Ethics & Trauma in Experimental Research

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Roadmap

cw: trauma, violence, injustice

How many of you have heard of...

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- Stanford Prison Experiment (1971)

Terrible episodes in the history of scientific research

- Josef Mengele's twin experiments at Auschwitz-Birkenau (1940s)
- Tuskegee Syphilis Study (1932-1972)
- Stateville Penitentiary Malaria Study (1940s)
- Sloan-Kettering Cancer Study (1952) + Brooklyn Jewish Chronic Disease Hospital Study (1962)
- Puerto Rico Pill Trials (1955)
- Tearoom Trade Study (pub. 1970)
- Stanford Prison Experiment (1971)
- Havasupai Genetics Studies Studies (1990s)
- AZT Trials in Zimbabwe (1994)

Terrible episodes in the history of scientific research

- Josef Mengele's twin experiments at Auschwitz-Birkenau (1940s)
- **Tuskegee Syphilis Study (1932-1972)**
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Tuskegee Syphilis Study

How it started in 1932

- **Goal:** study untreated syphilis
- **Participants:** 600 male sharecroppers
  - 399 were diagnosed with syphilis; none were told of the diagnosis (told they were being treated for "bad blood"
- **Setting:** Macon County, AL, which had a roughly 40% syphilis prevalence rate among the adult population in 1929 and was a prime target for public health attention
- **Planned timeline:** 6 months

Tuskegee Syphilis Study

What ultimately happened (1932-1972)

- Participants never treated
  - Penicillin became introduced as an effective syphilis treatment 15 years into the study
- 128 participants died of syphilis; only 74 participants in total were alive at the end of the study
  - 40 wives of participants were infected with syphilis
  - 18-19 children were born with syphilis

Tuskegee Syphilis Study

Articles published while the study was ongoing

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Tuskegee Syphilis Study

Aftermath

- $10 million settlement with participants and families
- Widespread distrust of public health and medicine in minoritized communities
- National Research Act of 1974
  - The Act made professional research ethics into federal law
  - It also created the National Commission for Protection of Human Subjects of Biomedical and Behavior Research
  - The Commission in turn released the "Belmont Report"
  - And the Report established 3 principles governing research ethics: respect for persons, beneficence, and justice

What *are* the legal standards for research ethics?

- **Respect for persons:** participants' autonomy must be preserved, including through informed consent and the right to withdraw from research at any time
- **Beneficence:** research must do no harm *and* maximize benefit while minimizing harms.
- **Justice:** research must not disadvantage certain societal groups and must not only study certain societal groups.
  - This one is a bit subtle: what it means is that the experience of being studied, should be equitably distributed — *both* to prevent the harms of research of accruing disproportionately on one group and to ensure that the benefits of having things known about their group are also not accruing disproportionately on one group.

How do we make sure that researchers behave ethically?

For the most part: institutional review boards (IRBs) that pre-evaluate every study with human subjects to make sure that it is consistent with legal ethics standards.

Have things gotten better in research ethics?

$\longrightarrow$ Yes

Have things gotten better in research ethics?

$\longrightarrow$ Yes

Are there outstanding questions about how to conduct and regulate research ethics, as well as an unfortunately large number of highly problematic studies?

$\longrightarrow$ Also yes

Roadmap

1. Quick History of Unethical Research

2. Trauma and Retraumatization
   - Motivations
   - Defining Retraumatization
   - Does Research Retraumatize People?
   - Normative Ethical Concerns
   - Recommendations for Best Practices

3. The Future of Research Ethics?

Research about Trauma and Sensitive Topics

- Experiences of soldiers and ex-combatants (Beber and Blattman, 2013; Annan et al., 2011; Green, 2017; Haer et al., 2013; Baaz and Stern, 2009)
- Sexual violence (Kreft, 2019; Baines, 2014; Finnbakk and Nordas, 2019; Koos, 2018)
- Abortion (Kalla, Levine and Broockman, 2022; Rosenfeld, Imai and Shapiro, 2016; Goren and Chapp, 2017; Daby and Moseley, 2022)

American Political Science Association (APSA) Ethics Guidelines

"Researchers should avoid traumatization and re-traumatization when possible, minimize traumatization and re-traumatization when avoidance is not possible, and not conduct research when the potential for traumatization or re-traumatization is excessive.

EGAP Memo on APSA Ethics Guidelines

"[T]he "Harm and trauma" subsection is overly vague, but without a clear fix. For instance, IRBs have denied surveys because they ask attitudinal questions about abortion or sexual assault for fear that mentioning the words might trigger trauma. . . it is unclear what the guidance should be."

Contested Concept

- Standard definition: the *reactivation* of the symptoms associated with a past traumatic experience (Leshner and Foy, 2012).
- Alternative definition: any traumatic stress reactions subsequent to a traumatic experience

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- Standard definition: the *reactivation* of the symptoms associated with a past traumatic experience (Leshner and Foy, 2012)
- Alternative definition: any traumatic stress reactions subsequent to a traumatic experience, maybe or maybe not disabling (Newman, Walker and Gefland, 1999)

$\longrightarrow$ Can retelling a trauma narrative or asking about trauma "retraumatize" someone?

Just Asking about Trauma Is Not Retraumatizing

Research participants may. . .

1. Find participation neutral (e.g. Newman, Walker and Gefland, 1999; Decker et al., 2011)
2. Find some participation upsetting, but feel that the benefits outweigh being upset or that being upset is in service of healing (Disch, 2001; Johnson and Benight, 2003; Hamberger, Larsen and Ambuel, 2020; Jaffe et al., 2015, e.g.)
3. Find research bothersome regardless of content or prior traumatic history (e.g. Johnson and Benight, 2003)
4. Have PTSD or something terrible happening such that research is not going to change that one way or another. (e.g. Johnson and Benight, 2003)

The Manner of Asking Can Be Upsetting

Two major ways for research to go wrong:

1. Researchers can make the participant feel disempowered, e.g., by using a completely inflexible questionnaire (Nguyen, 2011; Castor-Lewis, 1988)
2. The participant can have unreasonable expectations about what research is going to provide (Wood, 2013; Aroussi, 2020; Robins, 2010)

Is It *Wrong* to Work in a Traumatic Context?

- Research may not have as its goal helping the current set of participants (Affleck, 2017; Clark and Walker, 2011)
- Not obvious how to measure cost/benefit (Phillips, 2021; Campbell and Adams, 2009)

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$\longrightarrow$ Human subjects researchers usually have to buy into some sort of utilitarianism.

Bottom line: narrowly defined, retraumatization is not a concern for much political science research—but the narrowness of the concept obscures many of the ways that research can go wrong.

We can get some purchase on figuring out where concerns about retraumatization end and more salient trauma-related concerns begin by classifying paradigms for doing trauma-informed research.

Paradigm 1: "Holding Pattern"

What's working for us?

- Informed consent
- Debriefings
- Providing resource lists
- Collaborating with clinicians
- Excluding participants with cognitive impairments or extreme disorientation, or otherwise identified as high-risk

Paradigm 1: "Holding Pattern"

- Informed consent
- Debriefings
- Providing resource lists
- Collaborating with clinicians
- Excluding participants with cognitive impairments or extreme disorientation, or otherwise identified as high-risk

$\longrightarrow$ Probably a safe paradigm choice for many survey and lab researchers asking about attitudes.

Paradigm 2: Step-Up

- Multiple debriefings or debriefings that mimic therapeutic termination
- Researcher training in trauma-informed care or mental health practices
- Having clinicians onsite or oncall
- Enabling group/community engagement of participants
- Encouraging storytelling/narration/active processing

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$\longrightarrow$ Necessary for longitudinal research, field experiments, and fieldwork in violent/contested/high-risk contexts.

Paradigm 3: Overhaul

- Treating research as clinical practice
- Participatory action research
- Reflexivity about power differentials as an impediment to informed consent
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$\longrightarrow$ Appropriate for researchers who are uncomfortable with a utilitarian cost/benefit approach to human subjects research *or* who do not have the resources to provide appropriate support to research participants in the field.

Roadmap

Some questions for all of you...

- What do you see as the big issues in research ethics today?
- 20 years from now, what is going to make us look back and ask "how did we ever do that?"

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