

# BORN OF WAR

Protecting Children of  
Sexual Violence Survivors  
in Conflict Zones

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## Key Ethical Inquiries for Future Research

JULIE MERTUS

The preceding case studies and analysis in this collection have pointed to the need for future research on children born of wartime rape. As Giulia Baldi and Megan MacKenzie observe in their study on Sierra Leone, for example, more targeted studies are urgently needed to help inform the social and political responses to the issue and, if all goes well, to improve the lives of the children and families that are central to this query. Expanded analysis of existing data alone, although certainly needed, is not enough to advance significantly our understanding of this complex topic. To make compelling contributions to existing literature, researchers must press deeper into existing case studies and gather new information for further comparative analysis. Additional fieldwork is necessary, accompanied by a variety of research methodologies, such as focus groups, field observations, structured and unstructured interviews, surveys, and participatory research.

This chapter seeks to explore the key ethical issues that will continue to present themselves as such research proceeds. The chapter explores three criteria social scientists generally apply to research on human subjects:

1. The research should maximize possible benefits and minimize harm;
2. Informed consent should be given from potential research participants or, where appropriate, their proxies; and
3. Local participation in research design, application, and evaluation should be maximized whenever possible (see, e.g., Cassell and Jacob 1987).

For researchers studying children born of rape, the emergency nature of the research and the particular vulnerability of the research population shape how these three criteria may be addressed.

### Conducting Risk-Benefit Analyses with Vulnerable Populations

With children as research subjects, the first ethical question concerns the age at which one is no longer considered a child. This definition varies greatly among international conventions, researchers, aid agencies, communities, and children themselves. For the purpose of working with children born of wartime rape, researchers have a responsibility to inquire about the age of childhood (and age of capacity) in the country in which the child presently resides (where the status of *child* may substantially inform access to social services) and in the country of origin and/or any transit countries where harm occurred.

Once the legal status of children is determined, a risk/benefit analysis should be performed. For this analysis researchers should weigh any potential benefits of the new research against any potential costs. The range of potential benefits and possible harms associated with future research on children born of rape in conflict area differs from other studies on stable adult populations.

The contributors to this volume agree that the benefits of additional research on this topic could prove substantial for the particular children and communities under study as particular needs and concerns are identified. As Eunice Apio notes: "It is increasingly recognized that challenges associated with the assimilation of children born in armed conflict require more systematic study. . . . Little is known about these children and how they can integrate with their mothers back into their community" (chap. 6 herein). Given this lack of information, Susan Harris Rimmer similarly concludes, "The first imperative is to gain qualitative and quantitative data on the situation of these children and their mothers" (chap. 4 herein). Only then can the social reintegration process be improved. Work with children in structured research projects will also lead to a better understanding of the types of social services that best address their short-term and long-term needs. Other related benefits of future research may involve lowering the probability of harm for other children who have already been subjected to abuse and are at great risk of further harm.

Balanced against the significant benefits of working with children, however, are several possible harms. Whenever children are involved in any research endeavor, the physical, psychological, political, and legal consequences for research participants are potentially more dangerous

than in most research involving adult subjects. Children are at a legal and social disadvantage compared with adults, who enjoy greater protections under law and respect under social norms, enabling them greater latitude in exercising their agency. Poverty and its consequences, Marie Consolée Mukangendo observes, also severely curtail adequate access to food, education, and health, thus compounding children's vulnerability. This is particularly true with children born of rape, as Mukangendo highlights in her study on Rwanda: "Stigmatized as both illegitimate and as enemy children, their difficult situation seems complicated. . . . Often, the decision to keep the child causes conflicts in the family, pitting those who reject the child against those who want to raise the child" (chap. 3 herein).

The malfunctioning of legal and social institutions in emergency and post-conflict scenarios also renders children more vulnerable, when their precarious state is often compounded by their status as refugees, migrants, and noncitizens. By definition, noncitizens enjoy fewer rights than citizens. Noncitizens who are not afforded refugee status or some other official legal status stand outside the protection of both domestic legislation and international standards. The international guidelines that provide guidance on research with human subjects have not addressed research involving refugee populations. In his study of the ethics of conducting research on vulnerable populations, Jason Lott reports, "Neither the Declaration of Helsinki nor the Council for International Organizations of Medical Sciences (CIOMS) research guidelines specifically mention refugee populations, and neither the Belmont report and Nuremberg Code address the issue" (Lott 2005, 40). Without credible ethical guidance, refugees and other noncitizens are subject to breaches of ethically acceptable research protocols. Because refugees and other noncitizens are often economically destitute, researchers can easily entice them to participate in research for limited financial awards.

Even researchers with the best intentions may contribute to their research subjects' ongoing psychological stress. For many reasons this may be especially true in the case of children born of rape. As many of the contributors to this volume underscore, the agency of children born of rape and their mothers should be respected. However, the psychological distress that they have suffered may cloud their judgment and perceptions, thus interfering with their ability to choose to enter into and to participate freely in a research project. The stress of participation may be overwhelming for many research subjects because it forces them to relive the trauma. Moreover, the experience of children in wartime and post-conflict situations is of interest to many interviewers, and the same children and mothers may be put through multiple interviews, possibly with untrained or inexperienced interviewers. Less experienced interviewers may conduct interviews with families as groups, thus destroying any hope

children and mothers have of telling their stories in a safe and confidential environment.

Ethical problems also arise when researchers attempt to collect and use physical artifacts created by children, such as poems and drawings. To take one illustration, when children's artwork is handled by multiple agencies and moved from researcher to researcher, this leads to the invasion of children's privacy and the possible loss or damage of data. Because researchers have an obligation to protect and secure their data archives, research should not be conducted if security cannot be assured, yet in the rush to publicize the plight of children born of rape, these precautions are frequently not undertaken. The ownership by the children of drawings, writings, and other artifacts should be respected; it is the child, and not just the researcher, who should benefit from the use of his or her artifacts in a research project.

In sum, the nature of research as an intervention necessitates that the researcher engage with ethical concerns beyond not causing harm; the researcher must also consider who benefits from the research process and output. The researcher is clearly benefiting when the research fulfills a professional requirement. Professional benefit is perfectly legitimate, but the local participants in the research process must also benefit from the research process. The researcher should consider the ways in which the research can add value to the community rather than being only a situation in which knowledge is extracted. Ultimately, in making a cost/benefit analysis for future research on children born of rape, researchers should take into account the complicated impact of the emergency setting and of the post-conflict scenarios. The particular vulnerability of the research subjects due to their age and legal status should be a major factor in determining when and how to proceed. Another important factor in making these assessments should be whether the research subjects give free and informed consent, an issue to which we now turn.

### Obtaining Informed Consent with Vulnerable Populations/Emergency Scenarios

Researchers seeking to conduct future studies on children born of wartime rape face considerable challenges in obtaining informed consent, due to the emergency context in which they work and the often vulnerable state of their research subjects. This is especially true when the research subjects are children. The agency of children to decide whether, when, and how to participate in research should be respected. The requirement of informed consent is designed to protect potentially vulnerable research subjects by providing them with the kind of

information they need to exercise their agency. Informed consent, however, demands the capacity for rational, informed decision-making, characteristics that young children arguably do not possess. When children cannot give their consent, research may still proceed, but ethical codes suggest that in such circumstances children should not be subjected to interviews but only to surveillance.

Proxy consent may be an acceptable alternative for children who cannot give their own consent, but proxy consent may be extremely problematic as well. One question that arises concerns who is an appropriate proxy. Parents are likely candidates, but sometimes their interests diverge from those of their children, and often in wartime and post-conflict scenarios parents are not available to give consent. But even if a parent is an appropriate proxy, should proxy consent be permitted? The conditions under which proxy consent may be permissible are hotly debated. Medical researchers considering this question generally make a distinction between therapeutic (situations where the research is of direct value to the participants) and non-therapeutic research (situations where the research is not of direct value to the participants). Questions of consent are generally dealt with in a more permissive manner and proxy consent is more often accepted when the research is therapeutic. If this medical model were to be extended to the case at hand, given that research on children born of wartime rape is rarely therapeutic, proxy consent would rarely be permitted. This reasoning reflects the widely shared belief that proxy consent may not sufficiently protect children from research agendas that lack any direct benefit to the children. In such cases it appears that the researcher is taking advantage of children's vulnerability for the researcher's gain.

Complicating the issue of informed consent for research is the interplay between the definition of research and the realities of emergency situations and conflict scenarios. Researchers often seek to use reports and other written artifacts created in emergency scenarios. Are these considered "research"? And, if so, are there limits on how and when they can be used by researchers? Similarly, many NGOs collect program data that are meant to be internal but are later used by researchers. What ethical constraints apply to the use of "found data"? In answering these questions, researchers should consider whether the use of found data would subject research subjects to exposure, coercion, or retribution. To take a concrete example, researchers may seek to analyze as part of their work family-tracing databases for lost children. Yet these databases were created for humanitarian program purposes, not for researchers studying children born of wartime rape. Who should have control over the use of the data: the refugees who are the subject of the database or the humanitarian agency that created it? And how should the data be used? Child research subjects and their families have a strong argument for

restricting the use of such records when public disclosure would likely be harmful.

Some researchers argue that research should be limited in all phases of emergencies, where it is difficult or impossible to obtain informed consent. Others argue just the opposite, contending that the informed-consent model may be waived during the acute emergency phase for public data collection activities (surveillance, outbreak investigations), but only for a short period of time. For example, once a refugee camp is more established and refugee camps become more like institutions, the situation may be deemed changed and specific consent may be necessary. In any case, informed consent needs to be seen as an ongoing process, not just a one-time event. Local participation in the research design and application may help enable researchers to understand and adapt to this process.

### Encouraging Local Participation

Research interventions that do not take into consideration the capacities and existing coping mechanisms of people in the locality will be less effective and even harmful. In designing future projects for research on children born of wartime rape researchers can take steps to reduce the relative power imbalances between themselves and local parties by creating mutual obligations and giving beneficiaries control over some aspect of the process. The research technique most associated with valuing local expertise and enhancing local participation is known as participatory research.

A central tenant of participatory research is that control and ownership of the research process (or the creation of knowledge) should be shared among all participants rather than having a research process imposed (Nelson et al. 1998). Outsider-conceived projects require, at the very least, endorsement and agreement (Reason and Bradbury 2001). In this reciprocal research relationship the researcher and the participant are dependent on each other, and each brings a particular set of skills and competencies to the endeavor. The researcher's skill and contribution is the intellectual framework and knowledge of process, while the "problem owner" brings knowledge of the context. The contributions of each are valued and considered essential to conducting research. Especially as research involves an element of problem solving, participatory research recognizes the value of engaging stakeholders, especially oppressed people, in informing research interventions.

Participatory research suggests that setting the research agenda should be a two-way process. The involvement of problem owners in setting the research agenda, defining the most important problems, and determining