The Ethics of Asking and Not Asking about Trauma

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Overview

• Define concerns.
• Review relevant research.
• Which methods work… for researchers, science, participants and IRBs?

Handouts:
Approved IRB protocols
Sample debriefing pamphlet
Bibliography

We will cover

Interview and survey research in which adults report on trauma they or their children have experienced Trauma of all kinds.

We won’t focus on

Asking children about trauma.

Research (e.g. archival, observational) that does not involve directly asking participants about trauma.

Ethical trauma research is important

We have 2 problems:

1) Too many non-research-based, vague concerns about asking about trauma that serve to silence trauma survivors.

2) Not enough information about practices that actually protect participants. (Not a problem specific to trauma research.)

Ethical research that documents benefits to participants helps with both problems.

10 concerns from our experience*

1) “IRB won’t let me ask about trauma.”
2) “I don’t know how to ask or respond.”
3) “If I ask, I’ll have to report abuse.”
4) “I’ll lose participants.”
5) “Asking exposes participants to unusual, upsetting stimuli.”

*See Becker-Blease & Freyd (2006)
6) “It’s not ethical to ask participants to disclose stigmatizing information.”
7) “Questions about trauma directly cause harm.”
8) “Survivors are not emotionally stable enough to give informed consent or seek help if needed.”
9) “Asking has no benefits to participants.”
10) “Not asking has no costs.”

“IRB won’t let me ask about trauma.”
- IRBs have approved
  - Asking children about abuse over the phone
  - Asking children about abuse in classroom surveys
  - Asking parents about child abuse on an anonymous survey
  - Asking undergrads about abuse they’ve perpetrated on an anonymous survey
  - Asking participants in longitudinal studies about abuse

IRBs rarely refuse to approve a study
- Focus on specific concerns.
- Give examples of published studies using similar methodology.
- Ask other researchers
  - how many adverse reactions they had, and how they were handled.
  - evidence of positive reactions to trauma research.

Treat this as on-going issue and continually assess
- Assess, assess, assess!
  - Measures and items available to monitor responses
    - Response to Research Participation Questionnaire (Newman & Kaloupek, 2001)
  - Develop data base that can help you address these concerns. For example:
    - By always collecting response information, can examine how different questions, methods, stimuli relate to participant experience.
    - Gather data from non-trauma-related studies for comparison.

Questions asked in empirical investigations
- Sample questions, Walker et al., 1997
  - I gained something positive from filling out this survey
  - Completing this survey upset me more than expected
  - Had I known in advance what completing this survey would be like for me, I would have agreed
- Current form: Response to Research Participation Questionnaire (Newman & Kaloupek, 2001)

Kassam-Adams & Newman, 2002

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<thead>
<tr>
<th>Item</th>
<th>Pos</th>
<th>Neg</th>
<th>Neutral</th>
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<tbody>
<tr>
<td>I gained something positive from filling out this survey</td>
<td></td>
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<td>Had I known in advance what completing this survey would be like for me, I would have agreed</td>
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<tr>
<td>Current form: Response to Research Participation Questionnaire</td>
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</table>
Solutions: Develop relationship with your IRB

- Develop reputation for excellence in monitoring participant responses
  - Include response information in:
    - Annual continuation applications
    - New applications
      - Either from your own lab or colleagues’

Example IRB language

There are no known risks to you associated with completing the packet. However, if you become upset and would like to talk to someone, please call the Counseling Center at xxx-xxxx. There are no known benefits to participation but some participants may get satisfaction from contributing to research on family experiences.

“I don’t know how to ask or respond.”

- Important to learn how to ask and respond
  
  Asking
  - Sources of trauma measures
  - Consider piloting to see which method participants prefer
  
  Responding
  - Allow participants to privately access brochures from a range of community services
  - Give all participants non-threatening, informational pamphlet
  - Be prepared to call referral and crisis lines with or without participants

Solutions: Training

- RA training
  - Use graduate students when possible
  - Hold frequent debriefing meetings for RAs to discuss procedures
  - Ask RAs to record personal responses and details about the visit on a “How Did It Go” form at the end of each visit
  - Teach RAs about trauma reactions, self-care
  - May need help processing the difference in staff responsibility in clinical and research settings

“If I ask, I’ll have to report abuse.”

- Researchers may not be covered under state mandatory reporting laws.
  - Check before submitting IRB protocol.
- Clearly inform participants under what conditions you will report.
- When researchers are directly told about abuse or suspect abuse, we can
  - Encourage self-referral
  - Provide counselor to follow-up and determine risk
  - Offer to help make the call
  - Report abuse independently

Case Example: Asking Parents about Current Child Abuse

  - Participants: Children and parents
  - Recruited: From the community, flyers asked for children “who had and had not experienced life stress”
  - Method: Parents completed trauma survey in private room on computer or paper surveys sealed in privacy envelope
What we learned

- Computer was too difficult
  - Difficult for experimenter to fix the computer problem without seeing participant responses, but participant couldn’t continue until problem was fixed
- Parents are savvy
  - Know how to talk about problems without saying anything specific enough to trigger a report

Solutions: Strategies for anonymous data collection

- Participant-created code to link data longitudinally
- Self-guided computer surveys
- Surveys completed in private and sealed in envelope, linked by participant-created code

Solutions: Still address importance of reporting

- Educational materials
  - Information about child abuse reporting
    - Why important
    - How to do it
    - Regional, state, and national resources

“I’ll lose participants.”

- Researchers who have asked control group participants over time, and reported the abuse, do not report attrition is a problem.
- It is possible to collect data longitudinally in such a way that individual participants are not identified (and no abuse reported).

“ Asking exposes participants to unusual, upsetting stimuli.”

- Comes up in context of “minimal risk”, defined by federal law as
  - “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests” (45 CFR 46.102(i)).

- Survivors are exposed to all kinds of reminders without informed consent, voluntary participation assurances, or debriefing:
  - Media
  - Class assignments
- Survey and interview questions are not the kind of sensory-based reminders that people usually report
Ethics of Asking & Not Asking

**Empirical data**

- DePrince & Freyd, 2004
  - Distress relative to other things encountered in day-to-day life and cost-benefit ratio
  - Participants
    - 468 undergraduate volunteers
      - Age M: 20.4 (SD: 3.0), 73.5% female
    - 149 community participants
      - Age M: 38.7 (SD: 12.3), 64.0% female

**Question 1: Distress question**

For the questionnaire that asked about different personal life events before and after age 18, please rate whether you found answering the questions to be more or less distressing than other things you sometimes encounter in day to day life.

<table>
<thead>
<tr>
<th>Importance</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
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<tbody>
<tr>
<td>Much more distressing</td>
<td>2.9 (1.0)</td>
<td>3.0 (1.1)</td>
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**Question 2: Importance question**

For the questionnaire that asked about different personal life events before and after age 18, please rate how important you believe it is for psychologists to ask about these types of events in order to study the impact of such experiences:

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<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely not important</td>
<td>4.5 (.9)</td>
<td>4.3 (1.0)</td>
<td></td>
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**Question 3: Goodness question (cost-benefit ratio)**

For the questionnaire that asked about different personal life events before and after age 18, please consider both your experience answering the questions, and your feelings about how important it is that we ask the questions, and then rate how good of an idea it is to include such a measure in psychology research.

<table>
<thead>
<tr>
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<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very bad</td>
<td>4.4 (.8)</td>
<td>4.3 (.7)</td>
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**Cost-benefit ratio**

- Distress relative to importance
  - $d=1.7, 1.2$
- Distress relative to goodness
  - $d=1.7, 1.4$

**People who reported more distress than other things encountered in day-to-day life**

- Much more distressing:
  - $n=8$ (5.4%), 30 (6.4%)
- Somewhat more distressing:
  - $n=41$ (27.5%), 117 (25.0%)
- Of these 196 participants
  - 195 made higher ratings for the importance and goodness questions
  - The one individual who did not endorse higher ratings reported a 1 for the importance question and did not respond to the goodness question.
Perceptions by trauma exposure

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
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<tbody>
<tr>
<td>Question 1</td>
<td>2.8 (1.0)</td>
<td>4.6 (1.9)</td>
<td>4.6 (1.5)</td>
</tr>
<tr>
<td>Question 2</td>
<td>3.0 (1.0)</td>
<td>4.6 (1.5)</td>
<td>4.6 (1.4)</td>
</tr>
<tr>
<td>Question 3</td>
<td>3.2 (1.0)</td>
<td>4.6 (1.4)</td>
<td>4.6 (1.2)</td>
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</table>

DePrince & Freyd, 2004

Solutions

- Assess in ongoing manner for your particular measures, stimuli, participants

“It’s not ethical to ask participants to disclose stigmatizing information.”

- Particularly in interviews, it may be uncomfortable for participants to choose among disclosing, refusing to answer, and lying.
- Most studies do ask about stigmatizing information that many participants refuse to answer, e.g. income.

Solutions: Method considerations

- Limit potential for stigmatization
  - Set up methods researchers do not see participant responses in session
  - Questionnaires placed in sealed envelopes
  - Computer-based testing
  - In group settings, filler questions at the end to disguise participants who must complete many follow-up questions

Solutions: Personnel training

- Set tone from beginning of session
  - Communicate respect
- Research Team Confidentiality
  - Training
  - Signed statement from all team members
  - Tell participants about confidentiality measures!
- Develop formal policies and procedures for staff about interacting and responding to participants
“Questions about trauma directly cause harm.”

- Not all negative feelings are harmful.
- Just as grief is a healthy response to loss, sadness, anger, etc. are healthy responses to trauma.
- Consider studies designed to elicit distress – these are ethical with careful debriefing.
- Have a protocol for dealing with truly harmful responses (suicidal, homicidal feelings, etc).

Empirical research

- Newman & Kaloupek, 2004
- Review 12 studies
  - Range of ages and trauma exposure types
    - e.g., 9/11, domestic violence, MVA, assault, psychiatric inpatients, college students, veterans, refugees
- Conclusions
  - Most individuals participating in trauma-related research make favorable cost-benefit appraisals about participation;
  - A minority report experiencing negative emotions or more distress than expected.

Solutions

- Assess cost-benefits
  - At end of each sessions
  - Follow-up
    - Phone calls at 24-72 hours after participation (if safe)

Case Example: Undergraduate Perpetrators

  - Participants: Male undergrads
  - Recruited: Psychology participant pool
  - Methods: Anonymous survey completed in group setting. Signature on informed consent waived.

What we learned

- Some undergrad men were angry or offended by being asked these questions.
  - Need to distinguish between “distress” and being “offended”.

“Survivors are not emotionally stable enough to give informed consent or seek help if needed.”

- Research shows survivors generally do not regret participation, even when they experience distress.
- Treating survivors as emotionally unstable runs the risk of recreating trauma dynamics.
Solutions: Consent Quizzes

- Consent process
  - Written and verbal explanations
  - Set criteria for understanding consent information
  - Consent quiz
    - If children involved, parent takes ‘quiz’ first
    - Corrective information provided for any wrong answers
    - If cannot answer correctly on second try, do not test

Sample Consent quiz: Adults

- What types of questions you will be asked on the questionnaires?
- Will I know how you answered on the questionnaires?
- What will happen if you disclose abuse of a child or an elderly person?
- Do you have to answer every question?
- How will your confidentiality be protected?
- If you become upset at any time during the experiment today, what can you do?
- Do you have to complete the experiment because you signed the consent form?
- Do you have to have a “good reason” to end the experiment?

Sample Consent quiz: Children

- What kinds of things we’ll do today?
- What will happen if you tell me about a kid who is being hurt by someone?
- Do you have to do everything I ask you to do today?
- Do you have to answer every question I ask?
- Can you take a break whenever you want to?
- If you become upset or bored today, what can you do?
- Do you have finish the experiment today?
- Do you have to complete the experiment because you signed the consent form?
- Can you say “pass” any time you don’t want to do something or don’t want to answer a question I ask?

“Asking has no benefits to participants”

- Benefits include
  - Chance to help other trauma survivors and prevent trauma to others.
  - Receive help if needed.
  - Gaining personal insight, meaning

Case Example: Convicted Perpetrators

- Becker-Blease & Freyd (in press)
  - Participants: Convicted sex offenders in mandated treatment
  - Recruited: By research assistant who volunteered at center during group session
  - Method: Participants took survey, returned it to receptionist in exchange for gift card.
  - Signature on informed consent waived.

What we learned

- Offenders in mandated treatment on probation or parole considered “prisoners” by IRB
- Convicted offender comments were positive.
Solution: Assess benefits!
- Response to Research Participation Questionnaire
  - Personal benefits
  - Emotional reactions
  - Perceived drawbacks
  - Global evaluation

Solution: Maximize potential for benefits
- Incorporate methods that maximize benefits
  - DePrince and Chu (in preparation)
    - Greater personal benefits (relative to emotional reaction and perceived drawbacks) for interview study relative to survey

“Not asking has no costs.”
- What do we lose when we don’t ask about trauma?
  - Science loses information.
    - The strength of other variables is inflated.
  - Society loses effective prevention/intervention
    - without valid research.
  - Participants are harmed by silence
    - Missed opportunity to talk about important life events and get help
    - May get the message that trauma experiences are not important or not something researchers want to hear about.

Consider including all 4 cells in IRB protocols.

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<thead>
<tr>
<th></th>
<th>Risks</th>
<th>Benefits</th>
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<tbody>
<tr>
<td>Asking</td>
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<tr>
<td>Not asking</td>
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Relevant Citations