

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


Lori Peek, Ph.D.

Professor, Department of Sociology and Director, Natural Hazards Center
University of Colorado Boulder

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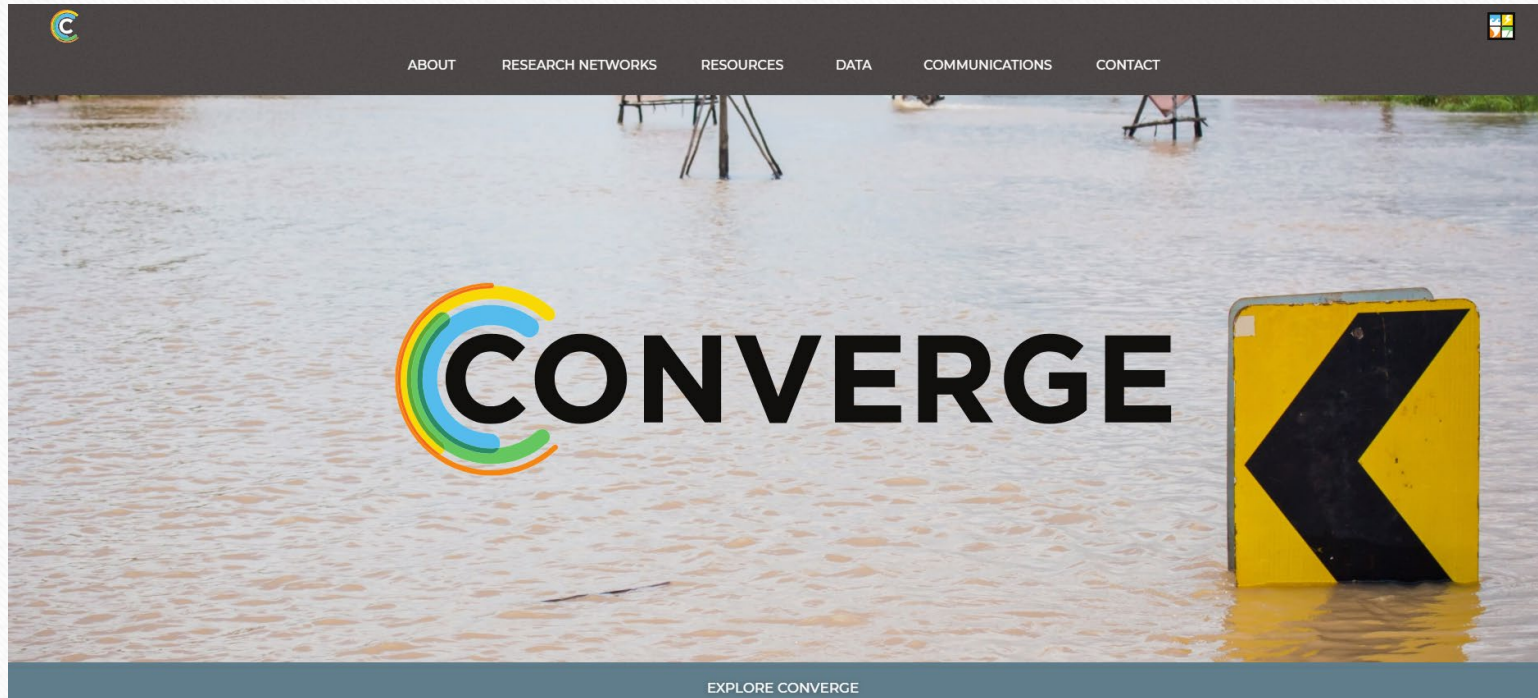


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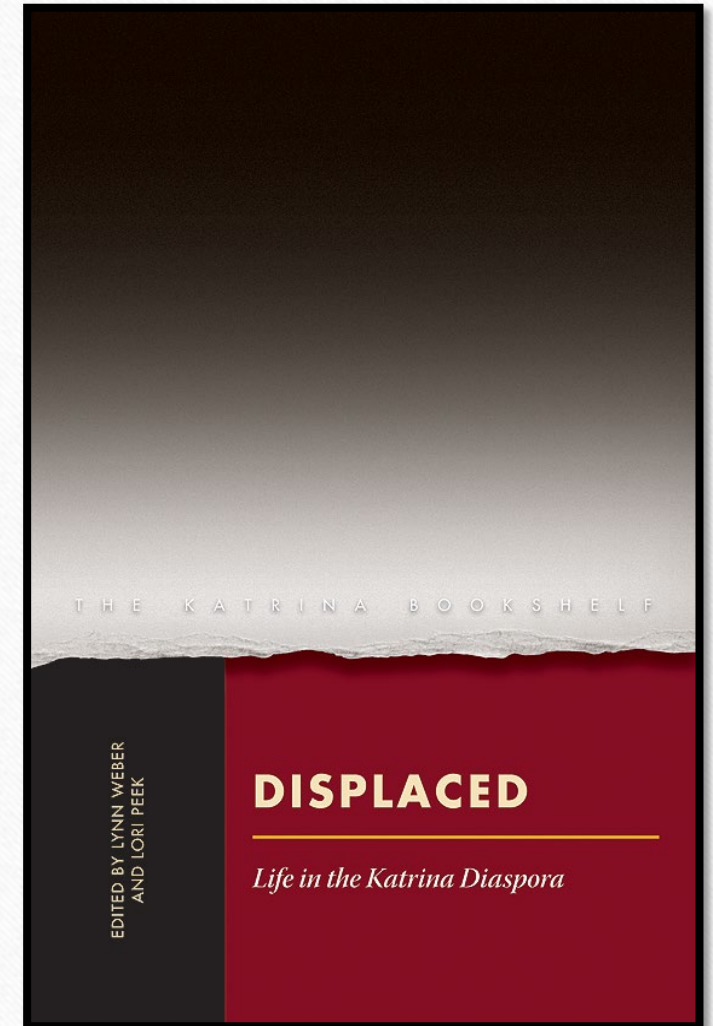
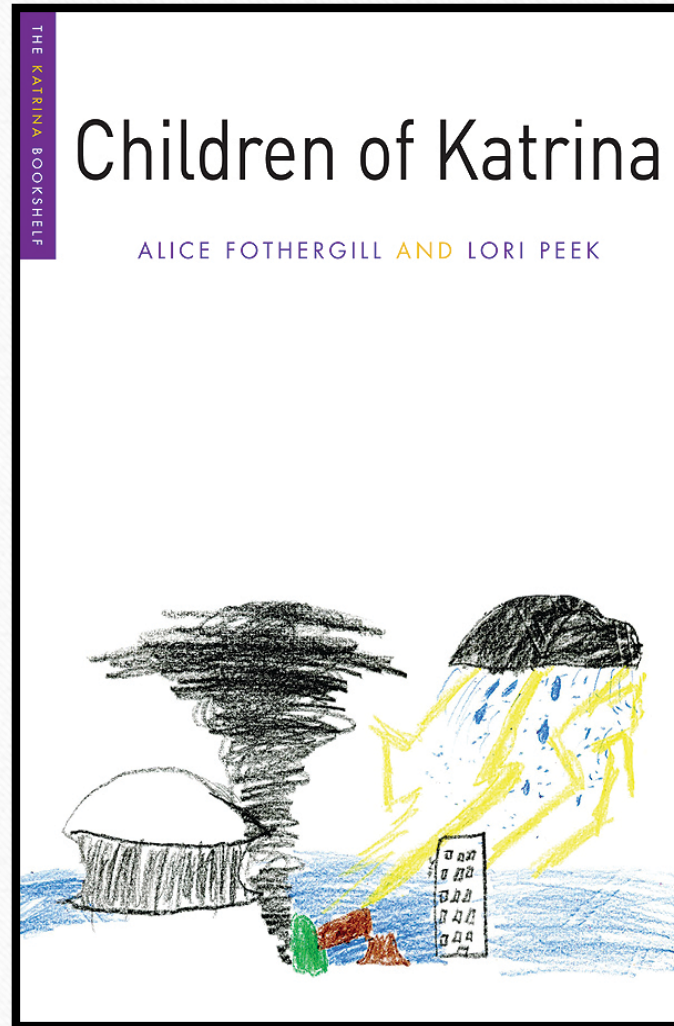
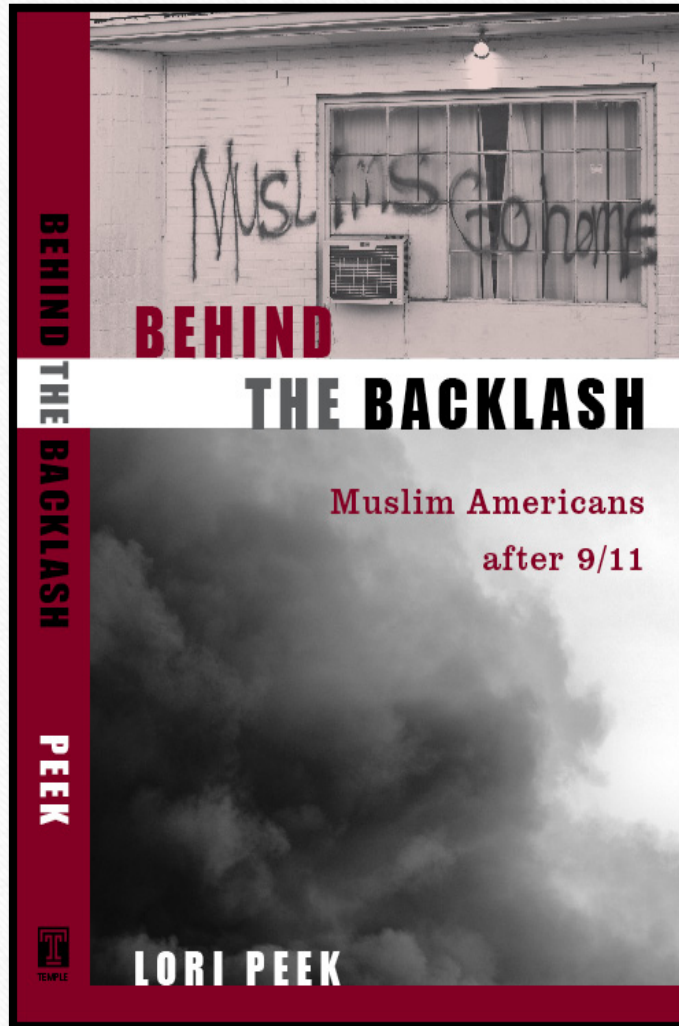


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Comment



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Disaster-zone research needs a code of conduct

JC Gaillard & Lori Peek

Study the effects of earthquakes, floods and other natural hazards with sensitivity to ethical dilemmas and power imbalances.

A magnitude 7.0 earthquake rocked Anchorage, Alaska, in late November 2018. Roads buckled and chimneys tumbled from rooftops. Business operations were disrupted. Schools were damaged across the district. This was the largest earthquake to shake the region in a generation, and there was much to learn. What was the state of the infrastructure? Might further quakes occur? How did people respond? Teams of scientists and engineers from across the United States mobilized to conduct field reconnaissance in partnership with local researchers and practitioners. These efforts were coordinated through the clearing house set up by the Earthquake Engineering Research

Institute in Oakland, California, which provided daily in-person and online briefings, as well as a web portal for sharing data.

But researchers are not always so welcome in disaster zones. After the deadly Indian Ocean earthquake and tsunami on 26 December 2004, hundreds of academics from countries including Japan, Russia, France and the United States rushed to the region to collect perishable data. This influx of foreign scientists angered and fatigued some locals; many declined researchers' requests for interviews. The former governor of Aceh province, Indonesia, where more than 128,000 people died, described foreign researchers as "guerrillas applying hit-and-run tactics".

Perspective

Stories for Interdisciplinary Disaster Research Collaboration

Mithra Moezzi^{1,*} and Lori Peek²

What if we used the stories that researchers and practitioners tell each other as tools to advance interdisciplinary disaster research? This article hypothesizes that doing so could foster a new mode of collaborative learning and discovery. People, including researchers, regularly tell stories to relate "what happened" based on their experience, often in ways that augment or contradict existing understandings. These stories provide naturalistic descriptions of context, complexity, and dynamic relationships in ways that formal theories, static data, and interpretations of findings can miss. They often do so memorably and engagingly, which makes them beneficial to researchers across disciplines and allows them to be integrated into their own work. Seeking out, actively inviting, sharing, and discussing these stories in interdisciplinary teams that have developed a strong sense of trust can therefore provide partial escape from discipline-specific reasoning and frameworks that are so often unconsciously employed. To develop and test this possibility, this article argues that the diverse and rapidly growing hazards and disaster field needs to incorporate a basic theoretical understanding of stories, building from folkloristics and other sources. It would also need strategies to draw out and build from stories in suitable interdisciplinary research forums and, in turn, to find ways to incorporate the discussions that emanate from stories into ongoing analyses, interpretations, and future lines of interdisciplinary inquiry.

KEY WORDS: Experience stories; folkloristics; hazards and disasters; interdisciplinary methods; storytelling

1. INTRODUCTION

This article is about the potential for using stories as a strategy to improve interdisciplinary hazards and disaster research. The main argument is that telling and paying attention to what we refer to as *experience stories* among research team members can provide a common ground that helps overcome disciplinary and institutional forces that might inhibit the consideration and communication of evidence, open-minded thinking, and translations that span disciplines and scholarly domains.

We define experience stories as stories that individuals tell about something that happened during the research process, generally combining descriptive observation, some level of interpretation, and embellishment. These can be first, second, or *n*th hand. They are usually oral and that is the form addressed here. These types of stories often do not make their way into formal published research accounts; however, because they can—and do—inform the trajectory of interdisciplinary research projects, we take their power and potential seriously.

Experience stories provide a naturalistic frame from which to view and make sense of the microincidents that constitute larger conditions or events. An experience story is a product of the teller but tends to have a character that is less processed, more alive, and more ambiguous than formal institutionalized or highly disciplinary accounts. Its liveliness provides

¹QQForward, San Rafael, CA, USA.

²Department of Sociology, University of Colorado, Boulder, CO, USA.

*Address correspondence to Mithra Moezzi, QQForward, San Rafael, CA, USA; mmoezzi@qqforward.com.

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

Katherine E. Browne
Department of Anthropology
Center for Disaster and Risk Analysis
Colorado State University

and

Lori Peek
Department of Sociology
Center for Disaster and Risk Analysis
Colorado State University

Email: kate.browne@colostate.edu

*This article argues for expanding the ethical frame of concern in disaster research from the early phases of site access to longer-term issues that may arise in the field. Drawing on ethical theory, these arguments are developed in five sections. First, we identify the philosophical roots of ethical principles used in social science research. Second, we discuss how ethical concerns span the entire lifecycle of disaster-related research projects but are not fully addressed in the initial protocols for gaining Institutional Research Board (IRB) approval. Third, we introduce the idea of the philosophically informed "ethical toolkit," established to help build awareness of moral obligations and to provide ways to navigate ethical confusion to reach sound research decisions. Specifically, we use the work of W. D. Ross to introduce a template of moral considerations that include **fidelity, reparation, gratitude, justice, beneficence, self-improvement, and non-maleficence**. We suggest that in the absence of a clear framework that researchers can use to think through ethical dilemmas as they arise, Ross' pluralist approach to ethical problem solving offers flexibility and clarity and, at the same time, leaves space to apply our own understanding of the context in question. Fourth, we draw on six examples from our research studies conducted following Hurricane Katrina. Using these examples, we discuss how, in retrospect, we can apply Ross' moral considerations to the ethical issues raised including: (1) shifting vulnerability among disaster survivors, (2) the expectations of participants, and (3) concerns about reciprocity in long-term*

Browne, Katherine E. and Lori Peek. 2014. "Beyond the IRB: An Ethical Toolkit for Long-term Disaster Research." *International Journal of Mass Emergencies and Disasters* 32(1): 82-120.

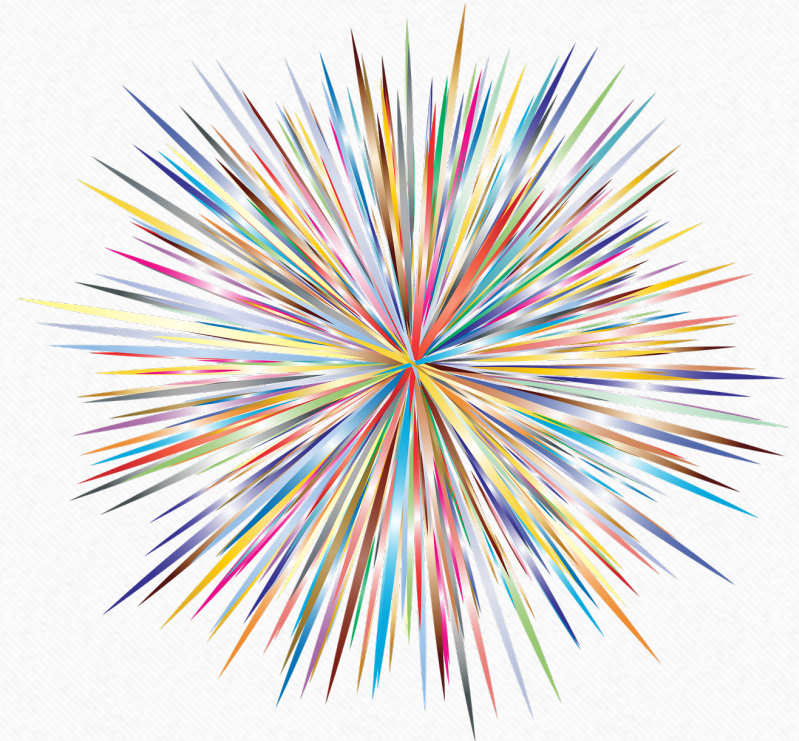
Ethical Dilemmas

- 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
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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?)

Categories of Concern

1. Shifting vulnerability

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2. Expectations

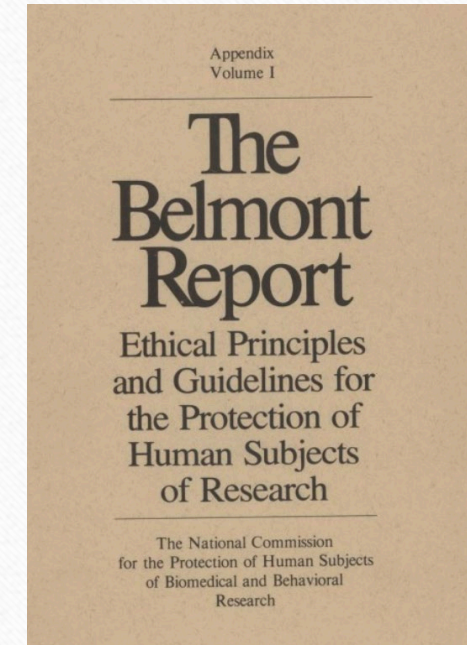
- Attention to participants may create expectations of researchers
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3. Reciprocity

- 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)



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**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?



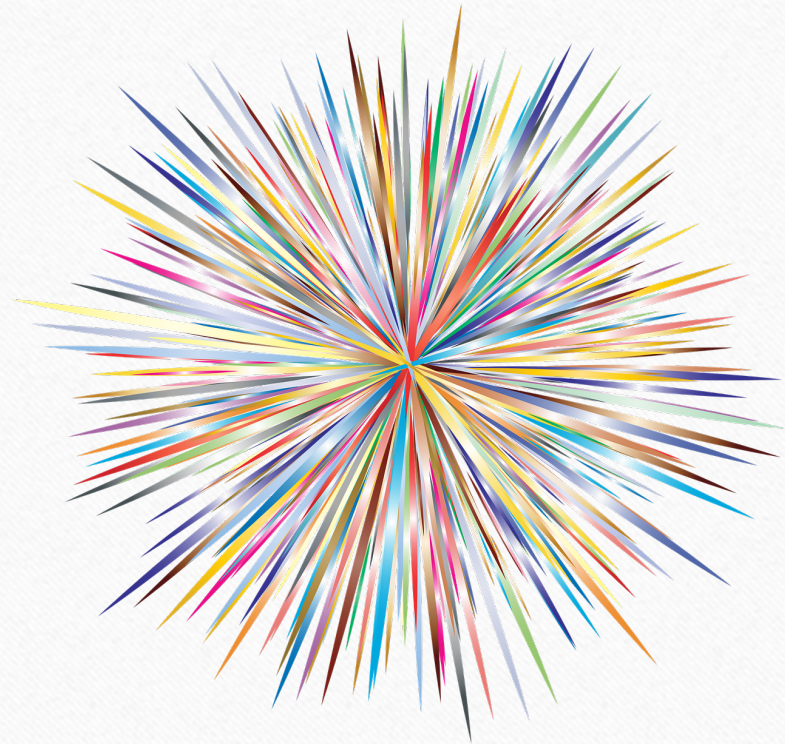
Beyond the IRB

- 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



Ethics-as-IRB

?

Ethics-as-All

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



Ethics-as-IRB

Ethical clarity achieved through reliance on IRB; relaxing ethical radar after IRB approval is gained

Ethics in Practice

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

Ethics-as-All

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

Ethical Toolkit



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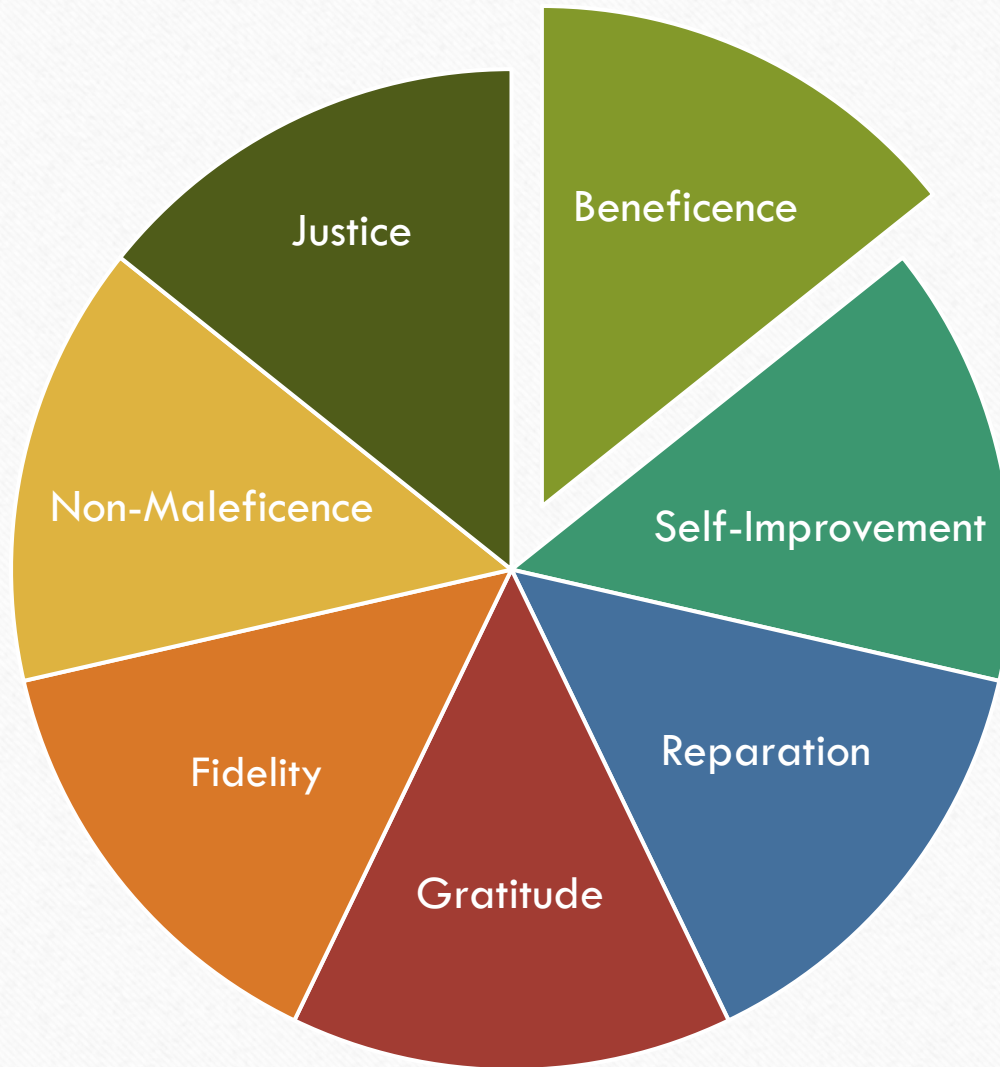
Developing an Ethical Toolkit

- 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

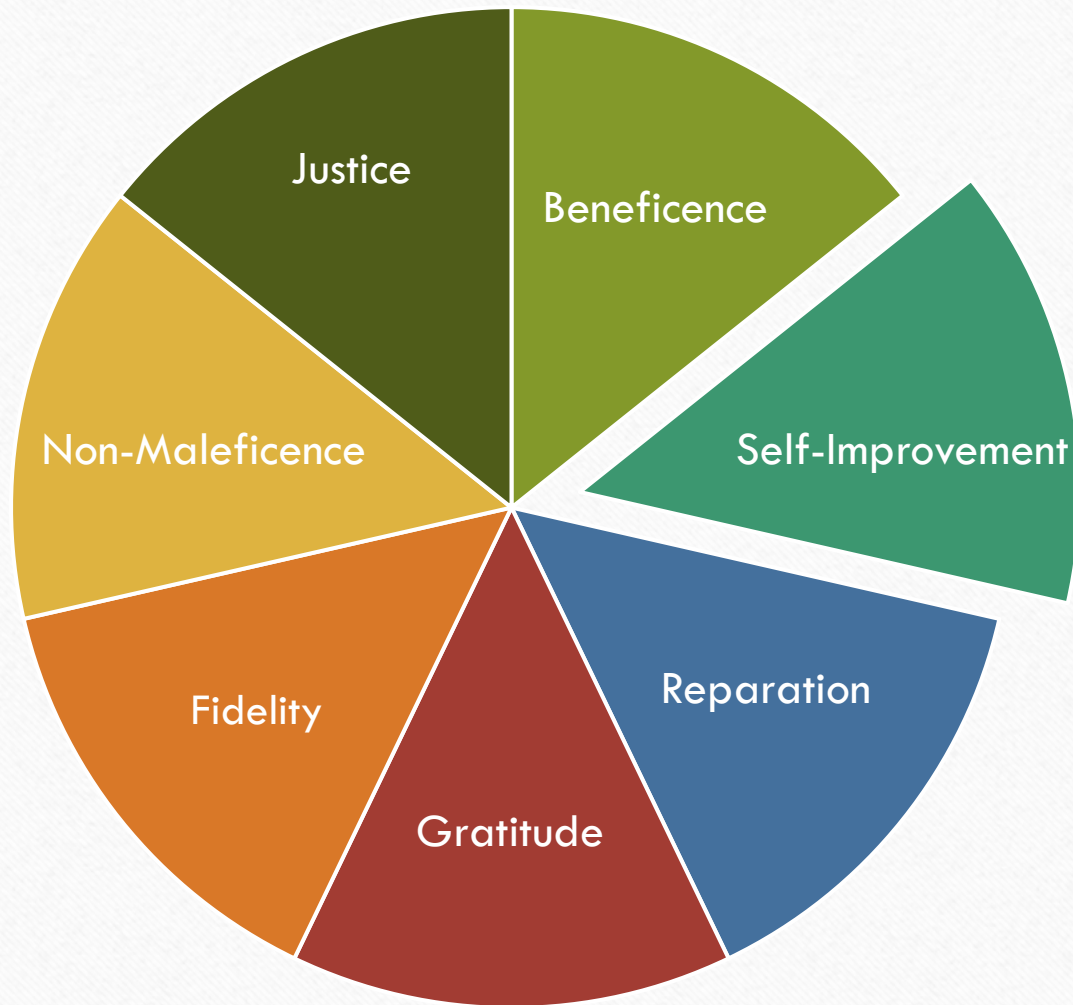
The Right and the Good

- 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

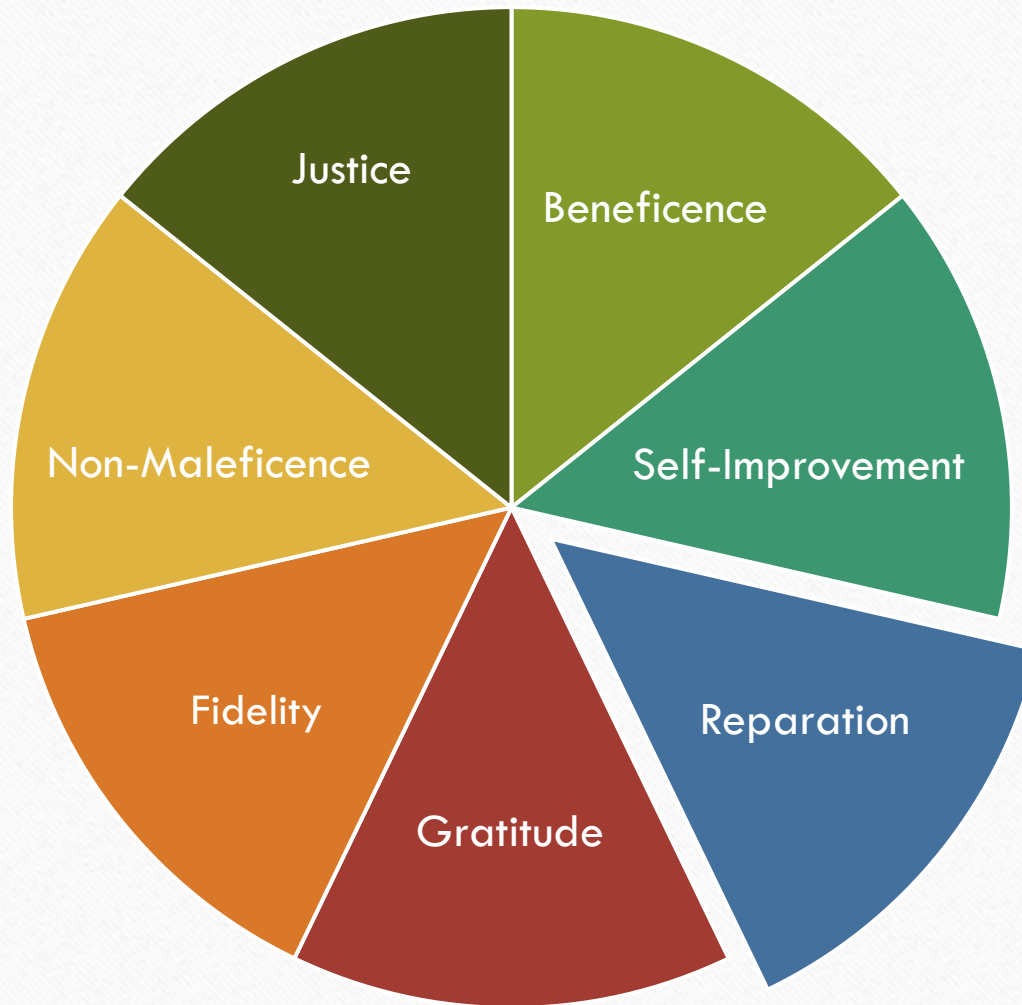




**Be kind to others; try
to improve their
health, wisdom,
security, happiness,
and well-being**



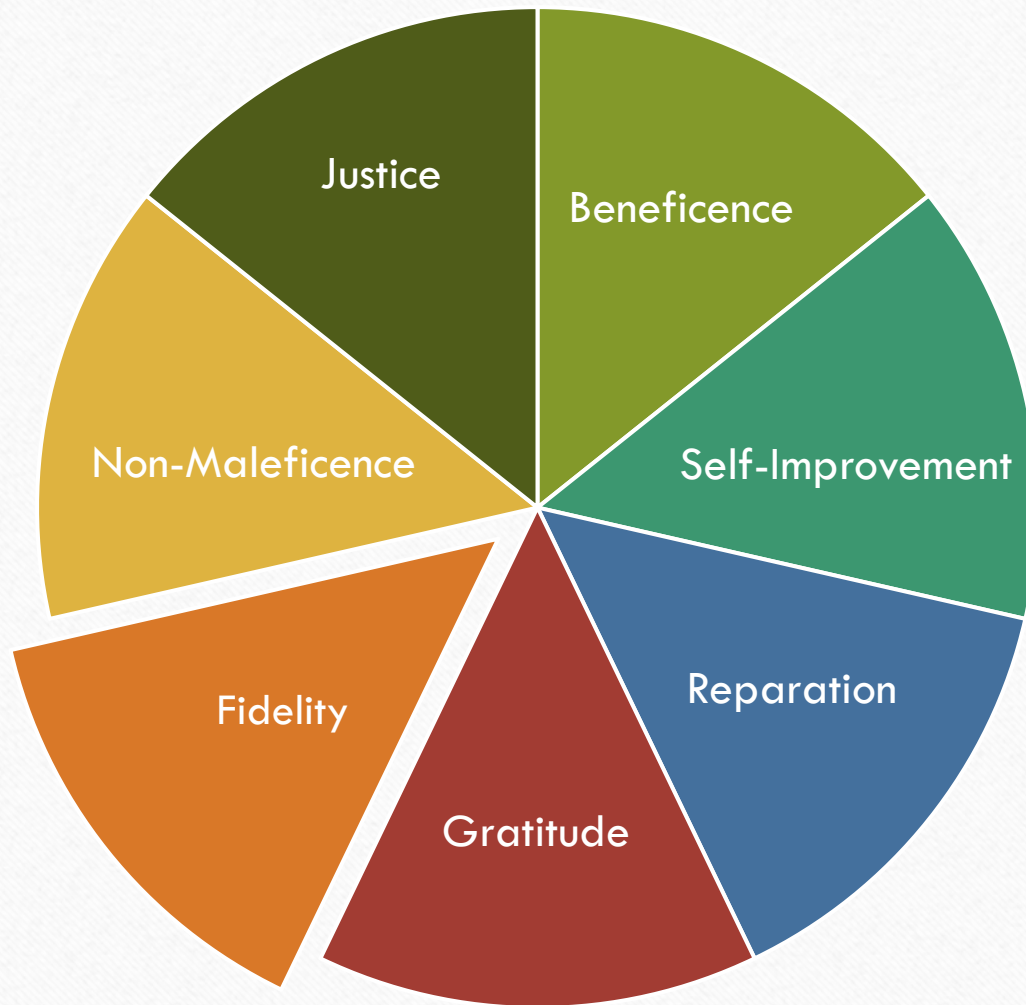
**Strive to improve
our own health,
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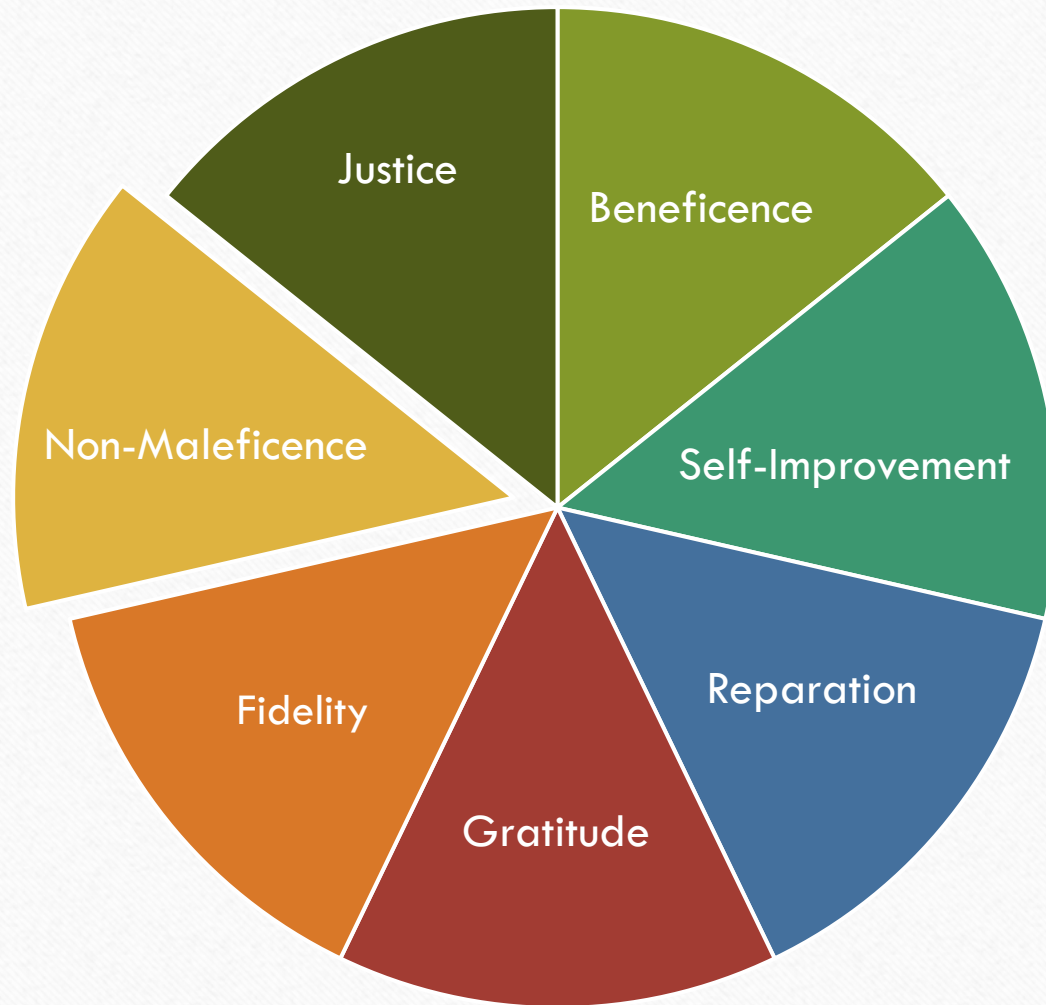
**Make amends when
we have wronged
another person**



**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**

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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



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Stories for Interdisciplinary Disaster Research Collaboration

Mithra Moezzi^{1*} and Lori Peek²

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