Introduction
Case study
Problem solving
Wrap up

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Types of research being done during or after disasters

- Clinical trials in public health emergencies
- Nested qualitative studies
- Observational studies
- Secondary analysis of field data

Table 1 – Research Articles by Disaster Type

<table>
<thead>
<tr>
<th>Type of disaster</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Earthquake</td>
<td>369</td>
</tr>
<tr>
<td>Tsunami</td>
<td>110</td>
</tr>
<tr>
<td>Flooding</td>
<td>56</td>
</tr>
<tr>
<td>Typhoon/cyclone</td>
<td>18</td>
</tr>
<tr>
<td>Creeping disaster</td>
<td>19</td>
</tr>
<tr>
<td>Hurricane/Tropical Storm</td>
<td>13</td>
</tr>
<tr>
<td>Forest fire</td>
<td>3</td>
</tr>
<tr>
<td>Dust storm</td>
<td>3</td>
</tr>
<tr>
<td>Landslide</td>
<td>3</td>
</tr>
<tr>
<td>Tornado</td>
<td>2</td>
</tr>
<tr>
<td>Snowstorm</td>
<td>2</td>
</tr>
<tr>
<td>Comparison between disaster types</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>600</td>
</tr>
</tbody>
</table>

Table 2: Research Topics

<table>
<thead>
<tr>
<th>Research Topic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health, neurology and stress physiology</td>
<td>213</td>
</tr>
<tr>
<td>Traumatology, wounds and surgery</td>
<td>119</td>
</tr>
<tr>
<td>Preparedness, response, and health systems functioning</td>
<td>70</td>
</tr>
<tr>
<td>Communicable diseases and outbreaks</td>
<td>43</td>
</tr>
<tr>
<td>Epidemiology, demographics and mortality rates</td>
<td>40</td>
</tr>
<tr>
<td>Nutrition and food security</td>
<td>26</td>
</tr>
<tr>
<td>Social inequality and health</td>
<td>18</td>
</tr>
<tr>
<td>Obstetrics, neonatal and maternal health</td>
<td>10</td>
</tr>
<tr>
<td>Non-communicable and chronic diseases</td>
<td>9</td>
</tr>
<tr>
<td>Quality of life</td>
<td>8</td>
</tr>
<tr>
<td>Social and cultural considerations</td>
<td>8</td>
</tr>
<tr>
<td>Reproductive health, contraception and family planning</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Research Design

<table>
<thead>
<tr>
<th>Research Design</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross sectional (survey or questionnaire)</td>
<td>290</td>
</tr>
<tr>
<td>Chart review (secondary data)</td>
<td>102</td>
</tr>
<tr>
<td>Mixed methods</td>
<td>52</td>
</tr>
<tr>
<td>Qualitative (interviews or field notes)</td>
<td>49</td>
</tr>
<tr>
<td>Cohort (prospective or retrospective)</td>
<td>36</td>
</tr>
<tr>
<td>Experimental study design (clinical trial)</td>
<td>25</td>
</tr>
<tr>
<td>Case series (several case studies)</td>
<td>15</td>
</tr>
<tr>
<td>Case-control (matching)</td>
<td>12</td>
</tr>
<tr>
<td>Ecological (aggregated population data)</td>
<td>7</td>
</tr>
<tr>
<td>Uncertain</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>600</td>
</tr>
</tbody>
</table>

Realities of research in disaster

• Speed

• Precarious settings & vulnerable populations

• Access to resources

• Impact of disaster on meeting local requirements - partners

• Impact of research on the aims & work of EMTs

• Secondary use of field data for research

• Methodological hierarchy driving what research will be done

• Knowledge translation and knowledge mobilazation
Two resources

   *Plos One*
   http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0157142

• Dónal O'Mathúna (2015) Research ethics in the context of humanitarian emergencies. *Jrl of Evidence Based Medicine*
Research Ethics in Disasters and Public Health Emergencies
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and Dónal O’Mathúna
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http://disasterbioethics.eu
Definition

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
Number of Climate-related Disasters Around the World (1980-2011)

- Floods: 3455
- Storms: 2689
- Droughts: 470
- Extreme Temperatures: 395

Frequency
The Economic and Human Impact of Disasters* in the last 12 years

$1.3 TRILLION DAMAGE (USD)

2.7 BILLION AFFECTED

1.1 MILLION KILLED

*Data source: EMERGIS International Disaster Database

KEY DISASTER EVENTS:
- South Asia: July 2002
- Europe: Aug 2002
- Buns Ganiru: Dec 2003
- Kashmir: Oct 2005
- Sichuan: May 2008
- Haiti: Jan 2010
- Japan: March 2011
Responding

• “We don’t really know which interventions are most effective in reducing risk, saving lives and rebuilding livelihoods after crises... It is extremely difficult for practitioners to access information about good practice in order to improve their own effectiveness, because information is scattered and is not available in a consistent format” (DFID, 2012, 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
• “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).
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.


Photo: Johan Von Schreeb

https://icrc.aoeducation.org
Dual Imperative

Evidence

Ethics

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

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. Independent review
7. Informed consent
8. Respect for recruited participants and study communities

Case study

• Divide into small groups.
• Identify one person to take notes on the page provided and report back at the end to the whole room.
• Each group will be assigned one phase of the research to discuss.
• Read over the case study provided.
• Use the (DRAFT) R2HC Ethics Framework 2.0 to guide your discussion of the 3 questions.
• Keep track of the time!
• Please provide your feedback on the case study sheet or by email (donal.omathuna@dcu.ie).
• We would also like feedback on the usefulness (or otherwise) of the draft Ethics Framework.
Beyond Codes and Guidelines

• “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
• Researchers and research teams need to develop the skills to:
  – identify ethical issues,
  – reflect on ethical issues,
  – reach ethical decisions that can be defended.
• AND, become virtuous researchers with the highest standards of personal and research integrity.
• Training and assessment is challenging.
• When researchers are tempted in some less than ethical direction, all they may have is their conscience and their virtues.
  – 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).
Further resources

- A handout with various resources is available here.

- [https://humanitarianhealthethics.net](https://humanitarianhealthethics.net)
- [http://DisasterBioethics.eu](http://DisasterBioethics.eu)
- [https://BioethicsIreland.ie/disasters](https://BioethicsIreland.ie/disasters)

Thank You!
Research ethics oversight in disasters and public health emergencies

April 26, 2017
Disaster Research Ethics Study Team

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Cathy Tansey
Anushree Davé
Disaster research ethics project

1. Interviews with REC members
2. Interviews with researchers
3. Systematic mapping of disaster research

REC: Research Ethics Committee
What attributes characterize a research ethics committee (REC) that is well suited to review crisis research?

"to be nimble and responsive to the needs of the field, and still deliver high quality reviews, [in] a timely manner."

(Respondent affiliated with the REC of an international organization)
3 key characteristics of effective ethics review:

- Timeliness
- Responsiveness
- Rigorousness
Timely Review

Procedures are calibrated so that specific research protocols, based on the degree of temporal urgency, are reviewed promptly and are not unduly delayed.

“we are sensitive to that in the sense of trying to speed up the protocol’s process of review... because we understand that somebody needs to act rapidly.”

REC chair
Responsive Review

Sufficient awareness of and appreciation for the realities of conducting research in a disaster, and access to knowledge about the locale where the disaster has occurred.

“it is very difficult to, while we are reviewing, to understand the situation within that area”

Respondent from a country where a disaster occurred in a remote region
Rigorous Review

Provision of due scrutiny to ensure that reviews provide sufficient protections for individuals and communities participating in research, while ensuring independence of the review process.
Rigorous Review

- May need to resist “the pressure of urgency” to ensure due level of ethical scrutiny

- May need to resist “the pressure of politics” to ensure independence of the review process, e.g. a REC sought to “maintain their independence” and “to not politicize the committee.”
What next?

- Further research
- Ask your ethics board what they are doing to help
- Develop policies for enabling ethical research in your organization
- Enable local capacity development in research, ethics review
- Be open, honest, self-critical: who will benefit? Who could be harmed?
- Visit hhe & COSTaction Disaster Ethics websites – cases, toolkit, blogs
- Join HumEthNet community of practice
- Follow @HumEthNet, @DisasterBioethics, #WADEMethics
- Johan von Shreeb – follow up with planning meetings