

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

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

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*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*

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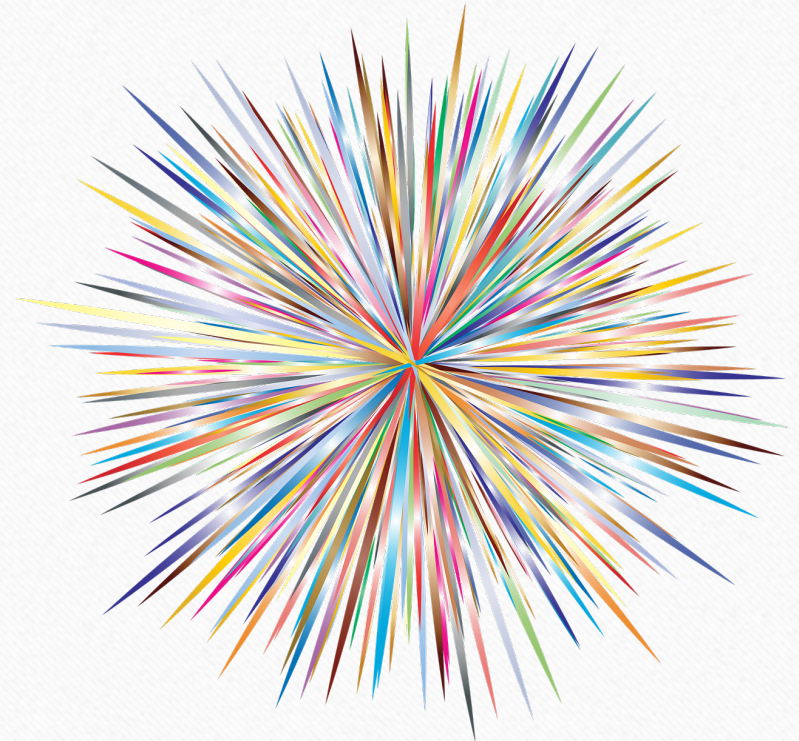
Ethical Dilemmas

- University IRB's 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



Categories of Concern

- **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

- Shifting vulnerability
 - Individuals enter and exit vulnerable states over time
 - May build cumulatively
- **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?*

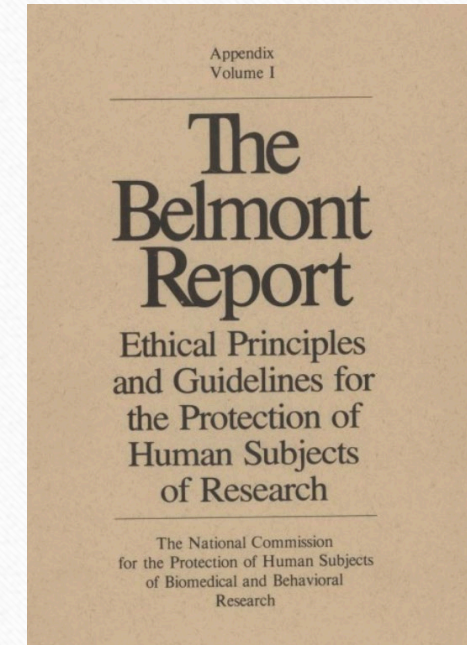
- Genuine desire to “do good” and express gratitude, but misalignment of expectations
- Unwilling to risk relationship and further contacts
- Paid Mekana what she had understood to be the correct amount

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?)

Ethics in Human Research

- Evolution of ethical codes in response to
 - Nazi scientists
 - Tuskegee Syphilis Study
 - Other “ethical failures”
 - Coercion; misrepresentation; risk; lack of benefits
- Belmont Report (1978)
- Institutional Review Boards (IRB) (NOT in every country)



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?



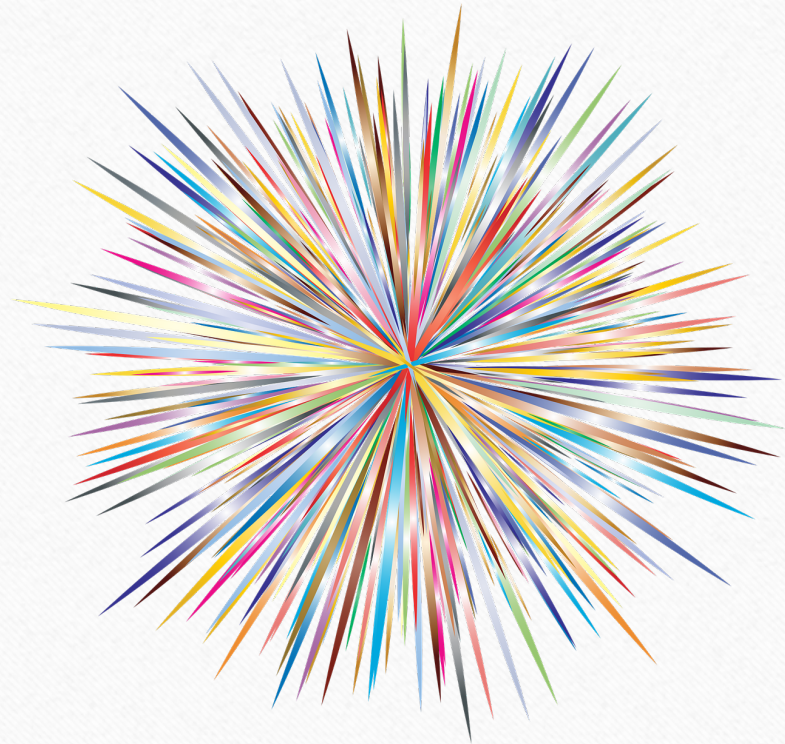
Beyond the IRB

- 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

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- 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 embedded in IRB***

IRB Violations vs. Ethical Landmines



Categories of Concern

- **Shifting vulnerability**
 - Individuals enter and exit vulnerable states over time
 - May build cumulatively
- **Expectations**
 - Attention to participants may create expectations of researchers
 - May lose trust, withdraw, or experience emotional harm
- **Reciprocity**
 - Difficulty deciding the appropriate amount to give back

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

Ethical Dilemma 6: Reciprocity (Lori)

- Ongoing study for seven years post-Hurricane Katrina
- Children and their families do not know each other
- Helping some of poorest families with food, clothing, school supplies, etc.
- Middle- and upper-class families did not face same need

Ethical Dilemma 5: *What Happened?*

- Is it “fair” to give gifts to only certain participants, even if they are hidden to others?
- Is it a violation of IRB protocol regarding compensation?
- Is it a moral and ethical violation to not help those in need?

Ethical Dilemma 5: *Reflections*

- No changes to actions (should we have contacted the IRB, though?)
- Upheld obligations to participants while avoiding doing harm to other participants

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



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

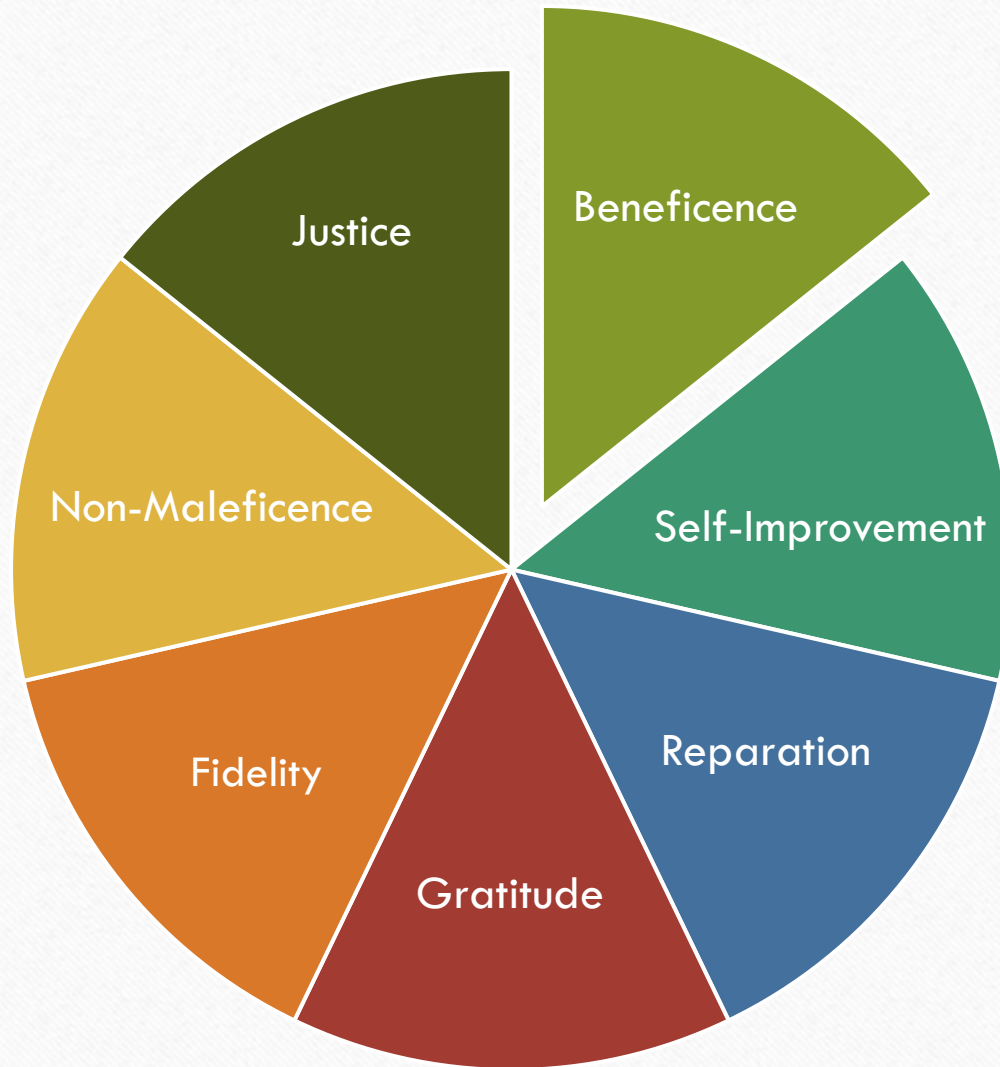
Developing an Ethical Toolkit

- 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 relevance in our own work

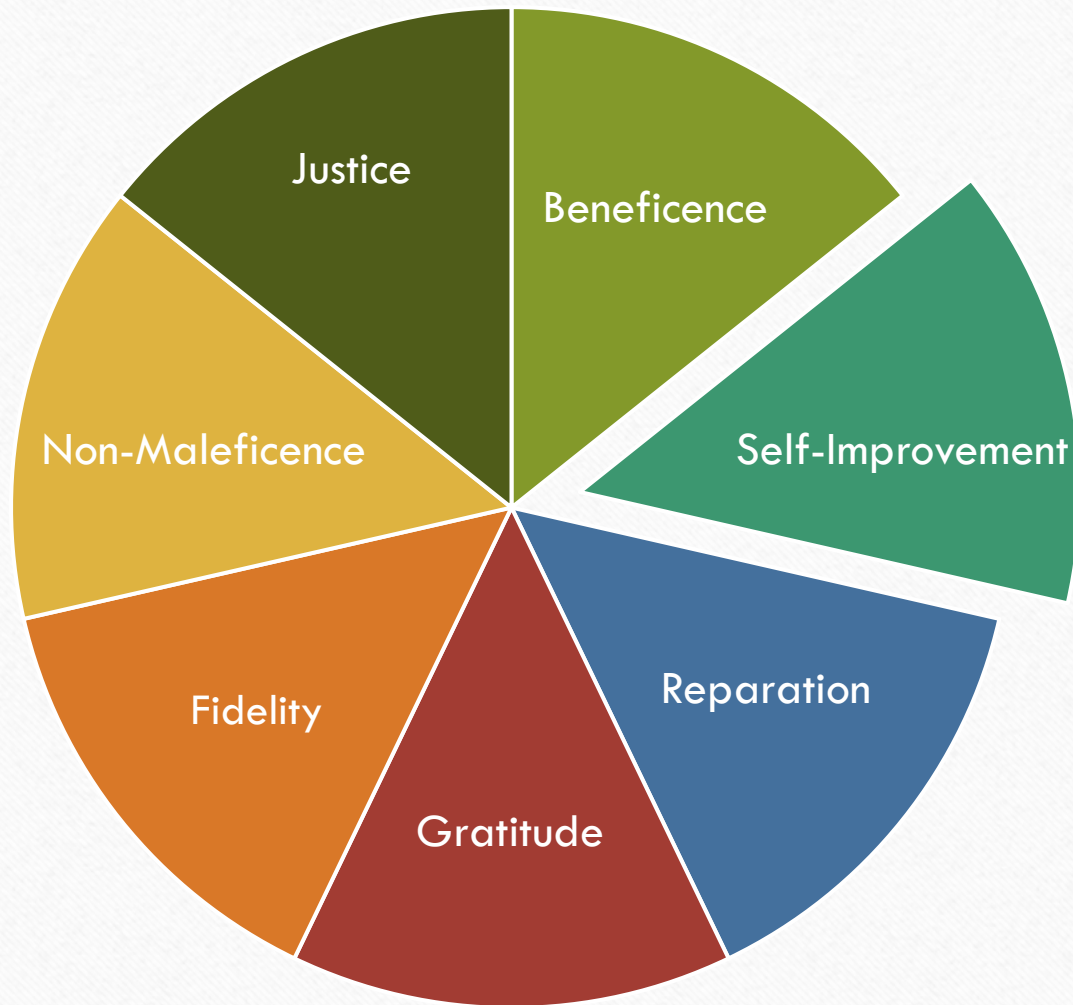
The Right and the Good

- 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**



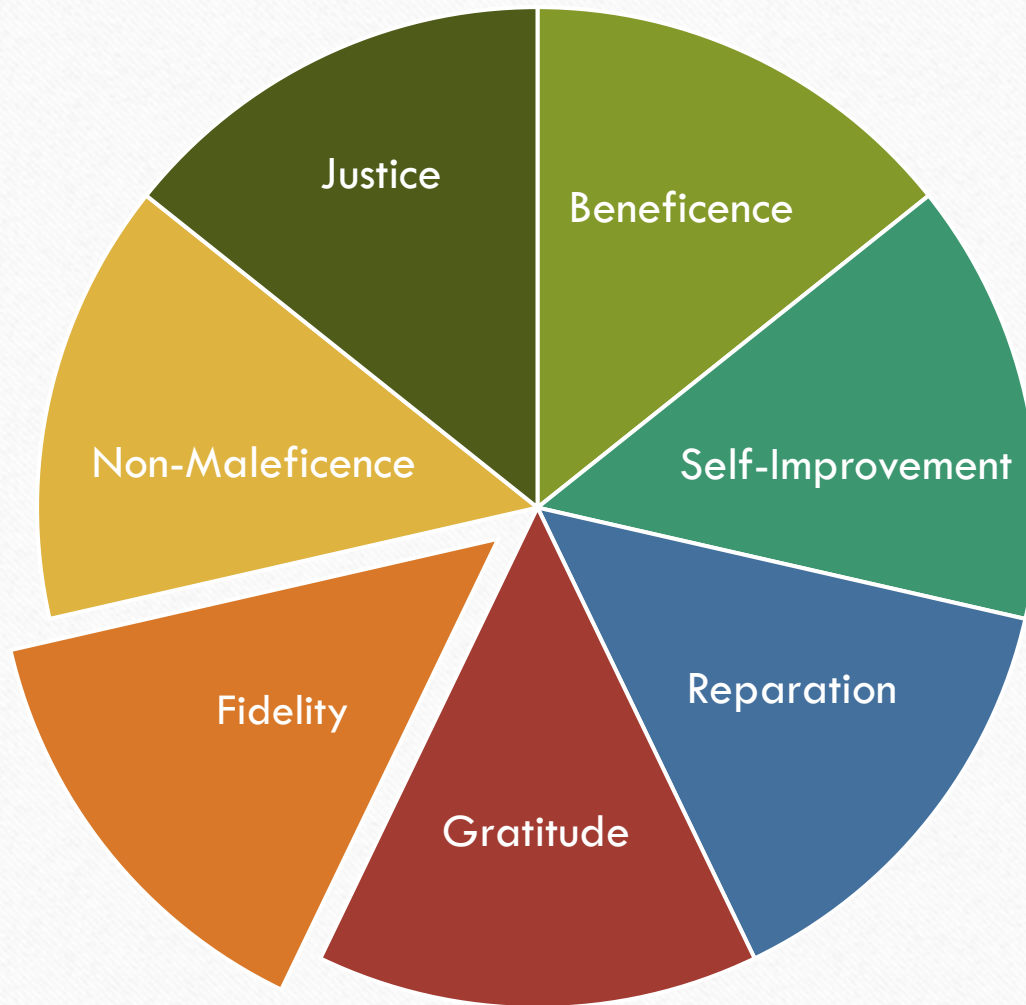
**Strive to improve
our own health,
wisdom, security,
happiness, and
well-being**



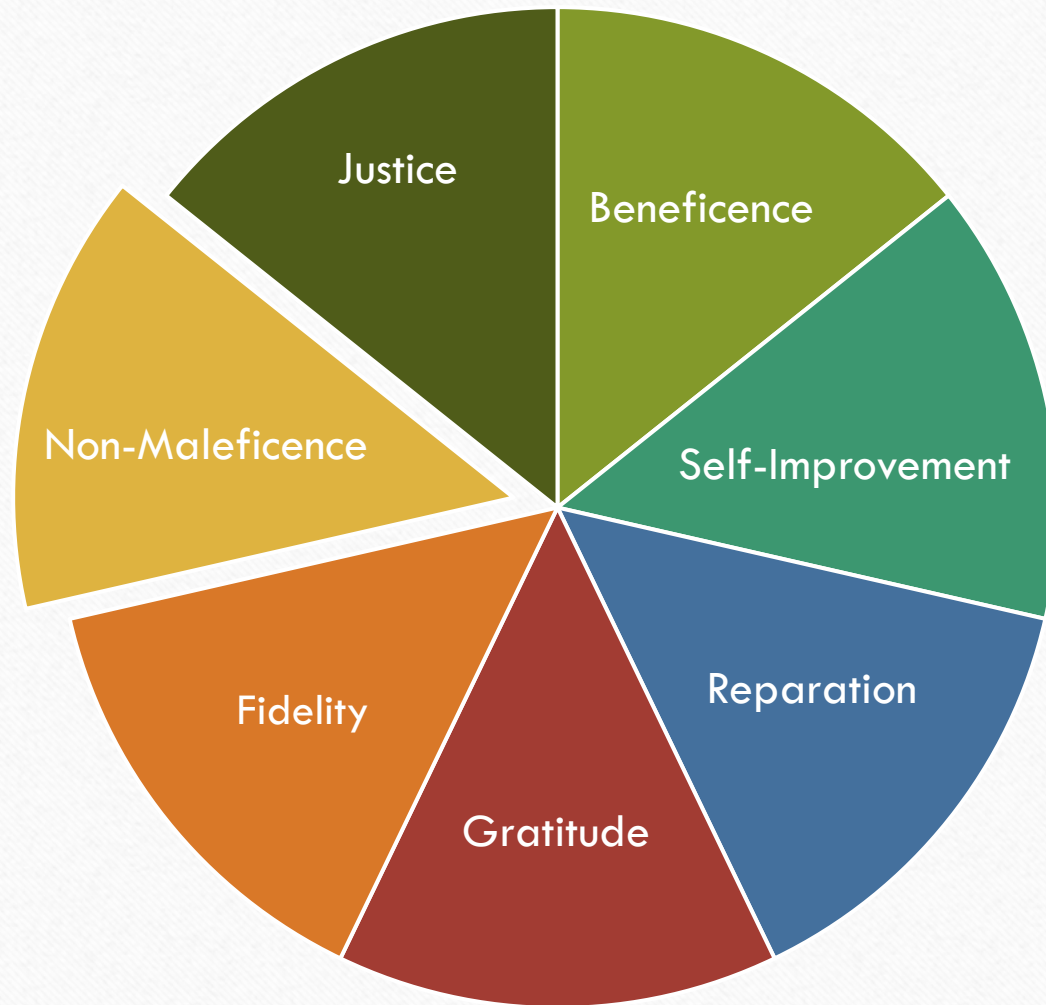
**Make amends when
we have wronged
another person**



**Be grateful to others
when they assist us; try to
return the favor**



**Keep promises, be
honest, and be truthful**

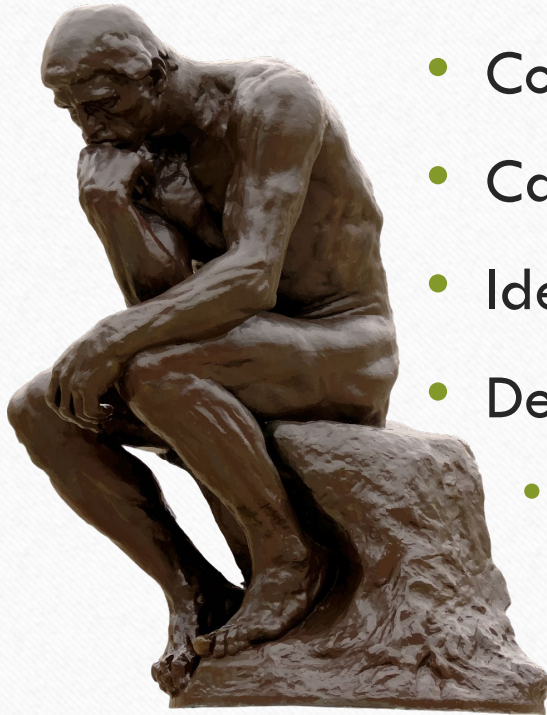


**Refrain from hurting
others, physically and
psychologically**



**Be fair; distribute
benefits and burdens
equitably and equally**

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?

