Disaster Research: A (Sometimes Uneasy) Dance of IRBs and Researchers

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Key Questions

• What is Disaster Research (and is it different from other forms of research)?

• What are the critical questions for IRBs and for researchers?

• Are there “best practices” for Researcher – IRB relationships in Disaster Research?
  – A Case Study of the Deepwater Horizon oil spill

Is Disaster Research Unique?

• “... from a methodological viewpoint, disaster research is hardly distinguishable from the general sociological enterprise.” (D Mileti, 1987)

• “What makes disaster research unique is the circumstances in which otherwise conventional methods are employed. Put differently, it is the context of research not the methods that makes disaster research unique.” (R Stallings, 2002)
10 Critical Questions

- Where does research fall along disaster continuum?
- What are risks & benefits to research subjects?
- How ephemeral are the data?
- Can one obtain local support or endorsement?
- What is the nature of exposure to disaster or agent?
- How should informed consent be structured?
- Who are the research subjects?
- How vulnerable are the research populations?
- How should informed consent be structured?
- How to handle referrals for help?
- What are the logistics of the research operation?
How long is a “disaster population” still a disaster population?

- Forever (e.g., a survivor is always a survivor – a fixed individual characteristic)
- Depends on level of exposure to disaster?
  - Directly affected by disaster (WTC tenants)
  - Secondarily affected (lower Manhattan res)
- If one returns to Joplin MO in 10 years and interviews all residents, is it a disaster study?
How ephemeral are the data?

- Time-bound because of research interest
  - Study of responders and response systems (emergent norms, evolving organizational patterns, decision-making under stress)
- Time-bound because of population shifts
  - Need to sample or create registry / list
  - Displacement & evacuation making identification of "exposed" increasingly difficult
- Not time-bound

Who are the research subjects

1. Exposed populations
2. Public officials / other public agents
3. Providers and responders
   a. Formal vs. informal
4. Other affected or control populations

How vulnerable are the research subjects?

1. Pre-existing vulnerable population
   a. Based upon 45 CFR 46: children, prisoners, pregnant women
   b. Special protected classes: cognitively impaired, terminally ill, aged/elderly
2. “Insufficient power, intelligence, education, resources, strength or other needed attributes” to protect their own interests (Comment on Council of International Organizations of Medical Sciences 2002 guidelines)
• Vulnerability as a question of equity:
  – Are research subjects experiencing an undue burden because of their vulnerable status

• Vulnerability as a question of decisional competency
  – Has the disaster rendered those exposed as vulnerable because of presumed impairment to make informed decision

What are the risks & benefits?

1. Risks:
   a. Re-telling may trigger PTSD and other psychological/emotional disorders
   b. Research may be mistaken for therapeutic intervention
   c. Stigmatizing effect of disaster association

2. Benefits:
   a. Re-telling may help subject objectify and offer distance from traumatic event
   b. Opportunities to network with other people exposed to disaster (e.g., in focus groups)

Are there means to obtain local support or endorsement?

• Community-based participatory research
  – CBO’s, coalitions, survivor groups
• Local or state governments
• Local academic partners
• Local IRB
  – Oklahoma model – single IRB as per governor with authority to approve research
  – WTC or Katrina model – distributed to any IRB with jurisdiction over research team
Are there referral systems?

- Are local health and social welfare systems sufficiently intact to receive referrals and provide care?
- Are there alternate systems of care?
- Can research team directly provide any services?

What are the logistics of the particular disaster research?

- How quickly does the research team have to move in to the field?
- What risks will the research team be exposed to?
- How difficult will it be to recruit / train / mobilize a research field team?
- How can researcher address IRB issues rapidly enough to get in to the field?
Kaplan-Meier survival estimates

ChiSq test for equality = 36.69, p < .0000

Sense of disaster victimization among a cohort of Katrina evacuees – 4 years after the Hurricane

<table>
<thead>
<tr>
<th></th>
<th>Still think of myself as a victim</th>
<th>Never thought of myself as a victim</th>
<th>Used to think of myself as a victim</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL</strong></td>
<td>36.0%</td>
<td>17.6%</td>
<td>46.5%</td>
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<tr>
<td><strong>By Race</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Black</td>
<td>37.5</td>
<td>20.1</td>
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<tr>
<td>White</td>
<td>31.4</td>
<td>15.4</td>
<td>53.1</td>
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<tr>
<td><strong>By Household Income</strong></td>
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<tr>
<td>&lt;$20k annually</td>
<td>44.6</td>
<td>13.9</td>
<td>41.6</td>
</tr>
<tr>
<td>&gt;$20k annually</td>
<td>22.4</td>
<td>23.4</td>
<td>54.2</td>
</tr>
</tbody>
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Deepwater Horizon Oil Spill: A Case Study
Chronology

- April 20, 2010  Deepwater Horizon Explosion
- June 21, 2010  NCDP and The Children’s Health Fund conduct Town Hall meetings / focus groups in the Gulf
Chronology

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- July 14, 2010 Contact CUMC IRB re rapid protocol

Research

- Key research questions:
  - Exposure: What proportion of the population living within a 10-mile radius of the coastline had been directly exposed to the oil spill? Were some groups within that area more likely than others to be exposed?
  - Effects on Children: What were the immediate and perceived long-term physical and mental health effects of the oil spill on children and on adults? What economic effects of the oil spill have been felt by the coastal population?
Research II

- Decisions: How has the oil spill begun to shape decisions faced by coastal residents? This includes such daily decisions as where children can play or whether local seafood is safe to eat, as well as projected decisions about whether or not people think they will have to move.

- Trust: Which public officials are most trusted to provide accurate and reliable information, and who is perceived to have been most (or least) responsive to the oil spill crisis? Do coastal residents have a trusted source for health information about the effects of the oil spill?

Methodology

- Study period: July 19 - July 25, 2010
- Random digit dial (1,203 respondents)
  - Louisiana (481 Hh) and Mississippi (722 Hh)
  - Landline
  - Cell phone
- Oversampling of households with children (518)
- This sample is representative of the 398,380 adults and 148,989 children living in the sampled area
  - The dataset was weighted by state of residence, gender, race, income, and age to reflect the demographic distribution
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- July 16, 2010  IRB submitted + approved
- July 19 – 25, 2010 Data collected
- July 29, 2010  Final data set ready for analysis

Key Findings

- Over 40% of the population living within ten miles of the coast had experienced some direct exposure to the oil spill.
- Over 30% of parents reported that their children had experienced either physical symptoms or mental health distress as a consequence of the oil spill.
- One in five households has seen their income decrease as a result of the oil spill, and 8% have lost jobs.
- Only 5% of coastal residents reported having received any cash or gift cards from BP, although over 15% believe they may be eligible for compensation from BP for health consequences of the spill.

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- Aug 2, 2010  NY Times coverage