

## 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.



## Trauma Research:

**What concerns do you have or have others shared with you?**




## 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)
    - Response to Research Participation Questionnaire – Child Version (Kassam-Adams & Newman, 2002).
    - DePrince & Freyd, 2004
  - 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 still would have agreed
    - Current form: Response to Research Participation Questionnaire (Newman & Kaloupek, 2001)

## Kassam-Adams & Newman, 2002



Reactions to Research Participation - Child Version (RRPQ-C)

	No	Maybe	Yes
Being in this study was boring			
I am glad that I was in this study			
It was my choice if I was in the study (I could have said no even if other people wanted me to say yes)			
Being in this study made me feel upset or sad			
The things I said will stay private (no one else will know I said them)			
I am sorry I was in this study			
Being in this study made me feel good about myself			
I was told the truth about the study before it started			
I feel good about helping other people by being in this study			
I knew I could skip questions or parts of the study if I wanted to.			
I knew I could stop at any time.			
I knew I could ask to take a break whenever I wanted.			

## 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

- Becker-Bleuse (2002), Becker-Bleuse & Freyd (2004)
  - 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

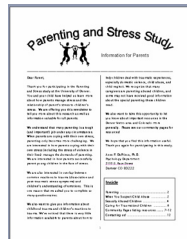
- Computer was too difficult
  - Difficult for experimenter to fix the computer problem without seeing participant responses, but participant couldn't continue until problem was fixed
- Parents are savvy
  - Know how to talk about problems without saying anything specific enough to trigger a report

## 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



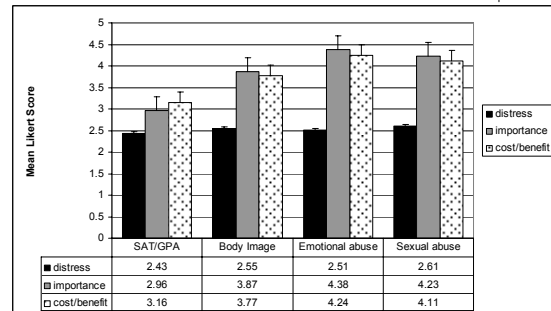
## Perceptions by trauma exposure

	Question 1 (How distressing?)	Question 2 (How important?)	Question 3 (How good an idea?)
<b>Gender</b>			
Community Men (n = 52)	3.0 (.9)	4.4 (.9)	4.2 (.9)*
Community Women (n = 96)	2.8 (1.0)	4.5 (.9)	4.5 (.7)
Undergraduate Men (n = 123)	3.2 (1.1)*	4.1 (1.1)*	4.2 (.8)*
Undergraduate Women (n = 341)	3.0 (1.1)	4.4 (.9)	4.4 (.7)
<b>Interpersonal Violence History</b>			
Community No (n = 31)	3.2 (1.2)	4.2 (1.1) <sup>^</sup>	4.3 (1.0)
Community Yes (n = 118)	2.8 (.9)	4.5 (.8)	4.4 (.8)
Undergraduate No (n = 243)	3.1 (1.1)	4.2 (1.1)*	4.3 (.8)
Undergraduate Yes (n = 209)	3.0 (1.1)	4.4 (.8)	4.4 (.7)
<b>Assault Before Age 18</b>			
Community No (n = 79)	3.0 (1.0) <sup>^</sup>	4.5 (.9)	4.4 (.9)
Community Yes (n = 70)	2.7 (.9)	4.5 (.9)	4.4 (.7)
Undergraduate No (n = 316)	3.1 (1.2)	4.3 (1.0)*	4.3 (.7)
Undergraduate Yes (n = 138)	2.9 (1.0)	4.4 (.8)	4.4 (.7)

\*p < .05 for comparison within sample (either community or undergraduate)  
<sup>^</sup>p < .10

DePrince & Freyd, 2004

## Cromer, Freyd, Binder, DePrince & Becker-Blease (in press)



## 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

- Becker-Blease, Friend & Freyd (2006)
  - 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?
- Can you stop if you feel like stopping without a "good reason"?
- 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-Bleuse & 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.

	Risks	Benefits
Asking		
Not asking		

## Relevant Citations

- Becker-Blease, K.A. & Freyd, J.J. (2006). Research participants telling the truth about their lives. *American Psychologist*, 61, 218-226.
- DePrince, A.P. & Freyd, J.J. (2004) Costs and benefits of being asked about trauma history. *Journal of Trauma Practice*, 4(3), 23-35.
- Griffin, M.G., Resick, P.A., Waldrop, A.E., & Mechanic, M.B. (2003). Participation in trauma research: Is there evidence of harm? *Journal of Traumatic Stress*, 16, 221-228.
- Johnson, L.E. & Benight, C.C. (2003). Effects of trauma-focused research on recent domestic violence survivors. *Journal of Traumatic Stress*, 16, 567-572.
- Kassam-Adams, N. & Newman, E. (2002). The reactions to research participation questionnaires for children and for parents (RRPQ-C and RRPQ-P). *General Hospital Psychiatry*, 24, 336-342.
- Newman, E. & Kaloupek, D.G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17, 383-394.
- Newman, E., Walker, E.A., & Gefland, A. (1999). Assessing the ethical costs and benefits of trauma-focused research. *General Hospital Psychiatry*, 21, 187-196.
- Walker, E.A., Newman, E., Koss, M., & Bernstein, D. (1997). Does the study of victimization revictimize the victims? *General Hospital Psychiatry*, 19, 403-410.