The Role of Beneficence in Humanitarian Research

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Beneficence: Definition

• A concept in research ethics which states that researchers should have the considered possible or potential benefits to the research participant as a goal of any research study

• Respect for Persons/Autonomy

• Justice

• Non maleficence

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The Evidence for Beneficence

• “While the baseline of ‘do no harm’ is recognized as an important starting point, there is a growing sense that research into human suffering ought only to be justifiable if it contributes to the ending of that suffering.”¹

• “I feel bad just leaving there again without leaving them anything or just.. Couldn’t do a lot for them”²

• “We are really fed up with people just coming and stealing our stories, taking our photos and we never get anything back, not even a copy of the report. Nothing ever changes”³

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Beneficence in Humanitarian Research: An opportunity

• Direct Beneficence

• Indirect Beneficence

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Direct Beneficence

• Compensation  
  • Cash based  
  • Alternatives

• Access to Services

• Incentives vs compensation

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Indirect Beneficence

• Programs

• Advocacy

• Policy

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Misapprehension and False Expectations

• Although the refugee in each instance provides information willingly, such willingness appears to be based on a misapprehension of the research process.²

• These views indicate that the purposes of research, possible outcomes, the steps that will be taken by researchers to protect participants and, indeed, the longer-term moral relationship between researchers and researched have all been seriously misunderstood.²
Potential Benefits of Beneficence

- Dignity for Research Participants
- Utilising an opportunity for assistance
- Improved relationship and trust with communities
- A reduction of research fatigue amongst participants
Potential Consequences of Beneficence

• Social Desirability Bias

• Coercion

• Lack of Justice (example of resettlement)
Case Study 1: Participatory Action Research

- Participatory Action Research (UNSW)
- UNHCR commissioned study to do qualitative interviews with survivors of sexual violence after a disaster
- Used a Participatory Action Research Method to conduct human rights and advocacy training with the final product being the women telling their stories in their own words

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Case Study 2: The Dharana Project

• A yoga and psychoeducation project to teach coping and resilience to unaccompanied refugee children who have experienced trauma

• Program is open to all, but only those who have consented will have the questionnaires and their data used
Case Study 3: RCT during a famine

• Randomised Controlled Trial of supplement (RTUF) vs the normal standard of care supplement during a famine

• Consider
  • Justice in Beneficence
  • Non maleficence

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The Challenge for Researchers

- Funding
- Ethics Review Board
- Time and Resource heavy
- Knowledge Base and Experience
- Cultivating trusting relationships with the community
- Lack of research capacity within vulnerable communities

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Tool for assessment of Beneficence

*How to derive the appropriate, non-coercive, ethical benefit for each unique project and each population.*

Qualitative interviews with researchers and previous study participants in various contexts and populations to understand

1. Positive and negative consequences of beneficence in research
2. Factors that should be considered in choosing form of beneficence
3. The place of beneficence on the research planning timeline.
Tool for assessment of Beneficence

Choose relevant topic

Communicate with stakeholders

Data Dissemination/Indirect Beneficence

Direct Benefit

Addressing False Expectations
Data Dissemination/Indirect Beneficence

- Who owns the data?
- Who does the data need to be disseminated to?
- Who are the NGOs in the area that have programs for the study population that could benefit from the information you collect?
- Does your study relate to any policy?
- What is the literacy level of the population? What is the best way to share the information you have collected?
- Would the information collected be risky to share to any of the stakeholders? How will you manage this?

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Direct Benefit

• How much time are you asking from each participant?
• How is taking this time from the participant affecting their daily life?
• How would be the best way to compensate for this time and effort given to you by the participant (e.g. transport costs, incentives)?
• Is the incentive/compensation you are providing too much? Could it coerce the participant into the study?
False Expectations

• Who is your research team made up of? Do any of the people hold important positions in the community or NGOs/International Organisations?

• What are the perceptions of the population to researchers?

• How much previous research has been done? And to what effect?

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How do we enhance beneficence in our projects?

• Finding an appropriate form of direct beneficence

• Clear and elaborate informed consent process

• Maximising indirect benefit through advocacy (including a data dissemination strategy)

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Conclusion: Recommendations for Researchers

- Think about the four ethical principles from the beginning
- Give yourself time to do the research project – it is hard to do ethical research quickly!
- Budget for compensation/beneficence
- Engage a bioethicist early, to ensure your review with the ERB goes smoothly and doesn’t take too much time
- Speak to experienced researchers
- Prepare an advocacy strategy

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References


• Research in disaster settings: a systematic qualitative review of ethical guidelines
  Mezinska et al. BMC Medical Ethics (2016) 17:62

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