Disaster Ethics: Issues for Researchers and Participants

Dónal P. O’Mathúna, PhD
Associate Professor
School of Nursing & Human Sciences
Dublin City University, Ireland
Director, Center for Disaster and Humanitarian Ethics
(http://www.ge2p2.org)
donal.omathuna@dcu.ie
T: @domathuna

http://disasterbioethics.eu
Disaster

“A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts.”

Effect may exceed local capacity requiring external assistance.

UN Office for Disaster Risk Reduction (UNISDR): https://www.unisdr.org/we/inform/terminology
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Complexities

- Natural disasters (e.g. floods, earthquakes, tsunamis)
- Technological disasters (e.g. industrial accidents, transport accidents)
- Conflict, terrorism
- Complex emergencies

Hurricane Katrina, 2005
“... the deaths caused by ‘natural’ disasters can often be attributed almost in their entirety to actions taken by people, which turned a natural process into a disaster. In that respect there is nothing ‘natural’ about them.”

— Robert S. White, *Who is To Blame?* 2014:19-20

- Poverty
- Pollution
- Corruption
- Conflict
Nothing new – Lisbon 1755

• The earthquake was an act of Nature,
• “but it was hardly Nature that had assembled there twenty thousand houses of six or seven stories. If the residents of this large city had been more evenly dispersed and less densely housed, the losses would have been fewer or perhaps none at all” (p. 331).

Conflict and Security
Moral Imperative

- Those in need deserve help.
- Those with the resources should help.
- How should we help?
- Good intentions are not enough.
Responding

• “We don’t really know which interventions are most effective in reducing risk, saving lives and rebuilding livelihoods after crises... At present, humanitarian decisions are often based on poor information” (DFID, p. 5).

http://www.alnap.org/resource/9823.aspx
“much of the existing operational research related to emergencies and disasters lacks consistency, is of poor reliability and validity and is of limited use for establishing baselines, defining standards, making comparisons or tracking trends” (p. 46).

• “The failure to generate and use evidence in policy and response makes humanitarian action less effective, less ethical and less accountable” (ALNAP, 2014, p. 5).

• It is “unethical to deliver interventions that are, at best not proven, are ineffective or, worse still, do actual harm” (DFID, 2012, p. 11).

http://www.alnap.org/resource/10441
Example: Surgery in Haiti (2010)

- Widely divergent amputation rates between surgical teams (from 1% to 45% of procedures conducted).
- Records often not kept.
- Allegations of “disaster tourism”.
- Led to retrospective studies, quantitative and qualitative.

O’Mathúna DP, Von Schreeb J. 
http://bit.ly/1z9NVgl

Photo: Johan Von Schreeb

https://icrc.aoeducation.org
• “Many practitioners consider research in disaster settings to be unethical. In addition to being perceived as taking away resources from humanitarian aid, there are concerns that research can be an imposition on those already suffering, and that it does not immediately help those being studied” (DFID, 2012, p. 11).
O’Mathúna DP. “The dual imperative in disaster research ethics”, in the SAGE Handbook of Qualitative Research Ethics, eds. Ron Iphofen and Martin Tolich (in press).
Research Ethics Frameworks


• Working Group on Disaster Research and Ethics (2011): [https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/](https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/)
Disaster research ethics received little attention before the 21st Century ...

“on the assumption that [disaster] research has very little potential for injuring the people and organizations that are studied and on the hope that it may ultimately actually do some good” (p. 6).

But then ...

- 2004 Indian Ocean Tsunami

- “they stole our stories”

- “unethical and potentially exploitative research”

- Not to mention, the unanticipated ethical challenges as well as the anticipated ones.
Is disaster research ethics distinctive?

- narrow windows of opportunity for research,
- multiple vulnerabilities,
- physical and psychological dangers,
- risks to participants and researchers,
- resource shortages,
- cross-cultural issues,
- political considerations,
- possible conflicts,
- Perfect ethical storm?
Qualitative Disaster Research Ethics

- Emphasis on interpersonal connections.
- Strength and ethical challenge
- “The often prolonged and personal interactions with those in the setting during field research create the possibility of myriad ethical questions, none of which are accompanied by easy solutions” (p. 15).
Multiple Vulnerabilities

- Vulnerable situations
- Pre-existing vulnerabilities
- Vulnerability to more harm, understood as involving much more than physical risks.
Advocacy Research

• “I cannot see any justification for conducting research into situations of extreme human suffering if one does not have the alleviation of suffering as an explicit objective of one’s research” (p. 96).
Balancing with Rigour

• “Qualitative research is not intrinsically more ethical or of better quality; an interview can be as unethical and poorly conceived as a bad questionnaire” (p. 315).
Benchmarks of Ethical Research

1. Collaborative partnership
2. Social value
3. Scientific validity
4. Fair selection of study population
5. Favorable risk-benefit ratio
6. Informed consent
7. Respect for recruited participants and study communities
8. Independent review


1. Collaborative Partnership

• Engage with local communities at all stages of research, from design to implementation to dissemination. Ethics does not begin with the research ethics (IRB) approval process.

• “The most appropriate decisions are likely to be made when ethical issues are thought about prior to starting research. Researchers are most likely to ‘do harm’ when they do not anticipate likely ethical challenges” (p. 13).
  

• Can be very difficult with disasters.
2. Social Value

• “The first and foremost obligation in acute disaster situations is to respond to the needs of those affected” (CIOMS, Guideline 20 Commentary).

• Responsible use of finite resources

• Starts with engagement with the local population.

• Harms are not justified if there is no social or scientific benefit.
3. Scientific Validity

- Is the study design appropriate to the research question?
- Is the study feasible given the disaster situation?
- Is sufficient funding available for all phases, including dissemination?
- Researcher training and support.
- “However, as is often the case in research, many of the ethical dilemmas and challenges were unexpected and faced only once the fieldwork had begun” (pp. 313).
4. Fair Subject Selection

- Participants should be chosen because of the aims of the research and its potential outcomes, not because of privilege, access, vulnerability, convenience, etc.
- Does the study need to be done in a disaster?
- Systematic review of disaster research ethics guidelines: vulnerability one of two core themes
- Are all appropriate groups included?
- Researchers “come in and just talk to the leaders and their wives—they never hear what it is really like in the camps”...; “We get no justice from the leaders, but they are the ones that UNHCR listen to” (p. 304).
5. Favorable Risk-benefit Ratio

- Risks relate to:
  - participant group
  - research methods (note psychosocial risks with qualitative research), and
  - research topic (especially social science topics).
  - AND researchers

- “If the research is determined to be of no benefit to the local population, then it should not be carried out” (p. s221).

- Principle of reciprocity and benefit sharing.

- Sets up other ethical challenges – e.g. providing direct benefits to participants and not the rest of the community.
6. Informed Consent

• “Ensure that ... the individual informed consent of participants is obtained even in a situation of duress, unless the conditions for a waiver of informed consent are met” (CIOMS, Guideline 20).

• Huge challenge: “When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce” (p. 234).

7. Respect for Participants and Communities

- Privacy and confidentiality must be protected.
- Participants have claimed researchers “stole our stories” (Pittaway et al., 2010).
- Requires careful engagement, e.g. Participant Action Research.
- “There is a conventional wisdom that ‘women do not talk about sexual abuse’. However, in camps and urban settings in five countries the researchers have found that by using this methodology, once trust is established and they have been involved in negotiating the process, the women are desperate to tell their stories and to share their experience’ (Mackensie et al., 2007: 314).
8. Independent Review

• Second core theme in systematic review of disaster research ethics guidelines:

• Researchers often have real and perceived conflicts of interests.
  – Humanitarian aid worker or researcher?
  – Duty to sending agency or survivors?
  – Association with military, political, commercial, religious goals.

• Slower review versus urgent window of research ‘opportunity.’

• “Health officials and research ethics committees should develop procedures to ensure appropriate, expedient and flexible mechanisms and procedures for ethical review and oversight” (CIOMS, Guideline 20).
Beyond Codes and Guidelines

• Codes and guidelines can undercut the “sense of personal accountability and, hence, of the importance of personal integrity”

• While informed consent is important, the most reliable safeguard to ethical research involving humans is:

• “the presence of an intelligent, informed, conscientious, compassionate, responsible investigator.”
• “the virtuous researcher”
  – ‘a focus on the internal ethical motivation of individual investigators, not only the rules and regulations that externally motivate investigators toward compliance’ (p. 32)

https://bioethicsarchive.georgetown.edu/pcsbi/node/558.html
• When researchers are tempted in some less than ethical direction, all they may have is their conscience, virtues and integrity.
  – O’Mathúna DP. “The dual imperative in disaster research ethics”, in the *SAGE Handbook of Qualitative Research Ethics*, eds. Ron Iphofen and Martin Tolich (in press).
Issues for research ethics governance

• Pre-approval of anticipated ethical issues is not enough.

• For committees:
  – Timely engagement
  – Flexibility
  – On-going interaction – both to monitor and support
  – Has resource implications

• For research teams:
  – Provide training in ethical decision-making
  – Provide field support
  – Engage in post-research reflection
  – Requires transparency

Beyond research ethics to research integrity

• Disaster research teams need to develop the skills to:
  – identify and reflect on ethical issues, including participants’ and their communities’ insights and concerns;
  – develop as virtuous researchers with high standards of integrity; and
  – learn lessons from post-research ethical analysis (www.preaportal.org/), again including listening to participants and their communities.
Further resources


- [http://DisasterBioethics.eu](http://DisasterBioethics.eu)

- [https://humanitarianhealthethics.net](https://humanitarianhealthethics.net)

- [https://BioethicsIreland.ie/disasters](https://BioethicsIreland.ie/disasters)

Thank You!
Comments or Questions? Stay connected:
donal.omathuna@dcu.ie and Twitter:
Personal: @domathuna   Disaster Bioethics network: @DisasterEthics
PREA project: @Ethics_Analysis   Interact project: @CrisTrans