

WORKING P A P E R

Ethical Principles in Social- Behavioral Research on Terrorism

Probing the Parameters

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SUMMARY

As the word *probing* in the title suggests, the workshop addressed unresolved issues for which insights are needed from representative, knowledgeable experts. The goal was to arrive at well-grounded and consensual parameters for ethical decisionmaking in social-behavioral research on terrorism. Increasingly, RAND and other research institutions are being asked to help answer profoundly important policy questions about the antecedents, processes, and consequences of terrorist actions against civil society in the United States and abroad. What conditions influence individuals to undertake such actions? How do these individuals find like-minded others to engage in actions that require shared effort? How are such collaborations organized and supported? What are the scope and longevity of these social networks?

Questions like these are viably pursued with well-established social and behavioral theoretical frameworks plus research procedures that include, but are not limited to, interviews, surveys, and focus groups. However, unusual factors in this research environment raise ethical concerns not present in other contexts, particularly when the research is to be conducted outside the borders of the United States. These ethical concerns can be grouped into three categories: deception and concealment vs. autonomy, maximizing beneficence and maintaining justice, and ensuring confidentiality.

Deception and Concealment vs. Autonomy

Deception (misleading a subject concerning certain facts about a study) and concealment (withholding facts about a study) sometimes seem to be the only valid means for conducting certain behavioral research. For example, in conducting surveys or interviews to assess the prevalence of racial prejudice in a given population, researchers may not want to disclose the study's purpose, since doing so could prompt subjects to shade their responses, rendering results invalid. Likewise, researchers conducting focus groups or surveys to gauge attitudes and

beliefs among certain populations on issues related to terrorism may view some degree of deception and/or concealment as essential to their projects. For example, among some populations, antipathy toward the United States may be such that disclosure of who is sponsoring the research, who is conducting it, and/or its purpose could lead to high refusal rates, unrepresentative participants, and/or skewed responses.

There has been a long-standing debate among researchers and ethicists about the propriety of deception and concealment, with some arguing that such techniques are improper under all circumstances because they are inconsistent with a subject's right to make an autonomous, free decision about whether to participate. The Common Rule requires that subjects be given all information needed to make a fully informed and voluntary decision about whether to take part in research. However, the Common Rule also allows an institutional review board (IRB) to waive some or all elements of informed consent if certain conditions are met. Some IRBs have interpreted this waiver provision as permitting the use of deception or concealment in limited cases, provided the misstatements or omissions do not increase risk to subjects and do not relate to facts material to a subject's decision to participate. The lead agency charged with interpretation and oversight of the Common Rule, the Office for Human Research Protections, Department of Health and Human Services (DHHS), has issued no formal guidance on the use of deception and concealment in research. For these reasons, the proper parameters of deception and concealment under research covered by the Common Rule merit concerned and careful deliberation.

This session opened with a presentation by Dr. Franklin (Frank) G. Miller from the National Institutes of Health (he presented his own views, not those of the agency) titled, "Deception, Respect for Persons, and Informed Consent." Dr. Miller noted that deception takes many forms in research, including misleading disclosures, fake or rigged procedures, play-acting by the researcher and confederates, covert procedures, and undercover observation. He noted that the use of deception not only violates the autonomy of research subjects but may cause them distress when the deception is discovered or revealed. To make deceptive studies compatible with the spirit of informed consent,

Dr. Miller suggested consideration of "authorized deception," in which prospective subjects are informed of and consent to the fact that research will involve the use of deception. Dr. Miller proposed experiments to determine how authorized deception may affect scientific validity. In addition, Dr. Miller argued that when researchers publish deception research, they should have to justify the use of deception, and he proposed reporting standards. He concluded that deception should be limited to studies in which its use is necessary to answer a valuable research question and that, if used, it should be authorized.

Following the comments by the expert panel, an open plenary discussion focused on the following areas:

- The need to consider the basis for applying ethical restrictions on the use of deception in research vs. other activities in which deception may take place
- Common types of deception proposed for terrorism research
- Ethical vs. unethical uses of deception in research
- The ethics of conducting research within the context of groups in conflict
- The effects of deception on the value of scientific research on behavior
- IRB development and capacity building.

Maximizing Beneficence and Maintaining Justice

The Common Rule derives from many sources, including the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). One of the three core principles identified in the Belmont Report is "beneficence," which requires that research protocols maximize potential benefits to subjects and minimize harms. Although taking part in routine social/behavioral research procedures usually poses little risk, it is unclear what the risk exposure might be to subjects who express extremely violent or radically moderate views of terrorist activity. In addition, in certain situations, participation in U.S.-sponsored projects might in and of itself be a source of risk to subjects should persons outside the research context learn of it. Another core principle of the Belmont

Report, that of "justice," requires that researchers seek to ensure that those who bear the burdens of research share equally in its benefits. It would appear difficult to reconcile this principle with many studies of terrorism, particularly those that involve overseas populations. How researchers might approach these issues in such environments has received little attention in the literature.

Session two opened with "Assessing Risks, Minimizing Harms, and Promoting Justice for Participants in Research on Terrorism: An Ethical Conundrum of Restraint and Possibility," a presentation by Dr. Patricia Marshall from the Department of Bioethics in the School of Medicine at Case Western Reserve University. Dr. Marshall noted that terrorism research is conducted in a complex social context with many stakeholders, both national and international. Although perspectives among stakeholders vary, there is general agreement that research on terrorism can potentially present a number of harms to subjects, as well as to researchers themselves. Potential harms to subjects that need to be mitigated include physical harm, psychological harm, social harm, economic harm, legal harm, and dignitary harm (i.e., not treating a subject or the subject's value system with full respect). Drawing on her experience in conducting ethical research in low-resource settings, Dr. Marshall offered a framework for fostering trust among stakeholders in terrorism research so that conducting research will be less risky. The framework's key principles are collaborative partnerships, capacity building, and respect for persons and communities. She noted that transparent research (i.e., research that is not deceptive) helps to build trust among stakeholders and to create conditions favorable to sustaining research in a setting or population. She argued against treating research on terrorism as an exceptional case that requires new regulations. Rather, additional guidance is needed to help IRBs identify and balance harms, risks, and benefits of proposed studies on terrorism using the ethical framework of the Common Rule. As an example, she suggested that when an IRB evaluates benefits in terms of how a proposed study might contribute to existing knowledge, it should do so in the context of a full range of information from existing sources, including journalism and media.

Following the comments of the expert panel, an open plenary discussion focused on the following areas:

- Lessons learned from research on offenders and criminal behavior and possible relevance to research on terrorism
- Issues regarding dual use of terrorism research
- Potential inconsistencies in applying principles of beneficence and justice when researchers and participants represent avowed enemy groups
- Dignitary harm and paternalism.

Ensuring Confidentiality

The Common Rule obligates researchers to provide robust protection for the resulting data so that confidentiality is not breached either inadvertently (e.g., by a focus group member recognizing another participant) or intentionally (e.g., via data seizure). In the case of research on terrorism, researchers may face particular challenges in seeking to protect confidentiality. For instance, if project data were brought back to the United States, it is possible that they could be obtained by law enforcement without a search warrant and under certain provisions of the USA PATRIOT Act. Also, in cases where data are collected abroad, it may be unclear how local police, security agencies, or military organizations would regard compliance with confidentiality assurances provided to subjects. These are matters that warrant serious discussion.

Dr. Eleanor Singer of the University of Michigan opened the third session with a presentation titled, "Confidentiality in Terrorism Research: Can It Be Assured?" Dr. Singer noted that it is important to protect the confidentiality of subjects not only for ethical reasons but also for practical ones, because worries about confidentiality reduce research participation. Confidentiality is a salient concern in terrorism research because interest in the subjects and their information may be shared by many parties, including military, intelligence, law enforcement, and terrorist organizations. Breaches of confidentiality can arise not only from carelessness but also from illegal intrusions, legal requests, and statistical inference. The IRB

needs to consider how much risk it will permit potential participants to undergo. A breach of confidentiality in a study of terrorism may expose subjects to very severe harms, including imprisonment and death. Breaches of confidentiality can also harm the researchers, the study sponsor, and the research enterprise. Dr. Singer concluded by noting the need to develop and implement strong and perhaps additional protections against breaches of confidentiality. The strength of certificates of confidentiality issued by federal agencies has apparently never been tested against demands for disclosure under the USA PATRIOT Act.

Following the comments of the expert panel, an open plenary discussion focused on the following areas:

- Ethical guidelines for whether, when, and how terrorism researchers should violate participant confidentiality (e.g., to prevent imminent harm to the participant or others)
- Expansion of IRBs to include persons with international research experience or to include outside experts
- Strengthening the legal bases for assurances of confidentiality.

Conclusion

The ethical concerns examined in this workshop threaten to preclude meaningful social and behavioral research on issues of vital worldwide significance or to lead to its pursuit in ethically inconsistent, ad hoc, or even negligent ways. In the long run, it is unwise to handle such concerns on a project-by-project or institution-by-institution basis, since they will be faced by many research organizations and research sponsors across the country. Instead, a national dialogue aimed at responding to questions about how principles of research ethics are to be applied to this emerging new policy domain is urgently needed.

The workshop was designed and conducted on the assumption that, while reasonable people in diverse settings will disagree about the appropriate response to an ethical question in any particular research

context, it is possible to aim for consensus on the general parameters that should guide ethical decisionmaking across cases.