Safety and Informed Consent in Human Rights Field Research: Challenges, Experiences, and Lessons Learned Discussant's Main Points

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1. General Comments

I believe we all owe a considerable debt of thanks to Romesh Silva for organizing this session on an important, but too often ignored, topic.

I also wish to thank the authors of our three papers for their highly informative presentations that help to set out the complexity of a number of the ethical and safety issues that arise in human rights field research.

My comments this morning are primarily issues-oriented rather than paper-oriented, although at the end of my remarks, I offer a few specific comments on each paper.

I have organized my general comments under three broad issues:

1. The range of threats we face (i.e., what are the harms we are trying to prevent),
2. The complex trade-offs between beneficence and harm we must deal with in human rights research, and
3. The range of protections available to us.

1.1 The Range of Threats

It is useful to think of threats in terms of the harms we are trying to prevent.

It is relevant to consider the range of threats arising from research or program activities whether one is considering the biomedical ethical model (the model that is the basis the Nuremberg Code, the Belmont report, Helsinki accord, and relevant US law) or looking at other models (that is, the threats arising in most social science research are often quite different from those arising in most biomedical research).

One needs to think about three different types of threats:

(a) Direct or intervention threats

These are the sorts of threats that basically underlie the biomedical model of research ethics.

(b) Non-invasive threats (e.g., information).

These are the sorts of threats that arise in most social science and human rights research, although they may also arise in biomedical research focused on genetics. (By the same token, some human rights research involving direct interviews with victims and survivors may be highly invasive from a psychological perspective.) A central problem arises because most formal ethical review processes are based on the biomedical model and thus largely ignore non-

invasive threats. In a human rights context, the wrong information in the wrong hands can be as life threatening as any disease.

(c) Threats to researchers

Perpetrators of human rights crimes or their sympathizers may not want your research to take place. It should be understood that all those involved in the research may be at risk, particularly all those out in the field (e.g., field supervisors, interviewers, drivers, house listers, and data entry clerks). While senior staff and other university trained researchers may be motivated by idealism and would willingly accept the risks involved, one can not assume that all those employed by the project are so motivated. They must be informed of the potential risks involved and protected.

It must be noted that the kind and degree of threat is often linked to when the study takes place in the course of the events being studied.

1.2 Beneficence versus Harm

It is often difficult to sort out the trade offs involved between the good we are trying to do in carrying out human rights research and the real harm that such research can cause. I suggest that one approach to addressing these trade offs is to consider the following two questions:

Who gets the benefit?

For example, is it the research subjects, others in the victim community, human rights victims in general, those collecting data, those conducting the research, those directing the research?

Who is exposed to harm?

Again, is it the research subjects, others in the victim community, human rights victims in general, those collecting data, those conducting the research, those directing the research

1.3 Range of Protections Available

What options are available?

(a) Formal Institutional Review Boards (IRBs)

If so, is the Board located in the country of study, in the US or other sponsoring country, or will IRBs in both places be used. It should be noted most IRBs are mandated to operate under a biomedical model and so may miss many of the main threats in human rights research. Moreover, most NGOs (who carry out the bulk of human rights research are only loosely covered by formal IRBs).

(b) Other ethical review processes

This in fact may be the best way of proceeding. That is, use or establish a small quasi-independent group that is knowledgeable about the research and the potential threats involved and who have no stake at all in whether the research proceeds.

Whatever option for review is used it is important to be clear about the ethical standard used: strict biomedical or one more suitable to social and human rights research.

2. A Few Comments on the Three Papers

My specific comments on the individual papers may appear to be highly critical. They are not intended to be. They are three very useful papers that well-illustrate many of my general comments. In the interest of time, my specific comments very briefly focus on what I thought was missing or over-emphasized in each paper.

2.1 Paper by Jana Asher and Cathy Furlong

This paper focused very heavily on IRB-based review processes. I wished it had given more attention to other types of ethical reviews.

2.2 Paper by Romesh Silva and Jasmine Marwaha

I would have liked this paper to have reduced considerably its presentation of the general methodology of the survey they carried out so that they could have expanded their description of the many useful safeguards they employed.

2.3 Paper by Shana Swiss

While this paper raises many important issues, I found that it focused too narrowly (at least for me) on studies that gathered data using non-probability samples. To serve its diverse users, human rights research requires both quantitative and qualitative studies, using both probability and non-probability approaches.

Finally, I would close by thanking the organizer and the paper authors for an excellent session.