

Chapter 2

Social Science Research in a Humanitarian Emergency Context

Gwenaëlle Luc and Chiara Altare

Abstract This case study about research in an emergency setting depicts how unexpected findings created conflicts of conscience for non-governmental organization (NGO) workers and exposed research participants and their community to retribution and compromised the local social structure. The community felt betrayed when unexpected findings from research about health seeking behaviours revealing illegal female genital mutilation were shared publicly and contributed to stigmatizing their culture. In addition, the NGO involved performed a dual role – that of assistance provider as well as researcher – which endangered the neutrality of the data collection and, in the end, the acceptability of the NGO as assistance provider.

Keywords Ethics • Female genital mutilation • Unexpected findings in research
Cultural relativity

Area of Risk of Exploitation

This case study covers two potential areas of ethics risks or potential for exploitation.

First, a potential for ethics risks can exist when the ethical standards developed in one context (Western medical research) are applied in another context without due attention to local social norms or communication with local communities. A case can be particularly serious if a local practice violates the laws of the country the research takes place in, as in this case.

Second, a conflict of interest can arise when an assistance provider also conducts research. For instance, this could create expectations among participants, and influence their consent to be enrolled in the study.

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Background

A major ethical dilemma when conducting research in a volatile emergency setting including culturally heterogeneous groups is the need to balance the risks and benefits for the research participants. An example of such a setting is a refugee camp. Acquiring a clear understanding of context-related risks is challenging: unanticipated risks, if not properly understood or taken into account, could lead to the exploitation of participants or communities.

Research in emergency settings is associated with a range of ethical challenges, as both implementers and participants might be situated in a position of vulnerability and insecurity. In addition, in an emergency setting there may be a need for a rapid response, and it might be difficult for local communities (or the aid providers) to distinguish relief from research, among other things.

In research, the “do no harm” imperative requires that research participants not be put at any additional risk (WMA 2013). This is particularly important in cases where vulnerable participants in emergency settings may not get any direct benefits from the research themselves, but may contribute to producing evidence that will improve interventions with similar populations or in similar settings in the future.

Here we describe a case where research activities did put participants at risk, while simultaneously providing no direct (personal) benefits to them, which led to community complaints. The community felt betrayed because the research did not respond to their needs and priorities, and contributed to stigmatizing their culture.

Specific Case and Analysis

A socio-anthropological research study on health-seeking behaviours was undertaken by a humanitarian non-governmental organization (NGO) in a rural village in an African country where the prevalence of child global acute malnutrition was high. The study focused on health-seeking practices during diarrhoea episodes among children under the age of five, as diarrhoea is one of the underlying causes of child undernutrition. The research aimed to study access to and utilization of health services. The country’s national ethics review committee approved the research.

Qualitative fieldwork was conducted which aimed to better understand the cultural values and practices related to the therapeutic path of children with diarrhoea. Interviews were conducted with parents and other key informants in the village (e.g. community leaders, elders, traditional healers).

Consent forms were signed by the participants, but as the NGO was mostly known in the area as an assistance provider, it was not always clear to the researchers whether participants freely consented to take part in the research or whether they assumed they had to participate in order to receive assistance, or out of gratitude.

During data collection, the investigator found that a traditional treatment for diarrhoea among baby girls (from three months of age) was female genital mutilation (FGM). This practice was intended to remove “impurity” that interfered with a girl’s well-being. FGM was practised in the village by a traditional healer with a razor blade and without hygienic precautions. “If the diarrhoea is caused by a worm, we have to remove the impure part of a girl’s body; it will kill the worm and cure the girl,” a traditional FGM practitioner said during an interview.

According to the testimonies gathered during the research, FGM is highly valued in the local culture. In addition to being considered an effective traditional cure for girls’ diarrhoea, FGM is part of the accepted and expected identity of a woman. “Uncircumcised” girls are marginalized, are a source of shame for their family and have difficulty finding a husband. FGM also has religious and social significance. This act is symbolically seen as a ritual of incorporation of the girl into the rest of the community.

At the global level, FGM is considered a violation of human rights, and it is also prohibited by law in the country where the research took place. “Female genital mutilation and cutting is a violation of the basic rights of women and girls,” said Carol Bellamy, then executive director of the UN’s Children’s Fund (UNICEF), on the International Day of Zero Tolerance for FGM in 2005. “It is a dangerous and irreversible procedure that negatively impacts the general health, child bearing capabilities and educational opportunities of girls and women.”

In the research setting of this case study, most of the participants in the interviews had never been to primary school and were illiterate. For them, local habits and regulations took precedence over national or international laws and codes of conduct.

The national ethical review committee¹ and the research team did not anticipate this finding, as their members did not have a deep understanding of the local culture and the norms of the specific community and individuals. Because this traditional cure for diarrhoea was an unexpected finding, participants had not been previously informed by the researchers of what they could be exposed to while they proudly exhibited their traditional culture.

When a researcher from an NGO witnesses a human rights abuse, there is always a risk of that organization, when managing the resulting conflicts, being accused of complicity, and/or of violating the interests of both the individuals and international ethical standards. In this case the researcher acted in accordance with his own model of norms and values, and one based on national and international codes of law and ethics, rather than with the way in which the causal model of illness was understood locally, and the implications of this for the social construction of female identity. The researcher and the NGO decided to report the practices in a public report in order to protect baby girls from a recognized and illegal human rights abuse.

¹The committee did not include lay members or representatives of the targeted communities.

However, this approach had serious consequences: it offended participants and the wider community, and led to the social rejection of girls who had not received FGM – they were stigmatized in the community – and intensified community tensions. It also jeopardized the NGO's capacity to operate in the area.

Communities felt betrayed by the NGO, as they were expecting humanitarian relief from the organization. They felt that the research was not responsive to their needs as they did not feel any benefit. On the contrary, its findings had exposed vulnerable communities and respondents to retribution from a coercive government, and endangered the local social structure.

Lessons Learned

This case study highlights the risks of exploitation of participants when researchers face conflicts of conscience and have to choose between abusing the trust of the community and protecting vulnerable individuals from violations of their fundamental rights in accordance with national and/or international laws and ethical codes. For the NGO involved, a lesson learned was that researchers need to anticipate the identification of potential ethical challenges by assessing the risks and benefits for potential participants with “due diligence” before a project commences. Risk assessments should not be a vertical and unilateral process, but rather a participatory exercise. This can facilitate the understanding of the context, as interpretations of benefits, risks and harm are specific to each setting.

In this context, it is important to engage in mediation with all stakeholders, which may result in an agreement according to which no actor needs to disown his/her values. The research could be ethically acceptable to all if the entire process and all the consequences are favourable (or at least neutral) for everyone. It is worth emphasizing that when opposing values are involved, it is crucial to engage in a discussion before taking action in order to reach an agreement. If no agreement can be reached before the research is commenced, then it is simply not possible to undertake the research involving that community, as some value gaps have proved impossible to overcome.

The NGO also learned that when the same organization is both conducting research and delivering aid in an area, biases can affect the voluntary informed consent of vulnerable participants, as well as the research design, data collection and interpretation, or the reporting of results. While power differences may be difficult or impossible to eliminate completely, steps can be taken to identify and minimize the most serious potential sources of bias, as long as thorough, transparent and culturally appropriate information has been given to participants.

Recommendations

- Carry out a thorough risk and benefit assessment involving community and participant representatives. Ethical approval should also be sought from the community, and community representatives should participate in the formal ethical review committee process.
- Beyond simply being asked for informed consent, communities should be trained and involved in the ethical approval process. Participants should be made aware of the limits of confidentiality and any duties the researchers have to report certain findings.
- Ensure effective ongoing communication (including with representatives of vulnerable subgroups). Communication mechanisms should not be dismantled after the departure of the research team from the data collection site, but must be maintained by local partners of the international researchers.
- Monitor and evaluate the process through which consent is negotiated with the community and obtained from participants.
- Participation in research should not be linked to receiving assistance, and researchers should make this very clear to participants to avoid any misunderstandings. In other words, if an assistance NGO operates in an area, it should be made clear that the benefits of assistance will be open to all, regardless of who, if anyone, works with the NGO on research.
- Further work is needed on how to approach unexpected findings that lead to fundamental conflicts of conscience for researchers. Data collection itself should be neutral. There should be a protocol in place regarding the consideration of and response to any unexpected findings.

Reference

WMA (2013) WMA Declaration of Helsinki: Ethical principles for medical research involving human subjects. World Medical Association. <http://jamanetwork.com/journals/jama/fullarticle/1760318>

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