time or skip any question they did not want to answer. (See Box 2.3 for an example of the informed consent form used in the WHO VAW study.) A more detailed explanation of the nature of the questions on violence was provided directly before the violence questions, and respondents were asked whether they wanted to continue and were again reminded of their option not to answer. It is a good idea to prepare a list of responses for questions that a woman might ask about the study, such as how she was selected for the study, what will the study be used for, and how her responses will be kept secret.



### BOX 2.2 ADAPTING ETHICAL GUIDELINES TO LOCAL SETTINGS

Researchers involved in the WHO Multi-country Study on Women's Health and Domestic Violence Against Women debated at length the value of mentioning violence directly in the initial consent process versus adding a second-order consent process immediately before the questions on abuse. Some researchers argued that it was important to alert women up front as to the true nature of the questions whereas others felt it was preferable to postpone introducing the notion of violence until immediately prior to the actual abuse-related questions. This would allow some rapport to develop, but still give a woman an opportunity to opt out of the violence-related questions.

The consent process was well received by respondents in all countries except Japan. During pilot testing, several Japanese respondents expressed a sense of betrayal because they had not been informed that the interview contained questions about violence. As a result, the Japan team modified its consent language to explicitly acknowledge violence up front. This is an excellent example of how ethical principles and actual experience can combine to guide practice.

#### Mandatory reporting of abuse

Some countries have laws that require certain kinds of professionals to report cases of suspected abuse to authorities or social service agencies. Such laws raise difficult issues for researchers because they throw into conflict several key ethical principles: respect for confidentiality, the need to protect vulnerable populations, and respect for autonomy. In the case of adult women, there is consensus among most researchers that the principles of autonomy and confidentiality should prevail and that researchers should do everything within their power to avoid usurping a woman's right to make autonomous decisions about her life. (Of course if a woman seeks support in reporting her abuse, researchers should oblige.)

The dilemma of whether to comply with legal reporting requirements is particularly problematic when dealing with child abuse. There is no consensus internationally about how to handle cases of child abuse

#### **BOX 2.3 INDIVIDUAL CONSENT FORM**

Used in the WHO Multi-country Study on Women's Health and Domestic Violence Against Women

Hello, my name is [\*]. I work for [\*]. We are conducting a survey in [study location] to learn about women's health and life experiences. You have been chosen by chance (as in a lottery/raffle) to participate in the study.

I want to assure you that all of your answers will be kept strictly secret. I will not keep a record of your name or address. You have the right to stop the interview at any time, or to skip any questions that you don't want to answer. There are no right or wrong answers. Some of the topics may be difficult to discuss, but many women have found it useful to have the opportunity to talk.

Your participation is completely voluntary but your experiences could be very helpful to other women in [country].

Do you have any questions?

(The interview takes approximately [\*] minutes to complete). Do you agree to be interviewed?

NOTE WHETHER RESPONDENT AGREES TO INTERVIEW.

[ ] DOES NOT AGREE TO BE INTERVIEWED

THANK PARTICIPANT FOR HER TIME AND END INTERACTION.

[ ] AGREES TO BE INTERVIEWED.

Is now a good time to talk?

It's very important that we talk in private. Is this a good place to hold the interview, or is there somewhere else that you would like to go?

#### TO BE COMPLETED BY INTERVIEWER

I CERTIFY THAT I HAVE READ THE ABOVE CONSENT PROCEDURE TO THE PARTICIPANT.

SIGNED: \_

(From WHO, 2004.5)

because children are generally considered more vulnerable and less able to act on their own behalf. The dilemma is particularly acute in settings where there are no effective services to assist troubled families, or where reporting is likely to trigger a cascade of events that might put the child at even greater risk (such as being removed from his/her home and placed in an institution). The WHO VAW study specifically excluded questions about child abuse, but required teams to develop local protocols

for handling cases of child abuse that interviewers might nonetheless come to know about. The guiding principle of these protocols was to act in "the best interests of the child," a standard that each team operationalized locally, based on advice from key agencies about prevailing conditions.

#### Community agreement

In many countries, it is also important to obtain community support for research, as well as individual consent. (Community consent, however, should never replace individual consent.) This is often sought by meeting with community leaders to explain the overall objectives of the research. For safety reasons, when obtaining community support for VAW research, it is important to frame the study in general terms—such as a study on women's health or life experiences rather than mention violence or abuse directly. If it becomes well known in the community that women are being questioned about violence, men may prohibit their partners from participating or may retaliate against them for their participation. In addition to potentially jeopardizing the safety of respondents, this could also undermine the study objectives and data accuracy.

#### MINIMIZING HARM TO **RESPONDENTS AND** RESEARCH STAFF

#### **Ensuring participant safety**

The primary ethical concern related to researching VAW is the potential for inflicting harm to respondents through their participation in the study. A respondent may suffer physical harm if a partner finds out that she has been talking to others about her relationship with him. Because many violent partners control the actions of their spouses closely, even the act of speaking to another person without his permission may trigger a beating.

No systematic studies have been performed to determine how often women suffer negative consequences from participating in research on violence. However, several VAW researchers have recorded chilling examples of experiences where women have been placed at risk as a result of inadequate attention to safety issues.8 For example, researchers from Chiapas, Mexico, describe how, when they first began researching domestic violence, they were not fully aware of the risks involved. They included a small set of questions on domestic violence within a larger study on reproductive health without taking any special precautions regarding safety of respondents. They were shocked to learn later that three respondents were beaten by their partners because they had participated in the survey.9

The WHO guidelines provide a number of suggestions about how to minimize risks to respondents, including:

- Interviewing only one woman per household (to avoid alerting other women who may communicate the nature of the study back to potential abusers).
- Not informing the wider community that the survey includes questions on violence.
- Not conducting any research on violence with men in the same clusters where women have been interviewed.4

#### Protecting privacy and confidentiality

His mother and sisters kept passing by, and would peek in the doorway to see what we were talking about, so we would have to speak really softly...and the girl said to me, "Ay, don't ask me anything in front of them." (Nicaraguan interviewer) 2

Protecting privacy is important in its own right and is also an essential element in ensuring women's safety. In addition to



interviewing only one woman per household, the WHO recommendations advise researchers to conduct violence-related interviews in complete privacy, with the exception of children under the age of two. In cases where privacy cannot be ensured, interviewers should be encouraged to reschedule the interview for a different time or place. Achieving this level of privacy is difficult and may require more resources than might be needed for research on less sensitive topics.

Researchers have developed a variety of creative methods for ensuring privacy.

Interviewers in Zimbabwe and Nicaragua often held interviews outside or accompanied women to the river as they washed clothes. Many studies have successfully used "dummy" questionnaires, containing unthreatening questions on issues such as breastfeeding or reproductive health.

Respondents are forewarned that if someone enters the room, the interviewer will change the topic of conversation by switching to a dummy questionnaire. Other members of the research team such as



Interview in Thailand

## BOX 2.4 SUGGESTIONS FOR MINIMIZING HARM TO WOMEN PARTICIPATING IN RESEARCH

- Interview only one woman per household.
- Don't inform the wider community that the survey includes questions on violence.
- Don't interview men about violence in the same households or clusters where women have been asked about violence.
- Interviews should be conducted in complete privacy.
- Dummy questionnaires may be used if others enter the room during the interview.
- Candy and games may be used to distract children during interviews.
- Use of self-response questionnaires for some portions of the interview may be useful for literate populations.
- Train interviewers to recognize and deal with a respondent's distress during the interview.
- End the interview on a positive note that emphasizes a woman's strengths.

supervisors and even drivers can also play a role in distracting household members who are intent on listening to the interview. In one instance in Zimbabwe, fieldworkers entered into lengthy negotiations to purchase a chicken from the husband of a respondent so that she could be interviewed in private. Other researchers have carried candy and coloring books to keep children busy during interviews.

Indeed, the Japanese team for the WHO VAW study found it so difficult to achieve privacy in Japan's crowded apartments that they had to depart from the protocol and use self-response booklets for especially sensitive questions. In this highly literate population, women were able to read and record their answers without the questions having to be read aloud.<sup>6</sup>

Ensuring privacy may be even more problematic in telephone surveys. Interviewers for the VAW survey in Canada were trained to detect whether anyone else was in the room or listening on another line, and to ask whether they should call back at another time. They provided respondents with a toll free number to call back if they wanted to verify





Respondent in Tanzania tells children to go play before starting her interview

that the interview was legitimate, or in case they needed to hang up quickly. About 1,000 out of a sample of 12,000 women called back, and 15 percent of the calls were to finish interrupted interviews.11

#### Minimizing participant distress

Interviews on sensitive topics can provoke powerful emotional responses in some participants. The interview may cause a woman to relive painful and frightening events, and this in itself can be distressing if she does not have a supportive social environment.12 Interviewers therefore need to be trained to be aware of the effects that the questions may have on informants and how best to respond, based on a woman's level of distress.

Most women who become emotional during an interview actively choose to proceed, after being given a moment to collect themselves. Interviewer training should include practice sessions on how to identify and respond appropriately to symptoms of distress as well as how to terminate an interview if the impact of the questions becomes too negative.

Interviewer training should also include explicit exercises to help field staff examine their own attitudes and beliefs around rape and other forms of violence. Interviewers frequently share many of the same stereotypes and biases about victims that are dominant in the society at large. Left unchallenged, these beliefs can lead to victim-blaming and other destructive attitudes that can undermine both the respondent's self esteem and the interviewer's ability to obtain quality data.

#### Referrals for care and support

At a minimum, the WHO guidelines suggest that researchers have an ethical obligation to provide a respondent with information or services that can help her situation. In areas where specific violencerelated services are available, research teams have developed detailed directories that interviewers can use to make referrals. In Canada's VAW survey, for example, the computer program used by telephone interviewers had a pop-up screen that listed resources near the respondent, based on her mail code. In Zimbabwe, Brazil, Peru, and South Africa, researchers developed small pamphlets for respondents that listed resources for victims along with a host of other health and social service agencies.10 All women were offered the pamphlet after being asked if it would be safe for them to receive it (cases have been reported where women have been beaten when a partner found informational material addressing violence). In Zimbabwe, interviewers carried a referral directory and wrote out addresses on physician referral pads so that the referral would not attract suspicion if discovered. Ideally, contact should be made in advance with the services so that they are prepared to receive referrals from the study.

In settings where resources are scarce or nonexistent, researchers have developed interim support measures. For example, a study on violence against women performed in rural Indonesia brought in a



counselor to the field once a week to meet with respondents.<sup>13</sup> In Ethiopia, the study hired mental health nurses to work in the closest health center for the duration of the fieldwork.14 The number of women who actually make use of such services is often quite low, but subsequent interviews with women indicate that they appreciate knowing that services are available if needed.11 In Peru and in Bangladesh, the WHO VAW team has used the study as an opportunity to train local health promoters in basic counseling and support skills. In this way, the team will leave behind a permanent resource for the community.

#### Bearing witness to violence

The image of these stories affects you, to see bow these women suffer, and especially the feeling that no one supports them. These are experiences that you never forget...

(Nicaraguan interviewer)<sup>2</sup>

Although preventing harm to respondents is of primary importance, researchers also have an ethical obligation to minimize possible risks to field staff and researchers. Sources of risk include threats to physical safety either as a result of having to travel in dangerous neighborhoods or from unplanned encounters with abusive individuals who object to the study. Some



Interview in Bangladesh

#### **BOX 2.5 PROTECTING RESPONDENT SAFETY IN CAMBODIA**

Researchers in a study performed in Cambodia found a young woman who was held prisoner in her own home by her husband. When the research team arrived to interview her, they found the woman locked in her house, with only a peephole where a chain was threaded through a crudely cut hole in the door. The woman conducted the interview through the peephole. During the interview, the husband appeared and was suspicious about their activity. The team gave him a false explanation for their visit and then left the home.

The next day, the team sought help from the Ministry of Women's Affairs, which cosponsored the study. Secretariat staff informed the researchers that the woman's husband had stormed into their office the preceding afternoon, dragging his wife by the arm. He demanded to know who had been at his door. He told the Secretariat personnel that if they couldn't confirm her explanation, then his wife would suffer. They readily confirmed her story. She was safe for the moment, but the researchers realized that it would be too dangerous to ever approach this woman again.

The team made several overtures with different government officials and the police to help get the woman freed, but everyone was afraid to intervene because the woman's husband had an important position. Researchers described the frustration that the team felt at not being able to free the woman and the guilt they felt at having put the woman in greater danger.

(From Zimmerman, 1995.8)

strategies to reduce the first source of risk include removing extremely dangerous neighborhoods from the sampling frame before drawing the sample (for example those controlled by narco-traffickers); outfitting teams with cell phones; and having male drivers accompany female interviewers into dangerous areas.

Abusive partners have also been known to threaten interviewers with physical harm. In a South African study, for example, a man came home from a bar in the middle of his partner's interview and pulled a gun on the fieldworker, demanding to see the questionnaire. Because of prior training, the interviewer had the presence of mind to give the man an English version of the questionnaire, which he was unable to read.10 "Dummy" questionnaires would also have been helpful in this situation.

The most common risk for fieldworkers, however, is the emotional toll of listening to women's repeated stories of despair, physical pain, and degradation. It is hard to overestimate the emotional impact that research on violence may have on fieldworkers and researchers. As the narrative from a Nicaraguan fieldworker presented at the beginning of this chapter illustrates, a study on violence often becomes an intensely personal and emotional journey for which many researchers are not prepared. Particularly when field staff have had personal experiences of abuse, the experience can be overwhelming. Judith Herman, in her work on psychological trauma in survivors of political and domestic violence, describes this as a common experience for those who study violence:

To study psychological trauma is to come face to face both with human vulnerability in the natural world and with the capacity for evil in human nature. To study psychological trauma means bearing witness to horrible events.15

Including discussions of violence in interviewer training is crucial for reducing distress during fieldwork. During fieldwork, another important measure is to provide interviewers and research staff with regular opportunities for emotional debriefing, or when necessary, individual counseling. Researchers have used a variety of creative strategies for protecting the emotional health of their staff. In Peru, for example, the WHO multi-country team employed a professional counselor to lead weekly support sessions that incorporated guided imagery and relaxation techniques. Experience has repeatedly demonstrated that emotional support for fieldworkers is essential. Not only does it help interviewers withstand the demands of the fieldwork, but it also improves their ability to gather quality data.

Transcripts of debriefing sessions with interviewers who participated in studies without adequate support illustrate this point:

... When I heard stories about women being beaten and tied up, I would leave there feeling desperate... I would be a wreck, and my supervisor would tell me

"get a hold of yourself, you cry for every little thing." But how could I control myself? I couldn't stand it... I would try, but sometimes it was impossible, and I would burst into tears during the next interview... (Nicaraguan interviewer)<sup>2</sup>

Other interviewers commented that they felt extremely drained and distracted by the interviews where women reported violence. One woman reported that she had stopped working for the study because she could not bear to listen to women's stories of abuse. 2

Experience has shown that traumarelated stress is not confined to field staff who are directly involved with respondents. Field supervisors, transcribers, drivers, and even data entry personnel may be affected. In one study in Belize, a transcriber broke down after hours of listening to in-depth qualitative interviews with survivors of abuse.16

It is particularly important to provide opportunities during training for interviewers to address their own experiences of abuse. Given the high prevalence of gender-based violence globally, it is likely that a substantial proportion of interviewers will have experienced gender-based violence themselves at some point. These experiences need to be taken into consideration. Most people learn to cope with painful past experiences, and usually do not dwell on them in their everyday lives. However, when trainees are confronted with the subject matter the information may awaken disturbing images and or emotions. For many trainees, simply acknowledging the fact that these reactions are normal and providing timely opportunities to discuss them will be sufficient to help them complete the training and participate successfully in fieldwork. In those rare cases where feelings become too overwhelming, trainees should be supported in their decision to withdraw from the study.



#### MAXIMIZING BENEFITS TO PARTICIPANTS AND COMMUNITIES (BENEFICENCE)

The principle of beneficence refers to the ethical obligation to maximize possible benefits to study participants and the group of individuals to which they belong. This principle gives rise to norms requiring that the risks of research be reasonable in light of the expected benefits, that the research design be sound, and that the investigators be competent both to conduct the research and to ensure the well-being of participants.

#### The interview as an intervention

Asking women to reveal stories of trauma can be a transforming experience for both researchers and respondents. Indeed, there is ample evidence that most women welcome the opportunity to tell their stories if they are asked in a sympathetic, nonjudgmental way. In our experience, women rarely refuse to answer questions on violence.

Many women who disclose violence in surveys have never told anyone about their situations.<sup>17</sup> Many studies find that participants find the experience to be so helpful that they ask fieldworkers to "interview" a friend or relative who has a story to tell. As Herman notes, "remembering and telling the truth about terrible events are prerequisites both for the restoration of the social order and for the healing of individual victims."<sup>15</sup>

Even the act of telling her story can offer a woman some small way of transforming her personal ordeal into a way to help others. Indeed, researchers sensitive to this issue encourage interviewers and field staff to take hope and satisfaction from their participation in the process of giving a voice to women's suffering.

A qualitative study of survivors of

abuse who had visited a women's crisis center in Nicaragua found that a central part of women's process of recovery and personal as well as collective empowerment came not only from increased knowledge of their rights, but also from the opportunity to share their experiences and to help other women in similar situations. In this sense, asking women about experiences of violence may be seen as an intervention in itself. At the very least, asking conveys the message that violence is a topic worthy of study, and not a shameful or unimportant issue.

In this same vein, many fieldworkers in the León, Nicaragua, research described the experience of listening to women's stories, as well as the opportunity to tell their own stories in the debriefing sessions, as a profoundly healing experience. One interviewer who had never before discussed her experiences said,

[when I joined this study] I felt that I had

finally found someone I could tell everything to, someone with whom I could share my burden, because it's horrible to feel so alone. Now I feel that a weight has been taken off me...I feel relieved...<sup>19</sup>

Remembering and telling the truth about terrible events are prerequisites both for the restoration of the social order and for the healing of individual victims. (Herman, 1992.15)

The interview is also an 1992. (15) opportunity to provide women with information on gender-based violence. Many studies have issued small cards that can be easily hidden in a shoe or inside a blouse with information about local resources for abused women and messages such as, "If you are being abused, there are ways out" or "Violence is never justified." Such messages may enable women to see experiences in a new light or to identify violence in others close to them.

Researchers also stress the importance of ending the interview on a note that emphasizes women's strengths and tries to minimize distress, particularly as a respondent may have revealed information that

made her feel vulnerable.20 A number of studies have carefully scripted such endings to ensure that the interview finishes with clear statements that explicitly acknowledge the abuse, highlight the unacceptability of the violence, and emphasise the respondent's strengths in enduring and/or ending the violence. The WHO study ends each interview with the words, "From what you have told me, I can tell that you have had some very difficult times in your life. No one has the right to treat someone else in that way. However, from what you have told me I can also see that you are strong and have survived through some difficult circumstances."7

One indication of how women have viewed the interview process can be obtained by assessing respondents' satisfaction with the interview. At the end of the WHO interview, respondents were asked the following question: "I have asked about many difficult things. How has talking about these things made you feel?" The answers were written down verbatim and coded by the interviewer into the following three categories: good/better, bad/worse, and same/no difference. The majority (between 60 and 95 percent in seven sites) of women who had experienced physical or sexual partner violence reported that

Looking for households in Samoa



they felt good/better at the end of the interview. In most countries, the range was similar between women who had or had not experienced partner violence. Very few women reported feeling worse after being interviewed. Between 0.5 and 8.4 percent of women reporting partner violence ever (highest in Peru) and between zero and 3.2 percent of women with no history of partner violence felt worse.17

#### Assuring scientific soundness

The CIOMS guidelines note: "A study that is scientifically unsound is unethical in that it exposes subjects to risk or inconvenience while achieving no benefit in knowledge."3 This principle is particularly important in the area of gender-based violence where women are asked to disclose difficult and painful experiences and where the act of research itself may put women at further risk of abuse. Thus the WHO guidelines note that violence researchers have an ethical responsibility to ensure the soundness of their work by selecting a large enough sample size to permit conclusions to be drawn, and by building upon current knowledge about how to minimize underreporting of violence. (See Chapter 7 for more discussion of sampling techniques.) Underreporting of violence will dilute associations between potential risk factors and health outcomes, leading to falsely negative results. Underestimating the dimensions of violence may also prevent violence intervention programs from receiving the priority they deserve in the allocation of resources.

Research demonstrates that disclosure rates of violence are highly influenced by the design and wording of questions, the training of interviewers, and the implementation of the study.2 In Chapter 6, we discuss this issue in much greater depth and outline the variety of measures that have been developed to enhance disclosure of violence.



#### Using study results for social change

It is important to feed research findings into ongoing advocacy, policy making, and intervention activities. Too often critical research findings never reach the attention of the policy makers and advocates best positioned to use them. The enormous personal, social, and health-related costs of violence against women place a moral obligation on researchers and donors to try to ensure that study findings are applied in the real world. It is also important that the study community receives early feedback on the results of the research in which it has participated. Chapter 14 addresses this issue in more detail and describes several successful examples of how research findings have been used to contribute to changing laws and policies on domestic violence.

One way to improve the relevance of research projects is, from the outset, to involve organizations that carry out advocacy and direct support for survivors of violence, either as full partners in the research or as members of an advisory committee. Such committees can play an important role in helping guide the study design, advise on the wording of questions, assist with interviewer training, and give guidance on possible forms of analysis and the interpretation of results. These groups also have a central role to play in publicizing and applying the project's findings.

# JUSTICE: BALANCING RISKS AND BENEFITS OF RESEARCH ON VIOLENCE AGAINST WOMEN

Research, like any endeavor that touches people's lives, involves inherent risks. The principle of distributive justice demands that the class of individuals bearing the burden of research should receive an appropriate benefit, and those who stand to benefit most should bear a fair proportion of the risks and burdens of the study.

In the case of gender-based violence research, the risks are potentially large, but so too are the risks of ignorance, silence, and inaction. Researchers and ethical review boards must constantly balance this reality. Lisa Fontes cites the case of a colleague from India who wanted to study wives who were hospitalized after having been burned by their husbands in disputes

over dowry. She ultimately decided not to conduct the research for fear that the research would put women at further risk. As Fontes observes, "Her decision eliminated the research-related risk to the participants, but also eliminated the potential benefit of reducing the terrible isolation and vulnerability of these victims."<sup>21</sup>

Women would ask me what this survey was for, and how it would help them. I would tell them that we won't see the solution tomorrow or the next year. Our daughters and granddaughters will see the fruits of this work, maybe things will be better by then. Nicaraguan fieldworker. (From Ellsberg, et al, 2000.19)

It is possible to conduct research on violence with full respect for ethical and safety considerations if proper care and resources are devoted to this end. We must remember that women living with violence are already at risk. Researchers cannot eliminate this reality, just as they cannot fully eliminate the possibility that further harm will be caused by their study. The obligation of researchers is to carefully weigh the risks and benefits of any study and to take every measure possible to limit possible harm and to maximize possible benefit. At the very least, we must ensure that when women take risks to share their stories, we honor that risk by using the findings for social change.



- 1. Ellsberg M, Heise L. Bearing witness: Ethics in domestic violence research. Lancet. 2002;359(9317):1599-1604.
- 2. Ellsberg M, Heise L, Peña R, Agurto S, Winkvist A. Researching domestic violence against women: Methodological and ethical considerations. Studies in Family Planning. 2001;32(1):1-16.
- 3. Council for International Organizations of Medical Sciences. International Guidelines for Ethical Review of Epidemiological Studies. Geneva: CIOMS; 1991.
- 4. World Health Organization. Putting Women's Safety First: Ethical and Safety Recommendations for Research on Domestic Violence Against Women. Geneva: Global Programme on Evidence for Health Policy, World Health Organization; 1999. Report No.: WHO/EIP/GPE/99.2.
- 5. World Health Organization. WHO Multi-country Study on Women's Health and Domestic Violence Against Women: Study Protocol. Geneva: World Health Organization; 2004.
- 6. Yoshihama M. Personal Communication. Ann Arbor, Michigan. Washington, DC. 2004.
- 7. World Health Organization. WHO Multi-country Study on Women's Health and Domestic Violence Against Women: Study Questionnaire V10. Geneva: World Health Organization; 2004.
- 8. Zimmerman K. Plates in a Basket Will Rattle: Domestic Violence in Cambodia, a Summary. Phnom Penh, Cambodia: Project Against Domestic Violence; 1995.
- 9. Health and Development Policy Project. Measuring Violence Against Women Cross-culturally: Notes from a Meeting. Takoma Park, Maryland: Health and Development Policy Project; 1995.
- 10. Jewkes R, Watts C, Abrahams N, Penn-Kekana L, Garcia-Moreno C. Ethical and methodological issues in conducting research on gender-based violence in Southern Africa. Reproductive Health Matters. 2000;8(15):93-103.
- 11. Johnson H. Dangerous Domains: Violence Against Women in Canada. Ontario, Canada: International Thomson Publishing; 1996.
- 12. Finkelhor D, Hotaling GT, Yllo K. Special Ethical Concerns in Family Violence Research. In: Finkelhor D, Hotaling GT, Yllo K, editors. Stopping Family Violence: Research Priorities for the Coming Decade. London: Sage; 1988.
- 13. Hakimi M, Nur Hayati E, Ellsberg M, Winkvist A. Silence for the Sake of Harmony: Domestic Violence and Health in Central Java, Indonesia. Yogyakarta, Indonesia: Gadjah Mada University; PATH, Rifka Annisa, Umeå University; 2002.

- 14. Gossaye Y, Deyessa N, Berhane Y, et al. Women's health and life events study in rural Ethiopia. Ethiopian Journal of Health Development. 2003;17(Second Special Issue):1-49.
- 15. Herman J. Trauma and Recovery: The Aftermath of Violence: From Domestic Abuse to Political Terror. New York: Basic Books; 1992.
- 16. Shrader E. Personal Communication. Washington, DC: 2000.
- 17. Jansen HAFM, Watts C, Ellsberg M, Heise L, Garcia-Moreno C. Interviewer training in the WHO Multi-country Study on Women's Health and Domestic Violence Against Women. Violence against Women. 2004;10(7):831-849.
- 18. Wessel L, Campbell J. Providing sanctuary for battered women: Nicaragua's Casas de la Mujer. Issues in Mental Health Nursing. 1997;18:455-476.
- 19. Ellsberg M. Candies in Hell: Research and Action on Domestic Violence in Nicaragua [Doctoral Dissertation]. Umeå, Sweden: Umeå University; 2000.
- 20. Parker B, Ulrich Y. A protocol of safety: Research on abuse of women. Nursing Research. 1990;38:248-250.
- 21. Fontes LA. Ethics in family violence research: Cross-cultural issues. Family Relations. 1998;47:53-61.