The Ethics and Practice of Conducting Qualitative Research with Potentially Vulnerable Populations

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Disaster-zone research needs a code of conduct

Mirela Resen [1] and Lotfi Peck [2]

1. INTRODUCTION

This article is about the potential for using stories as a strategy to improve interdisciplinary research. The main argument is that telling and hearing stories can help researchers in understanding the complexities of the research process. The authors suggest that stories can provide a common ground that helps researchers to share their experiences and insights. They believe that stories can also help in the consideration and communication of evidence, cross-disciplinary thinking, and transmission that goes beyond disciplinary boundaries.

Stories for Interdisciplinary Disaster Research Collaboration

Mirela Resen [1] and Lotfi Peck [2]

1. INTRODUCTION

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Beyond the IRB: An Ethical Toolkit for Long Term Disaster Research

Ethical Dilemmas

• University Institutional Review Boards (IRBs) require investigators to complete annual progress reports and to report any deviations from their protocols.

• Most institutions do not, however, require the reporting of “ethical dilemmas” — here defined as situations that raise moral or ethical concerns where there is no obvious, clear-cut resolution.
Ethical Landmines

• Potentially explosive moments in which a poor ethical choice may produce detrimental effects on:
  • Participants
  • Our relationships with participants
  • Research project as a whole
  • Our discipline or field
Ethical Toolkit

A strong, yet flexible framework comprising a basic set of moral concepts for researchers to draw from as they engage with an ethical dilemma or a landmine.
Categories of Concern

1. Shifting Vulnerability
2. Expectations
3. Reciprocity
Categories of Concern

1. Shifting Vulnerability
   - Individuals enter and exit vulnerable states over time
   - May build cumulatively
Ethical Dilemma 1: How to Manage Shifting Vulnerability (Kate)

- Four years post-Hurricane Katrina
- Interview with Potchie and Charles, two men in the large family Kate was studying
- Darlene, Potchie’s wife, overheard question about the men’s feelings about Katrina, its ongoing impacts, and whether to stay or leave
- Darlene interjected that she would leave if given the chance, but was overridden by the men, creating an uncomfortable tension
Ethical Dilemma 1: What Happened?

- Darlene’s emotional vulnerability not acknowledged or managed
- “Sense of mission” to interview Potchie and Charles, as primary research participants (and underrepresented male voices), placed above consideration for Darlene
- In supporting men’s positions (“It really is a special place”); Darlene may have felt “ganged up on”
- Reinforced gender/power dynamic
Ethical Dilemma 1: Reflections

- Recognize how vulnerability remains after a traumatic event
- Recognize obligations to peripheral members of research projects
- Balance positions and obligations when there is conflict
Categories of Concern

1. Shifting Vulnerability
   • Individuals enter and exit vulnerable states over time
   • May build cumulatively

2. Expectations
   • Attention to participants may create expectations of researchers
   • May lose trust, withdraw, or experience emotional harm
Ethical Dilemma 4: Fulfilling Expectations and Promises (Lori)

- Two years post-Hurricane Katrina
- Difficulty locating interviewees who had relocated to Colorado
- Mekana, 18 years old, good contact for recruiting larger sample, unemployed and in “desperate need” of money
- Miscommunication about $50/family vs. $50/person
Ethical Dilemma 4: **What Happened?**

- Genuine desire to “do good” and express gratitude, but misalignment of expectations
- Unwilling to risk relationship and further contacts
- Paid Mekana what she had understood to be the correct amount
Ethical Dilemma 4: Reflections

- Duty to keep promises even in the face of miscommunication
- Make promises and commitments more explicit (e.g., a brief written contract)
- Recognize power differential when considering what is fair and feasible
- Recognize social location of the researcher (Lori was in a position to actually pay Mekana – what if she wouldn’t have had the funds in her bank account?)
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3. Reciprocity
   • Difficulty deciding the appropriate amount to give back
Ethics in Human Research

- Evolution of ethical codes in response to
  - Nazi scientists and human rights violations
  - Tuskegee Syphilis Study
  - Other “ethical failures”
    - participant coercion; misrepresentation; risk; lack of benefits
- Belmont Report (1978)
- Institutional Review Boards (IRB) (NOT in every country)
Now Available

- Social Vulnerability and Disasters
- Disaster Mental Health
- Cultural Competence in Hazards and Disaster Research

★ Free!
★ Online
★ 30-60 minutes to complete

Coming Soon

- Conducting Emotionally Challenging Research
- Institutional Review Board (IRB) Procedures for Hazards and Disaster Researchers
- Broader Ethical Considerations for Hazards and Disaster Researchers
- Social Science Methods and Approaches for Hazards and Disaster Research
Ethics in Human Research

• Approaches
  • Utilitarian
  • Kantian
  • W.D. Ross
Utilitarian Theory

- Jeremy Bentham (1748-1832); John Stuart Mill (1806-1873)
- Based on outcomes of one’s actions
  - Most “good”
  - Least “bad”

A moral act is one that results in the most benefits for the most people.
Kantian Theory

- Immanuel Kant (1724-1804)
- Based on sense of duty to universal moral law
- Categorical Imperative
  - Humanity Formula: Treat people as ends in and of themselves
  - Autonomy Formula: Respect individuals’ dignity and rational will

A moral act is one that is a product of duty and reasoned moral good.
Principles of IRB: A combination of Utilitarian and Kantian Theories

- **Respect for Persons**
  - Recognize individuals’ dignity and autonomy
  - Voluntary, informed consent

- **Beneficence**
  - Protect participants from harm
  - Minimize risk, maximize benefits of research

- **Justice**
  - Fair selection of participants
  - Fair distribution of the research’s risks and benefits
IRB Requirements

• Concerned with initial stages of research
• How will researchers
  • Gain access to participants?
  • Recruit and interview participants?
  • Obtain informed consent?
  • Protect vulnerable populations?
Beyond the IRB

- Ethical dilemmas arising during longer-term ethnographic research
- May stem from:
  - Competing interests among those involved in the research
  - Misunderstandings
  - Promises that can no longer be kept
Beyond the IRB

- Ethical dilemmas arising during longer-term research
- May stem from:
  - Competing interests among those involved in the research
  - Misunderstandings
  - Promises that can no longer be kept
  - *Conflicts between Utilitarian and Kantian ethics*
IRB Violations vs. Ethical Landmines
Ethical clarity achieved through reliance on IRB; relaxing ethical radar after IRB approval is gained

Ethical clarity achieved through deliberate research design and shared research decisions with participants
Ethical clarity achieved through reliance on IRB; relaxing ethical radar after IRB approval is gained.

Ethical uncertainty arises in course of research; researcher acutely aware of their moral responsibilities to participants.

Ethical clarity achieved through deliberate research design and shared research decisions with participants.
Ethical Toolkit

A strong, yet flexible framework comprising a basic set of moral concepts for researchers to draw from as they engage with an ethical dilemma or a landmine.
Developing an Ethical Toolkit

• Not one right decision, but a chance to make a better decision
• Living part of ourselves
  • Must exercise to strengthen
• No two identical toolkits
  • Gains conceptual (and contextual) relevance in our own work
The Right and the Good

• W. D. Ross (1877-1971)

• **Pluralist** list of moral considerations
  • Not hierarchical
  • Offers flexibility and clarity through considering the relative importance of each ethical concern
  • Gives careful consideration to contextual factors
Be kind to others; try to improve their health, wisdom, security, happiness, and well-being.
Strive to improve our own health, wisdom, security, happiness, and well-being
Make amends when we have wronged another person
Be grateful to others when they assist us; try to return the favor.
Keep promises, be honest, and be truthful.
Refrain from hurting others, physically and psychologically
Be fair; distribute benefits and burdens equitably and equally
Categories of Concern

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Ethical Dilemma 5: Reciprocity (Kate)

• Four years after Hurricane Katrina
• Katie, central character in documentary film, received dramatically lower flood insurance compensation than her sisters
• Kate provided funding and recruited volunteers to build a porch for Katie’s new home
• Backlash from a family member
Ethical Dilemma 5: *What Happened?*

- Family members perceived unjust compensation = harm to relationship with researcher
- Could cause damage to relationship between sisters
- “Justice” outweighed other moral considerations
Ethical Dilemma 5: Reflections

- Don’t assume your actions will be perceived as just
- Consider ripple effects throughout the extended network of participants
- Talk through the situation with other participants who may participate in deciding what is fair and right (rather than making assumptions)
Applying Ross’ Framework

- Consider the landmine or the dilemma
- Carefully weigh the list of ethical considerations
- Identify those that are at work in your situation
- Decide which you will honor as the most important
  - *Remember: Not all situations will honor the same considerations!*
Thank you!

Any questions?
Comment

Disaster-zone research needs a code of conduct

Understanding and Lessening

A trestle collapse, an earthquake, volcanic eruption, drug-resistant pathogen, or terrorist threat are examples of why we need a code of conduct for disaster research. Such codes are intended to convey agreement on certain values, norms, or principles. Many codes of conduct are written for research in other domains, such as medical research, military research, and anthropological research. These codes are used to provide guidance on what constitutes ethical research and to encourage and discourage certain behaviors.

In the context of disaster research, a code of conduct could be used to establish guidelines for the conduct of research in response to disasters. These guidelines could cover issues such as the use of research findings, the protection of research participants, and the sharing of research data.

We propose that a code of conduct for disaster research would be beneficial in several ways. First, it would provide a common framework for researchers working in different disaster zones. This would help to ensure that research is conducted in a consistent and ethical manner. Second, a code of conduct would help to build trust between research participants and researchers. This is especially important in disaster zones, where trust can be difficult to establish.

Another important aspect of a code of conduct is the promotion of transparency and accountability. By establishing clear guidelines for research, a code of conduct can help to prevent research from being used in ways that could cause harm.

In conclusion, a code of conduct for disaster research would be a valuable tool for ensuring the ethical conduct of research in disaster zones. It would provide a common framework for researchers, help to build trust between research participants and researchers, and promote transparency and accountability.

Perspective

Stories for Interdisciplinary Disaster Research Collaboration

Mika Mixtir and Lori Peth

Introduction

Disaster research is inherently interdisciplinary, requiring the integration of knowledge and skills from various fields. This complexity is echoed in the diverse range of participants involved in disaster research, including researchers, practitioners, policymakers, and community members. The challenge lies in how to effectively communicate and mobilize these diverse perspectives to advance our understanding of disaster phenomena.

In this perspective, we propose the use of stories as a narrative strategy to bridge the gaps between disciplines. Stories have the power to evoke emotions, engage the audience, and convey complex ideas in a relatable and accessible manner. By sharing stories, we can foster a deeper understanding of the human experiences surrounding disasters and inspire collaborative action.

We define disaster stories as narratives that capture the experiences of individuals, communities, or organizations affected by disasters. These stories often highlight the resilience, adaptability, and ingenuity of those impacted by disaster events. They also expose the vulnerabilities and challenges faced by those in the disaster zone, thereby raising awareness and stimulating dialogue.

Incorporating stories into the research process allows us to capture the subjective experiences of disaster survivors, which can inform and enrich our understanding of the disaster phenomena. Through narratives, we can gain insights into the emotional and social dimensions of disasters, offering a more nuanced perspective than quantitative data analysis alone.

To effectively utilize stories in disaster research, it is essential to consider the following:

1. **Engagement**: Stories should be designed to engage a diverse audience, including researchers, policymakers, practitioners, and community members. By tailoring the stories to resonate with these different stakeholders, we can facilitate a more inclusive and collaborative approach to disaster research.

2. **Authenticity**: To ensure credibility, stories should be based on genuine experiences. This can be achieved through collaborating with local communities and ensuring that the narratives accurately reflect the perspectives of those affected by disasters.

3. **Consistency**: A consistent approach to storytelling is crucial for effective communication. Establishing a narrative structure or framework can help to guide the collection, analysis, and dissemination of stories, ensuring coherence and relevance.

4. **Feedback**: Incorporating feedback from participants is vital to refine and improve the storytelling process. This not only enhances the quality of the narratives but also strengthens the trust and collaboration between researchers and stakeholders.

By leveraging stories as a communication tool, we can break down disciplinary boundaries and foster a more integrated and empathetic approach to disaster research. This approach not only enriches our understanding of disasters but also empowers communities to take ownership of their recovery and resilience strategies.