

Reactions to Research Participation in Studies of Sensitive Topics

Rosemary Cogan, Ph.D., ABPP, CIP
and Patricia Pujals, B.A.
Texas Tech University
11/01/2011

Abuse

Overview

Becker-Blease, K. A., & Freyd, J. J. (2006). Research participants telling the truth about their lives: The ethics of asking and not asking about abuse. *American Psychologist, 61*, 218-226. doi:10.1037/0003-066X.61.3.218

Most discussions of the ethics of self-report research on abuse and interpersonal violence focus on the risks of asking participants about their experiences. An important element of the cost-benefit analysis--the costs of not asking about child abuse--has largely been ignored. Furthermore, little research has been conducted on the costs and benefits of child abuse research, leaving researchers to make decisions based on individual beliefs about such issues as the prevalence of abuse, the likelihood of disclosure, the effects of child abuse, and the ability of abuse survivors to give informed consent. The authors suggest that these beliefs tend to overemphasize survivors' vulnerability and ignore the costs of avoiding asking about abuse. In fact, these beliefs may reinforce societal avoidance of abuse and ultimately harm abuse survivors.

Edwards, V. J., Dube, S. R., Felitti, V. J., & Anda, R. F. (2007). It's OK to ask about past abuse. *American Psychologist, 62*, 327-328. doi:10.1037/0003-066X62.4.327

Comments on the article by K. Becker-Blease and J. Freyd (see record 2006-03947-003), which addressed the ethics of asking and not asking research subjects about abuse. In their article, they systematically reviewed often-voiced concerns about and objections to asking questions about child maltreatment in survey research. They concluded that by failing to ask about a history of child maltreatment, an important predictor of later-life problems may be overlooked. The current authors discuss the Adverse Childhood Experiences (ACE) study, which provides strong evidence of the association between early traumatic experiences and some of the major public health problems facing our nation. Results from the ACE study have shown an association between traumatic childhood experiences and a broad range of health outcomes, including liver disease, ischemic heart disease, reproductive health, and mental illness, as well as a variety of health risks such as obesity, smoking, and alcoholism. The associations that these studies showed demonstrate that researchers studying health outcomes who do not ask study subjects about traumatic childhood experiences are overlooking an important risk factor for many of the major health issues of our day.

Primary Literature

Black, M. C., Kresnow, M., Simon, T. R., Arias, I., & Shelley, G. (2006). Telephone survey respondents' reactions to questions regarding interpersonal violence. *Violence and Victims, 21*, 445-459.

Concerns have been raised regarding the appropriateness of asking about violence victimization in telephone interviews and whether asking such questions increases respondents' distress or risk for harm. However, no large-scale studies have evaluated the impact of asking such questions during a telephone interview. This study explored respondents' reactions to questions regarding violence in two large recently completed telephone surveys. After respondents were asked about violence, they were asked if they thought surveys should ask such questions and whether they felt upset or afraid because of the questions. In both surveys, the majority of respondents (regardless of their

victimization history) were willing to answer questions about violence and were not upset or afraid because of the questions. More than 92% of respondents thought such questions should be asked. These results challenge commonly held beliefs and assumptions and provide some assurance to those concerned with the ethical collection of data on violent victimization. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Clements, K., & Holtzworth-Munroe, A. (2009). Participation in laboratory research result in emotional distress with one's partner: Comparing violent and nonviolent couples. *Journal of Family Violence, 24*, 283-295. doi:10.1177/ 1077801210397756

The present study compared impact of participating in laboratory research assessments on couples experiencing partner violence and nonviolent couples. Across two studies, 192 couples participated in a variety of potentially distressing laboratory procedures, including discussing relationship problems, viewing videotapes of their discussions, and completing questionnaires about personal and relationship problems. At the end of each laboratory session, participants rated their emotions about their partners as a result of having participated in the study procedures. Couples, recruited from the community, were placed into one of three groups: experiencing violence (V), nonviolent but maritally distressed (NVD), and nonviolent and non-distressed (NVND). Overall, study participants did not report high levels of negative feelings toward their spouses at the end of lab sessions. Few differences between V and NVD spouses were statistically significant, suggesting that violent spouses are not at greater risk than NVD spouses for negative feelings following study participation, although the finding of greater fear among V partners in one study deserves future attention. Relative to V and NVD couples, happy couples reported more positive and fewer negative feelings; NVD wives were the most likely to report negative emotions, in sessions involving a marital problem discussion. These findings can be used in discussions with Institutional Review Boards about the potential risks of laboratory procedures for violent couples recruited from the community.

Decker, S. E., Naugle, A. E., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of Empirical Research on Human Research Ethics, 6*, 55-64.

While many studies ask participants to disclose sensitive information or to participate in emotionally arousing tasks, little is known about participants' subjective experiences of discomfort and benefit. Ethics review committees, therefore, have little information about participant experiences to guide their informed decisionmaking. We asked undergraduate females about their experiences in a study that included an experimental session, interviews, and self-report measures on sensitive topics. We examined results overall, and compared the responses of individuals with and without childhood abuse experiences. Participants who had experienced child abuse were more likely to report distress due to remembering the past, but also more likely to report that participation was helpful. Implications for future research, and recommendations for review boards, are discussed.

DiLillo, D., DeGue, S., Kras, A., Di Lorento-Colgan, A. R., & Nash, C. (2006). Participant responses to retrospective surveys of child maltreatment: Does mode of assessment matter? *Violence and Victims, 21*, 410-424. Retrieved from EBSCOhost.

This study examines the impact that different methods of assessing child maltreatment history may have on adult participants. A total of 334 female undergraduate students were randomly assigned to complete a retrospective measure of child sexual and physical abuse in one of three conditions: paper-and-pencil questionnaire, face-to-face interview, or computer-administered survey. Disclosure rates of abuse, psychological distress and mood change, preferences for assessment format, and perceptions of confidentiality were examined across the three assessment formats. Although

disclosure did not vary by condition, participants with a history of abuse reported more distress and mood change than did nonvictims, particularly in the computer condition. Nevertheless, the computer condition was rated as the most preferred format and was viewed by participants as the most confidential means of assessing maltreatment history. Participants reporting abuse through interviews were more likely than those in other conditions to state a preference for another type of assessment format. The implications of these findings for abuse history research are discussed.

Disch, E. (2001). Research as clinical practice: Creating a positive research experience for survivors of sexual abuse by professionals. *Sociological Practice: A Journal of Clinical and Applied Sociology*, 3, 221-239.

A team of practitioners created a research process that we hoped would be educational and healing for survivors of sexual abuse by professionals. In order to look at the impact of the study, we included a follow-up debriefing questionnaire designed to gather data about respondents' experiences. Nearly all respondents found the study both helpful and difficult. The potential for research to be educational or healing is demonstrated by these findings. The fact that research on trauma is likely to be painful or upsetting even when it is helpful to respondents underscores the importance of making potential risks of participation very clear

Langhinrichsen-Rohling, J., Arata, C., O'Brien, N., Bowers, D., & Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyway? *Violence and Victims*, 21, 425-444.

Distress related to answering personal survey questions about drug use, suicidal behavior, and physical and sexual abuse were examined in multiple convenience samples of adolescents. Samples varied in consent procedures utilized (active vs. passive parental consent), data collection setting (school vs. juvenile justice), developmental level (middle school vs. high school). Participation rates differed across consent procedures (e.g., 93% with passive vs. 62% with active parental consent). Results indicated that small percentages of adolescents in every sample reported frequently feeling upset while completing the survey (range 2.5% to 7.6%). Age, race, gender, and data collection strategy did not emerge as significant predictors of feeling upset. Instead, as hypothesized, adolescents reporting a history of suicidal ideation or attempt, illicit drug use, or experiences of physical or sexual victimization endorsed more frequent feelings of upset while completing the survey than peers without these experiences. Taken together, however, these sensitive event experiences explained only 6.6% of the variance in adolescents' upset ratings. The scientific and ethical implications of these findings are discussed with regard to adolescent participation in survey research about sensitive topics. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Owen, D. J., Heyman, R. E., & Smith Slep, A. M. (2006). The risk of partner aggression research: Impact of laboratory couples conflict protocols on participants. *Violence and Victims*, 21, 483-497. doi:10.1891/vivi.21.4.483

The impact of male-to-female intimate partner violence (IPV) research on participants is unknown. A measure of impact was given to participants in an IPV study to assess systematically the impact of completing questionnaires, engaging in conflict conversations, and being interviewed individually about anger escalation and de-escalation during the conversations. Participants completed the six question, Likert-scaled, impact measure. Both male and female participants rated the impact of the study as helpful to them personally and to their relationships. Female participants rated different segments of the study as more helpful to themselves and their relationships, while male participants did not find any segment of the study to have a different impact than other segments.

Rojas, A., & Kinder, B. N. (2007). Effects of completing sexual questionnaires in males and females with histories of childhood sexual abuse: Implications for Institutional Review Boards. *Journal of Sex & Marital Therapy*, 33, 193-201. doi:10.1080/00926230701267795

Few studies have sought to examine empirically the immediate effects of participation in sexual abuse research. The present study investigated the effects of childhood sexual abuse on measures of personality and psychological functioning in 250 males and females. The null hypothesis was that sexually abused and nonabused groups would show no significant differences between pre- and post-testing on measures of state anxiety, state depression, and state anger. No significant differences between pre- and post-testing were observed between nonabused, abused, and severely abused participants. In addition, there were no gender differences among the groups. Findings from this study support those of Savell, Kinder, and Young (2006) and have significant implications for Institutional Review Boards (IRB) as they suggest that participation in childhood sexual abuse or sexuality research does not place sexually abused individuals at greater than minimal risk for immediate increases in anxiety, depression, or anger.

Savell, J. K., Kinder, B. N., & Young, M. S. (2006). Effects of administering sexually explicit questionnaires on anger, anxiety, and depression in sexually abused and non-abused females: Implications for risk assessment. *Journal of Sex & Marital Therapy*, 32, 161-172. Retrieved from EBSCOhost.

Human sexuality researchers and institutional review boards often are concerned about the sensitive nature of the information that they obtain and whether this type of research increases the psychological risks to participants. To date, there are almost no empirical data that address this issue. We administered state and trait measures of anger, anxiety, and depression to 207 females who were administered four questionnaires that asked them to reveal highly sensitive, sexually explicit information, including questions regarding childhood sexual abuse. Then they were readministered the state and trait measures of distress. We found no significant differences, even among those who reported being sexually abused as children, suggesting that such studies do not significantly increase the risk of psychological harm to participants. \

Shorey, R. C., Cornelius, T. L., & Bell, K. M. (2011). Reactions to participating in dating violence research: Are our questions distressing participants? *Journal of Interpersonal Violence*, 26, 2890-2907. doi:10.1177/08862605.10390956

In recent years, there has been increased research focus on dating violence, producing important information for reducing these violent relationships. Yet Institutional Review Boards (IRBs) are often hesitant to approve research on dating violence, citing emotional distress of participants as a possible risk of participation. However, no known research has examined the reactions of research participants to questions about dating violence. The current study examined the reactions among college students to completing a self-report measure on dating violence. Results showed that participants reported numerous positive experiences as a result of their research participation, with only mildly increased negative emotional reactions evident for some. Findings are discussed in relation to IRB proposals and appropriate informed consent for research participants.

Walker, E. A., Newman, E., Koss, M., & Bernstein, D. (1997). Does the study of victimization revictimize the victims? *General Hospital Psychiatry*, 19, 403-410. Retrieved from EBSCOhost.

Although the number of questionnaire surveys examining the sequelae of prior sexual and physical victimization has increased over the last decade, little attention has been given to understanding the impact of such studies on participants. As part of a larger study of long-term effects of prior sexual and physical victimization, 500 randomly selected women in an HMO received a comprehensive questionnaire including multiple symptomatic distress measures and several items inquiring into

previous history of sexual, physical, and emotional abuse and neglect. They also completed a short rating scale asking about their reactions to completing the questionnaire. Despite the sensitive content, the women who participated generally found the experience to be a positive one. Only a small number of women were more upset than they had anticipated, but the vast majority felt they would have completed the survey even if they had known in advance how they would feel. The subset of women who did express distress was significantly different from the group that did not, with respect to other measures of symptomatic distress and trauma exposure. These data suggest that surveys that inquire into prior episodes of childhood victimization are generally well tolerated by women who participate, and that, although a small number may be disturbed by these investigations, in general, adverse reactions may be less common than previously anticipated.

Deception

Overview

Kelman, H.C. (1967). Human use of human subjects: The problem of deception in social psychological experiments. *Psychological Bulletin*, 67, 1-11. doi:10.1037/h0024072

Though there is often good reason for deceiving SS in social psychological experiments, widespread use of such procedures has serious (1) ethical implications involving not only the possibility of harm to S, but also the quality of the E-S relationship; (2) methodological implications relating to the decreasing naiveté of SS and (3) implications for the future of the discipline. To deal with these problems, it is necessary to (1) increase active awareness of the negative implications of deception and use it only when clearly justified, not as a matter of course; (2) explore ways of counteracting and minimizing negative consequences of deception when it is used; and (3) develop new experimental techniques that dispense with deception and rely on S'S positive motivations. (PsycINFO Database Record © 2006 APA, all rights reserved)

Pittenger, D.J. (2002). Deception in research: Distinctions and solutions from the perspective of utilitarianism. *Ethics & Behavior*, 12, 117-142. doi:10.1207/S15327019EB1202_1

The use of deception in psychological research continues to be a controversial topic. Using Rawls's explication of utilitarianism, I attempt to demonstrate how professional organizations, such as the American Psychological Association, can provide more specific standards that determine the permissibility of deception in research. Specifically, I argue that researchers should examine the costs and benefits of creating and applying specific rules governing deception. To that end, I offer 3 recommendations. First, that researchers who use deception provide detailed accounts of the procedures they used to minimize the harm created by deception in their research reports. Second, that the American Psychological Association offer a definition of deception that describes techniques commonly used in research. Finally, I recommend that the informed consent procedure be revised to indicate that the researcher may use deception as part of the study.

Primary Literature

Epley, N., & Huff, C. (1998). Suspicion, affective response, and educational benefit as a result of deception in psychology research. *Personality and Social Psychology Bulletin*, 24, 759-869. doi:10.1177/0146167298247008

Evaluated college students' reactions to deception in experiments by having them participate in a replication of a deception experiment. The experiment used a 2 (debriefing: partial, full) by 2 (performance feedback: positive, negative) by 2 (time of measurement: postexperiment, 3-mo

follow-up) factorial design, with the last factor varying within Ss. Half of the Ss were made aware of the deception immediately, whereas the other half were not. Ss reported little negative impact from being deceived, but significant negative effects were reported on the basis of receiving negative feedback (a manipulation in the deception experiment). Furthermore, Ss who were informed of the deception became more suspicious than uninformed Ss, and this effect lasted for 3 mo after the initial experience. Thus, deception may not be as costly to participants as commonly believed. From a cost-benefit standpoint, other issues (e.g., suspicion and negative stimuli in experiments) should be of greater concern.

McFarland, C., Cheam, A., & Buehler, R. (2007). The perseverance effect in the debriefing paradigm: Replication and extension. *Journal of Experimental Psychology*, *43*, 233-240.
doi:10.1016/j.jesp.2006.01.010

A classic study conducted by Ross, Lepper, and Hubbard (1975) revealed a perseverance effect wherein people who received positive performance feedback on an alleged social perceptiveness test reported more favorable self-perceptions in this domain than those who received negative feedback despite the fact that they had received standard outcome debriefing (i.e., been informed about the false, predetermined, and random nature of the feedback) prior to reporting self-assessments. The present studies extend this past research by revealing that (a) there is a form of outcome debriefing (i.e., informing participants about the bogus nature of the test as well as the bogus nature of the feedback) that effectively eliminates the perseverance effect, (b) the perseverance effect that occurs after standard outcome debriefing is limited to perceptions of specific task-relevant skills rather than more global abilities, and (c) affective reactions do not underlie the perseverance effect that occurs in the false feedback paradigm

Ross, L., Lepper, M. R., & Hubbard, M. (1975). Perseverance in self-perception and social perception: Biased attributional processes in the debriefing paradigm. *Journal of Personality and Social Psychology*, *32*, 880-892. doi:10.1037/0022-3514.32.5.880

Two experiments with a total of 60 female high school students and 144 female undergraduates demonstrated that self-perceptions and social perceptions may persevere after the initial basis for such perceptions has been completely discredited. In both studies Ss first received false feedback, indicating that they had either succeeded or failed on a novel discrimination task and then were thoroughly debriefed concerning the predetermined and random nature of this outcome manipulation. In Exp II, both the initial outcome manipulation and subsequent debriefing were watched and overheard by observers. Both actors and observers showed substantial perseverance of initial impressions concerning the actors' performance and abilities following a standard "outcome" debriefing. "Process" debriefing, in which explicit discussion of the perseverance process was provided, generally proved sufficient to eliminate erroneous self-perceptions. Biased attribution processes that might underlie perseverance phenomena and the implications for the ethical conduct of deception research are discussed.

Smith, S. S., & Richardson, D. (1983). Amelioration of deception and harm in psychological research: The importance of debriefing. *Journal of Personality and Social Psychology*, *44*, 1075-1082.
doi:10.1037/0022-3514.44.5.1075

Determined the effects of deception and harm on research participants' perceptions of their experiences in psychology experiments. In addition, the role of debriefing in reducing any negative effects was examined. 464 undergraduates who had participated in psychology experiments during the academic quarter completed questionnaires on their perceptions of harm and benefit, adequacy of debriefing, and experimenters' behavior. Ss who had been deceived evaluated their experience more positively than those who had not participated in deception experiments. Also, effective debriefing seemed to eliminate negative effects perceived by Ss who felt they had been harmed.

Disaster

Primary Literature

Boscarino, J. A., Figley, C. R., Adams, R. E., Galea, S., Resnick, H., Fleischman, A. R., Bucuvalas, M., & Gold, J. (2004). Adverse reactions associated with studying persons recently exposed to mass urban disaster. *Journal of Nervous and Mental Disease, 192*, 515-524. Adverse reactions associated with studying persons recently exposed to mass urban disaster. Retrieved from EBSCOhost.

This study assesses the psychological consequences of participation in a mental health study among people recently exposed to the September 11 attacks. Using cross-sectional telephone surveys, we interviewed random samples of English-speaking or Spanish-speaking adults living in New York City during the attacks 1 year after this event. Altogether, 2,368 people completed the surveys, including a random sample of 1,173 respondents who received mental health services after the attacks. Results indicated that 15% of New Yorkers found some of the survey questions stressful, whereas 28% of those who sought treatment found this to be the case. However, less than 2% reported being upset at survey completion, and among these persons, only four people consented to speak to the study's mental health consultant. Although the majority of those expressing adverse reactions had sought postdisaster treatment, even among these subjects, only 3% were still upset at survey completion, and 2% wanted more information about counseling services. In addition, more than 70% of participants expressed positive sentiments about survey participation. Predictive models indicated that respondents who met study criteria for posttraumatic stress disorder, depression, or anxiety were more likely to find questions stressful, with people having posttraumatic stress disorder or depression the most likely to be upset and to consent to psychiatric consultation at completion. We suggest that, with the proper safeguards, research with persons exposed to a recent mass urban disaster generally can be conducted safely and effectively.

Dyregrov, K., Dyregrov, A., & Raundalen, M. (2000). Refugee families experience of research participation. *Journal of Traumatic Stress, 13*, 413-426. Retrieved from EBSCOhost.

Examined the attitudes towards research of refugee parents and children who had previously participated in an interview process. Ss were 74 members (aged 6–73 yrs) of 20 Bosnian families residing in Norway and who had previously been interviewed about the difficult question of repatriation after arriving in a new country. Results show that parents perceived participation in the research study as very positive and children rated their experience as positive. No S experienced the research situation as completely negative. Parents in 3 families indicated they lacked information that could have enabled them to inform their children better before the interviews. It is concluded that studies on traumatized populations can have beneficial effects.

Galea, S. Nandi, A., Stuber, J., Gould, J., Acierno, R., Best, C. L., Bucuvalas, M., Rudenstine, S., Boscarino, J. A., & Resnick, H. (2005). Participant reactions to survey research in the general population after terrorist attacks. *Journal of Traumatic Stress, 18*, 461-465. doi:10.1002/jts.20053

There remains concern that survey research after a disaster can precipitate or exacerbate distress among study participants. The authors surveyed 5,774 persons in three random-digit-dial telephone surveys of the general population of New York City conducted 1-2 months, 4-5 months, and 6-9 months after the terrorist attack on September 11, 2001. Overall, 746 (12.9%) people who finished the surveys said that the survey questions were upsetting but only 57 (1.0% overall) were still upset at the end of the interview, and 19 (0.3%) wanted assistance from a counselor. Ten persons who did not finish the survey also received counselor assistance. Persons with mental health symptoms were more likely to find the survey questions emotionally upsetting as were participants who lacked salutary resources, including health insurance and a regular health care provider. Although relatively

few of those interviewed found the survey assessment disturbing, the presence of a small number of respondents who wanted mental health assistance suggests the need for a mental health backup system for research conducted soon after exposure to large-scale traumatic events.

Psychiatric/Medical

Reviews

Dunn, L. B. (2006). Capacity to consent to research in schizophrenia: The expanding evidence base. *Behavioral Sciences and the Law*, 24, 431-445. doi:10.1002/bsl.698

Capacity to consent to research, fundamental to informed consent and thus vital to the ethical conduct of research, may be impaired among a variety of research populations. Until recently, relatively little empirical evidence has been available to inform discussion and policy-making regarding whose capacity should be assessed, what should be measured, and how it should be measured. Capacity to consent to research has emerged as a central topic in the field of “empirical ethics,” an important area of biomedical research devoted to bringing evidence-based methods to the study of ethically salient issues in biomedical and biopsychosocial research. In this paper, empirical studies of capacity to consent to research are reviewed, with a particular focus on studies involving people with schizophrenia. These studies provide intriguing data regarding the nature, correlates, and modifiability of decisional abilities among potentially vulnerable research populations, including individuals with serious neuropsychiatric illnesses. Areas in need of further empirical ethics research are highlighted. Copyright © 2006 John Wiley & Sons, Ltd.

Jorm, A. F., Kelly, C. M., & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 27, 917-926. doi:10.1017/S0033291706009779

Background. There has been ethical concern that participants in psychiatric research will become distressed and their mental state might worsen.

Method. A systematic search was carried out for studies that examined distress following participation in research that involved the assessment of psychiatric state or associated risk factors. There were 46 relevant studies.

Results. A minority of participants become distressed immediately after participation, with distress more likely in studies of traumatic experiences. There is limited evidence on longer-term effects, but what there is suggests no adverse impact. Positive reactions to participation show little association with distress and these are more common than negative reactions. Very few studies of distress in research have used control groups to establish causal associations. However, what evidence there is suggests no causal role, including for research on suicidality. Researchers in this area have made a range of suggestions about ethical practice.

Conclusions. A minority of participants in psychiatric research become distressed, but there is no evidence of longer-term harm. Nevertheless, researchers need to take account of ethical concerns in designing studies. Future research in the area needs to be carried out with stronger designs involving control groups.

Yanos, P. T., Stanley, B. S., & Greene, C. S. (2009). Research risk for persons with psychiatric disorders: A decisional framework to meet the ethical challenge. *Psychiatric Services*, 60, 374-383. doi:10.1176/appi.ps.60.3.374

Objective: There is a lack of consensus on how to evaluate the risk of research studies conducted with persons who have psychiatric disorders. The authors reviewed research on vulnerability, risk, and procedures to mitigate risk in studies with this population to help inform evaluation of such research.

Methods: Searches of MEDLINE (1966–2006), PsycINFO (1967–2006), and Google Scholar used combinations of the terms mental illness, vulnerable, psychiatric, schizophrenia, and depression combined with terms such as research risk, vulnerability, research harm, capacity, risk, and mitigation of risk. Articles were identified from reference lists, and additional searches used terms from identified articles. Results: Evidence for two types of vulnerability—capacity based and power based—is presented, which supports the notion of vulnerability as a state, rather than a trait, among persons with psychiatric disorders. Three categories of risk are described—minimal risk, minor increment over minimal risk, and greater than minor increment. Evidence shows that many common types of studies pose risk in the first two categories when conducted with this population. The literature also describes procedures for reducing vulnerability and mitigating risk that should be considered in study evaluations. The authors offer a framework for evaluating the category of risk posed by a study. Conclusions: Although more research is needed, there is sufficient evidence that many common types of research present minimal risk or only a minor increment over minimal risk for large segments of the population of persons with psychiatric disorders, as they do for persons in the general population.

Primary Literature

Boothroyd, R. A. (2000). The impact of research participation on adults with severe mental illness. *Mental Health Services Research, 2*, 213-231.

Experiences of adults with mental illness who participated in a 12-month managed care study are summarized. During exit interviews, participants were asked about consent procedures, study purpose, if questions were intrusive or anxiety producing, and concerns about information disclosure. Respondents rated their experience and likelihood of future participation. Almost 38% did not remember the consent procedures. Among those who did, 22.4% reported they lacked adequate detail about the scope of the study. Nearly 3% felt pressured into participating. Although most participants (96%) reported positive experiences, 8.8% became anxious, 16.8% were afraid responses would be disclosed, and 16.7% indicated questions were invasive. Age, race/ethnicity, and gender were not associated with adverse reactions. Symptomatology and perceived inadequacies in consent procedures were significantly, albeit weakly, associated with adverse reactions. Although most participants experienced no distress, rates of adverse responses among persons with mental illness exceeded those of community-

Boothroyd, R. A., & Best, K. A. (2003). Emotional reactions to research participation and the relationship to understanding of informed consent disclosure. *Social Work Research, 27*, 242-251.

Experiences of adults with mental illness who participated in a 12-mo managed care study are summarized. During exit interviews, participants were asked about consent procedures, study purpose, if questions were intrusive or anxiety producing, and concerns about information disclosure. Respondents rated their experience and likelihood of future participation. Almost 38% did not remember the consent procedures. Among those who did, 22.4% reported they lacked adequate detail about the scope of the study. Nearly 3% felt pressured into participating. Although most participants (96%) reported positive experiences, 8.8% became anxious, 16.8% were afraid responses would be disclosed, and 16.7% indicated questions were invasive. Age, race/ethnicity, and gender were not associated with adverse reactions. Symptomatology and perceived inadequacies in consent procedures were significantly, albeit weakly, associated with adverse reactions. Although most participants experienced no distress, rates of adverse responses among persons with mental illness exceeded those of community-based samples. Strategies for minimizing negative reactions are discussed. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Celio, A. A., Bryson, S., Killen, J. D., & Taylor, C. B. (2003). Are adolescents harmed when asked risky weight control behavior and attitude questions? Implications for consent procedures. *International*

Journal of Eating disorders, 34, 251-254.

This study explores whether asking minors about **risky weight control** behaviors and attitudes increases the frequency of those behaviors and attitudes. Participants were 115 sixth-grade girls who responded to **questions** on **risky weight control** behaviors and attitudes at baseline and at 12-month follow-up. An additional 107 girls, who had not been part of the baseline, provided data only at follow-up. The two groups were compared on **risky weight control** behaviors and attitudes at follow-up using chi-square analyses, Mann-Whitney U tests, Cohen's effect sizes, and odds ratios. No evidence of a negative effect in the twice-assessed group was found. All rates decreased from baseline to follow-up. There is only minimal risk and perhaps even some benefit of asking **questions** about **risky weight control** behaviors and attitudes. Implications for determining appropriate consent procedures are discussed. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Cook, A. S., & Bosley, G. (1995). The experience of participants in bereavement research: Stressful or therapeutic? *Death Studies*, 19, 157-170.

21 bereaved Ss (aged 31–69 yrs) who had participated in an interview study of funeral rituals by G. M. Bosley and A. S. Cook (see record 1994-26358-001) completed follow-up questionnaires to assess their thoughts and feelings about the process and outcome of their participation. Ss viewed the overall experience as positive and as an opportunity to express their feelings regarding their loss. They also believed their participation in the research project was beneficial to themselves and to others in a variety of specific ways. These preliminary findings raise questions about the relationship between stress and emotional intensity in a research context. The need for bereaved Ss to have a voice in discussions of ethics in bereavement research is emphasized. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Daugherty, T. K., & Lawrence, J. W. (1996). Short-term effects of research participation on college men. *Journal of Psychology*, 130, 71-77.

College students in a social science core curriculum course were given an option of completing a packet of psychological inventories and demographic questions. The last inventory in the packet, the Lazarus Stress Questionnaire, evaluated the emotional impact of answering the questionnaires. Positive feelings were endorsed significantly more than negative feelings. Further analyses, using the Eysenck Personality Questionnaire and the Life Experiences Survey, revealed characteristics that may predispose participants to positive or negative emotional reactions to participation in research. Results are discussed in terms of self-focus mechanisms and ethical standards in the treatment of students who participate in research.

deGraaf, R., ten Have, M. van Dorsselaer, S., Schoemaker, C., & Vollebergh, W. A. M. (2004). Negative and positive participant responses to the Composite International Diagnostic Interview: Results of the Netherlands Mental Health Survey and Incidence Study. *Social Psychiatry and Psychiatric Epidemiology*, 39, 521-527.

Background:

Little is known about the emotional responses of participants in community surveys to standardised psychiatric interviews like the Composite International Diagnostic Interview (CIDI). This study investigates the proportion of subjects responding negatively or positively to the CIDI, and identifies their sociodemographic, psychopathological, personality and social characteristics.

Methods:

At the end of the three-wave Netherlands Mental Health Survey and Incidence Study, 4796 participants aged 18–64 at baseline were questioned about how the interviews had affected them.

Results:

In all, 2.7% found the interviews quite distressing and 9.5% somewhat distressing. Compared to

those without distress, they were more likely to be female, not living with a partner, not in paid employment, and to have a somatic disorder. A total of 5.7% of subjects reported that participation had helped them cope better with problems, and 3.4% reported they could now seek help more easily. These were more likely to be older, less educated, not in paid employment (except those seeking help more easily) and to have a somatic disorder. Both negative and positive responses were associated with mood, anxiety and substance use disorders and comorbidity, as well as with neuroticism, external mastery, low self-esteem and low social support.

Conclusion:

Only a small minority of participants reported distress from the interviews. This is an important finding for ethics committees charged with approving general population surveys that use the CIDI. It can also be valuable for planning such studies, enabling researchers to inform participants more fully about the effects of the interview before asking them for informed consent.

Fendrich, M., Lippert, A. M., & Johnson, T. P. (2007). Respondent reactions to sensitive questions. *Journal of Empirical Research on Human Research Ethics*, 2, 31-37. doi:10.1525/jer.2007.2.3.31

We administered debriefing probes to gauge respondent discomfort in reaction to sensitive questions. These probes assessed respondents' own reactions to being asked to report on substance use (subjective discomfort), as well as their beliefs about the reaction of others (projective discomfort). We investigated whether a sample of men from the general population were more uncomfortable with questions about drug use than a sample of men who have sex with men (MSM) surveyed from the same city (Chicago). We also investigated whether those who disclosed drug use on the survey experienced higher levels of discomfort. Contrary to opinions often expressed as research ethics committee (REC) recommendations, questions about drug use do not generate much subjective discomfort. MSM did not differ from the general population with respect to subjective discomfort. General population males did, however, report higher levels of "drug specific" projective discomfort. Respondents disclosing recent drug use reported higher levels of subjective discomfort. Implications for the REC practice, researcher and REC education, and directions for future research are discussed.

Ferrier-Auerbach, A. G., Erbes, C. R., & Polusny, M. A. (2009). Does trauma survey research cause more distress than other types of survey research? *Journal of Traumatic Stress*, 22, 320-323. Retrieved from EBSCOhost.

Members of institutional review boards who evaluate trauma research protocols frequently face the task of balancing potential risk with potential benefit. However, no known study has examined the relative effect of participating in a trauma-related survey compared to participating in a nontrauma survey. The authors randomly assigned participants receiving care in an outpatient PTSD treatment program to complete questionnaires assessing either trauma-related or nontrauma content. Participants completing trauma-related questionnaires reported feeling sadder and more tense than other participants, though they did not report differences in perceived gain from participation or retrospective willingness to participate. Results suggest that level of distress after participating in trauma research was insufficient to reduce willingness for, or perceived benefit from, participation in trauma survey research.

Halek, K., Murdoch, M. and Fortier, L. (2005). Spontaneous reports of emotional upset and health care utilization among Veterans with posttraumatic stress disorder after receiving a potentially upsetting survey. *American Journal of Orthopsychiatry*, 75, 142-151. doi:10.1037/0002-9432.75.1.142

This study assessed the effects of a potentially distressing mailed survey on the emotional well-being and health care utilization (HCU) of 4,918 male and female veterans who applied for posttraumatic stress disorder disability benefits. Content analysis of spontaneous comments, in combination with analysis of subjects' HCU before and after receipt of the survey, suggested that spontaneously

disclosed episodes of emotional upset were rare. In general, surveyed veterans' HCU decreased after receipt of the survey.

Henderson, A. S., & Jorm, A. F. (1990). Do mental health surveys disturb? *Psychological Medicine*, 20, 721-724.

We have tested the assumption that mental health surveys do not cause distress. At the end of a two-wave community survey of psychiatric symptoms and personality factors, respondents were asked specific questions about how the interviews affected them. Being interviewed was distressing for some individuals, but it was seen as beneficial by a larger number. Those reporting distress were more likely to have had neurotic symptoms prior to both interviews and to have personality characteristics which would indicate proneness to distress. Whether the distress lasted beyond the interview situation is unknown. These results suggest that surveys of mental health should tell intended respondents about the possible effects of the interview, both positive and negative. Some studies should try to estimate the duration of any distress reported to have been induced.

Herjanic, B., Hudson, R., & Kotloff, K. (1976). Does interviewing harm children? *Research Communications in Psychology, Psychiatry and Behavior*, 1, 523-531.

In an effort to establish guidelines for assessing the possible risks involved in administering structured research interviews to children, 99 parental and 70 child responses to a follow-up questionnaire and 88 child responses to a questionnaire given immediately after the structured interview were analyzed. Children were aged 6-17 yrs. Only 3 mothers of pre-adolescent boys and 1 pre-adolescent girl indicated possible bad effects from the interview experience. All of the remaining 253 responses were neutral or favorable, giving a risk ratio of approximately 1 to 63. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Jacomb, P. A., Jorm, A. F., Rodgers, B., Korten, A. E., Henderson, A. S., & Christensen, H. (1999). Emotional response of participants to a mental health survey. *Social Psychiatry and Psychiatric Epidemiology*, 34, 80-84.

Following participation in a mental health survey of 2725 adults aged 18–79, respondents were asked if the questionnaire had made them feel distressed or depressed, and if it had been an intrusion on privacy or had made them feel good about themselves. While 5% reported feeling distressed, 3% depressed and 3% were concerned about privacy, 35% reported feeling good about themselves. The participants reporting negative feelings were more likely to be younger women, to be higher on negative personality measures, to report more anxiety and depression symptoms, and to have had more childhood adversity and lower social support. Those who reported positive feelings had higher positive personality scores, more social support and lower anxiety and depression. This group was more likely to be older women. Despite the sensitive nature of many of the questions, only a small percentage of respondents reported distress, while many found that the questionnaire had made them feel good about themselves. This is important information to present to Institutional Ethics Committees and to future participants in such studies.

Jorm, A. F., Henderson, A. S., Scott, R., Mackinnon, A. J., Korten, A. E., & Christensen, H. (1994). Do mental health surveys disturb? Further evidence. *Psychological Medicine*, 24, 233-237.

In a community survey of 873 persons aged 70 years or over, focusing on dementia, cognitive decline, depression, and current life circumstances, we included an enquiry into the emotional impact of the interview. A large majority reported at the end of the interview that it had no adverse effect on their emotional state. About 4% reported that it made them distressed, 1% that it depressed them, and 2% that it had intruded on their privacy. By contrast, 52% said it had made them feel good about

themselves. Distress seemed to be largely related to performing poorly on cognitive tests. There is no information on the duration of these effects in the period following the interview. It is recommended that respondents in community surveys, including the elderly, be informed that they can decline to answer any question, and that interviewers be trained in how to respond to the few who will be distressed by the experience.

Kreicbergs, U., Valdimarsdottir, U., Steineck, G., & Henter, J.-I. (2004). A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer. *Lancet*, *364*, 787.

A proposed nationwide postal questionnaire to Swedish parents who had lost a child due to cancer between 1992 and 1997 was denied approval by the local ethics committee. However, a pilot study to assess the harm and benefit of the questionnaire was approved. 95% of parents found the pilot study valuable; thus, we were allowed to proceed with the main study, which consisted of 129 questions about the child's care and death and five about the parents' perceptions of the study. 423 (99%) parents found the investigation valuable, 285 (68%) were positively affected, and 123 (28%) were negatively affected (10 [2%] of whom, very much). Although the numerical data cannot be directly translated to ethical conclusions, they can provide guidance for future ethical decisions.

Marshall, R. D., Spitzer, R. L., Vaughan, S. C., Vaughan, R., Mellman, L. A., MacKinnon, R. A., & Roose, S. P. (2001). Assessing the subjective experience of being a participant in psychiatric research. *American Journal of Psychiatry*, *158*, 319-321. doi:10.1176/appi.ajp.158.2.319

To address both clinical and ethical concerns in psychiatric research, this study assessed the subjective experience of being a participant in a feasibility study of outcome in long-term psychodynamic psychotherapy and psychoanalysis. A questionnaire assessing positive and negative reactions to 3 typical research methodologies (self-report questionnaires, structured diagnostic interviews, and tape-recording of sessions) was administered to 23 patient-therapist pairs. Patients reported that questionnaires and interviews were slightly to moderately helpful in promoting self-realization and facilitating therapy, and not at all to slightly intrusive and disruptive. Adjustment to audio taping of sessions was rapid (within 2 sessions). Therapists significantly overestimated the negative effects and underestimated the positive benefit patients reported from participating in research. The authors conclude that traditional objections to research in dynamic psychotherapy on the grounds that patients experience research procedures as significantly intrusive and disruptive appear to be unfounded.

Mosher, D. J., Schultz, S. K., Arndt, S., Benjamin, M. L., Fleming, F. W., Brems, C. S., Paulsen, J. S., Applebaum, P. S., & Andreasen, N. C. (2002). Capacity to provide informed consent for participation in schizophrenia and HIV research. *American Journal of Psychiatry*, *159*, 1201-1207.

OBJECTIVE: The degree to which people with psychiatric symptoms and cognitive dysfunction can provide informed consent to participate in research is a controversial issue. This study was designed to examine the capacity of subjects with schizophrenia and subjects with HIV to provide informed consent for research participation and to determine the relationships among cognitive dysfunction, psychiatric symptoms, and decisional capacity. **METHOD:** Twenty-five men and women with a DSM-IV diagnosis of schizophrenia and 25 men and women with HIV were recruited. The groups were compared in terms of neuropsychological functioning, psychiatric symptoms, and ability to provide informed consent to a hypothetical drug trial. **RESULTS:** Eighty percent of the subjects with schizophrenia and 96% of the HIV-positive subjects demonstrated adequate capacity to consent to the hypothetical drug trial, but subjects in the schizophrenia group had significantly lower scores on two of the four aspects of decisional capacity. For the subjects with schizophrenia, neuropsychological functioning and psychiatric symptoms (e.g., apathy and avolition), but not psychotic symptoms (e.g.,

hallucinations and delusions), were significantly associated with decisional capacity.

CONCLUSIONS: The majority of subjects who are recruited and willing to participate in schizophrenia or HIV research will have adequate capacity to provide consent. Cognitive dysfunction and the symptoms shown to be associated with impaired decisional capacity are not unique to schizophrenia and may occur with many other forms of illness. These findings underscore the importance of considering how decisional capacity will be assessed in all types of research, regardless of the specific condition being studied.

Parslow, R. A., Jorm, A. F., O'Toole, B.I., Marshall, R. P. & Grayson, D. A. (2000). Distress experienced by participants during an epidemiological survey of posttraumatic stress disorder. *Journal of Traumatic Stress, 13*, 465-471. doi:10.1023/A:1007785308422

We examined the potential for epidemiological studies of mental disorders, specifically of posttraumatic stress disorder (PTSD), to cause further harm to participants involved. Of 1,000 randomly selected Australian Vietnam veterans, 641 agreed to participate in an epidemiological survey. Participants were asked about distress experienced during the interview when traumatic events were raised. Significant distress attributed to the interview was reported by 75.3% of those with current PTSD, 56.5% of those with past PTSD, and 20.6% of those with no PTSD diagnosis. Distress did not affect participants' use of medical services following the interview nor did it affect their willingness to continue participating in the study. We concluded that research interviews about PTSD may cause short-term distress, but found no evidence of long-term harm.

Turnbull, J. E., McLeod, J. D., Callahan, J. M., & Kessie, R. C. (1988). Who should ask? Ethical interviewing in psychiatric epidemiologic studies. *American Journal of Orthopsychiatry, 58*, 228-239.

In a recent survey examining responses to life stress, difficulties were encountered by lay interviewers. These are addressed, as are ethical issues arising from the combination of survey and clinical methodologies. The issues of respondent harm and informed consent are discussed and initial strategies outlined.

Widom, C. S., & Czaja, S. J. (2005). Reactions to research participation in vulnerable subgroups. *Accountability in Research, 12*, 115-138.

This paper describes the extent to which vulnerable individuals (defined by economic, social, psychological, physical health, and child maltreatment status) react to research participation. As part of an ongoing longitudinal study, participants (N = 896) completed a lengthy and intrusive in-person interview and provided a small amount of blood through finger pricks. At the end of the interview, participants were asked eight questions about their reactions to the research experience. Vulnerable individuals in general agreed more strongly about having an emotional reaction, but were not less willing to continue to participate. In addition, psychologically vulnerable individuals more strongly agreed they would continue to participate, were treated with respect and dignity, and found their participation meaningful. Compared to whites, nonwhites reported stronger agreement about the meaningfulness of the research and the belief that their responses would be kept private. Like others, individuals vulnerable by virtue of their prisoner status or homelessness (past or current) agreed more strongly about having an emotional reaction to the interview, but otherwise did not differ in their reactions. These results suggest that researchers and institutional review boards should not be deterred from conducting research on sensitive topics with potentially vulnerable populations.

Zimmerman, M., Farber, N. J., Hartung, J., Lush, D. T., & Kuzma, M. A. (1994). Screening for psychiatric disorders in medical patients: A feasibility and patient acceptance study. *Medical Care, 32*, 603-608.

Examined patient responses to being asked to complete a questionnaire about substance-use and emotional problems and determined whether SCREENER, a newly developed, brief questionnaire that screened for several psychiatric disorders, was easy for patients to complete. 703 Ss (mean age 59.2 yrs) were asked to complete the SCREENER and to answer a 2nd questionnaire about their opinions on the 1st measure. Both long and short forms of the SCREENER were used. Only 3.1% of Ss indicated that the questions were difficult to answer, and between 80% and 90% of Ss were not embarrassed, upset, annoyed, or uncomfortable about answering the questions. Ss with a history of psychiatric treatment and poorer current mental health were the most likely to have a negative reaction to the questionnaire. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Zimmerman, M., Lush, D. T., Farber, N. J., Hartung, J., Plescia, G., Kuzma, M. A., & Lish, J. (1996). Primary care patients' reactions to mental health screening. *International Journal of Psychiatry in Medicine*, 26, 431-441.

Objective: The authors examined whether there is empirical support for the notion that medical patients are upset by being asked questions about psychiatric disorders. *Method:* Six hundred and one patients attending a primary care clinic completed the SCREENER—a newly developed, brief self-administered questionnaire that surveys a broad range of psychopathology. In addition, they completed a second questionnaire that assessed their attitudes toward the SCREENER. *Results:* We found a high level of acceptance by patients. The questions were judged easy to answer, and they rarely aroused significant negative affect. Fewer than 2 percent of the patients judged the questions difficult to answer, and fewer than 3 percent were "very much" embarrassed, upset, annoyed, or uncomfortable with the questions. Individuals with a history of psychiatric treatment and poorer current mental health reacted more unfavorably to the questionnaire. *Conclusions:* From the patient's perspective, it is feasible and acceptable to use self-administered questionnaires for routine screening of psychiatric problems in primary care settings.

Sexual Abuse

Overview

Wager, N. (2011). Researching sexual revictimisation: Associated ethical and methodological issues, and possible solutions. *Child Abuse Review*, 20. Online Preview. doi:10.1002/car.1152

This paper has been inspired by the processes of preparing for ethical scrutiny and seeking ethical approval for a series of studies examining causal mechanisms that might facilitate sexual revictimisation. The focus here is on just four of the issues that arose in the context of the first study: a web-based survey. One of the aims of the survey is to test whether victims of child sexual abuse who experienced a period of psychogenic or dissociative amnesia demonstrate an exaggerated risk for adolescent/adult sexual assault during this amnesic phase. That is, cases where survivors report 'suddenly remembering' in adulthood that they were abused as children, but state that prior to this 'remembering' they had no prior knowledge of their abuse. The study design is considered to be the first ethical issue. To enhance the methodological robustness a strategy has been employed to reduce the erroneous inclusion of currently amnesic participants in the non-abused comparison group. Secondly, consideration is given to the likely harms and benefits that might be incurred or bestowed upon the participants. Thirdly, problems of both re-traumatisation and vicarious traumatisation in relation to the researcher are contemplated and juxtaposed against the possibility of the facilitation of post-traumatic growth and a personal shift towards wisdom and generativity. Finally, the survey title was originally criticised as negating 'fully' informed consent and a defence is therefore offered that ultimately gained ethical approval. It is hoped that these deliberations and insights may prove useful to others in planning their own research and ethics proposals.

Primary literature

Campbell, R., & Adams, A. E. (2009). Why do rape survivors volunteer for face-to-face interviews? A meta-study of victims' reasons for and concerns about research participation. *Journal of Interpersonal Violence*, 24, 395-405. doi:10.1177/0886260508317192

There is growing interest in understanding how different research methods are perceived by victims of violence and what survivors will reveal to researchers (termed meta-research or meta-studies). The purpose of this project was to conduct a qualitative meta-study on why rape survivors chose to participate in community-based, face-to-face interviews. Participants mentioned four primary reasons for why they decided to participate in this study: (a) to help other survivors, (b) to help themselves, (c) to support research on rape/sexual assault, and (d) to receive financial compensation. Implications for designing research recruitment protocols are discussed.

Edwards, K. M., Kearns, M. C., Calhoun, K. S., Gidycz C. Z. (2009). College women's reaction to sexual assault research participation: Is it distressing? *Psychology of Women Quarterly*, 33, 225–234. Retrieved from EBSCOhost.

This study assessed college women's reactions to participating in sexual assault research. Women with sexual victimization histories reported more negative emotional reactions than nonvictimized women, but also greater benefits. Benefits to research participation outweighed costs for both women with and without sexual victimization histories. Women with and without sexual victimization histories evidenced significant improvements in several domains of mood over the course of the study, although victimized women improved less in several areas of mood. Participants' pre-survey mood, assault severity, perpetrator aggression, self-blame, and perceived benefits to research participation all uniquely predicted participants' immediate negative emotional reactions to the research protocol. Descriptive analyses showed that only a small number of women reported negative emotional reactions to the research protocol.

Martin, J. L., Perrott, K., Morris, E. M., & Romans, S. E. (2001). Participation in retrospective child sexual abuse research: Beneficial or harmful? What women think six years later. In L. M. Williams & V. L. Banyard (Eds.), *Trauma and memory* (pp. 149-159). Thousand oaks, CA: Sage.

(from the chapter) We present findings about women's reactions to research focusing on child sexual abuse (CSA) and mental health that have both ethical and practical implications for researchers interested in pursuing links between trauma and memory. A two-stage survey (1989, 1995) in a community sample of 497 women gave us the opportunity to ask about long-term reactions to involvement in child sexual abuse research. Exactly 10 times more CSA reporters remembered the first interview as positive than remembered it as negative. The number of women who felt positive was twice the number who evaluated the interview either neutrally or negatively. As well, CSA reporters were significantly more likely to evaluate positively than were non-CSA reporters. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Rabenhorst, M. M. (2006). Sexual assault survivors' reactions to a thought suppression paradigm. *Violence and Victims*, 21, 473-481.

Trauma survivors may experience harm from participating in research on sensitive topics. The current study assessed reactions of sexual assault survivors with and without symptoms of post-traumatic stress disorder (PTSD) immediately following an experimental thought suppression task and at a 2- to 4-week follow-up period, by asking open-ended questions regarding thoughts about the experiment, feelings following the experiment, and willingness to participate in similar experiments. At both time periods, most participants reported neutral/positive thoughts (e.g.,

"interesting") and feelings (e.g., "fine, good") and indicated that they would participate in a similar study. Findings suggest that the majority of sexual assault survivors were not harmed in the short- or long-term by participation in a thought suppression paradigm in which the target of suppression/expression was their own trauma. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Suicidality

Primary Literature

Asgard, U., & Carlsson-Bergstrom, M. (1991). Interviews with survivors of suicide: Procedures and follow-up of interview subjects. *Crisis, 12*, 21-33.

Described the experience of informants and examined their attitudes concerning the life and suicide of a close relative. 91 primary informants were interviewed face-to-face, and 62 informants were interviewed by phone at follow-up to determine their attitudes toward the initial interview. One-third of the Ss thought that the initial interview shed new light on the suicide, and two-thirds considered the interview emotionally beneficial. In all, the initial interview was a positive or neutral experience for 54 Ss and was negative for 6. All but one of the latter group were recognized as problematic at the initial interview. The remaining 2 Ss could not be judged at follow-up. To avoid negative consequences of interviews, the investigator should adjust the procedures and provide support in cases of crisis reaction. (German & French abstracts) (PsycINFO Database Record (c) 2010 APA, all rights reserved)

Beskow, R. B. (1991). Reactions of survivors of suicide victims to interviews. *Acta Psychiatria Scandinavica, 83*, 169-173.

Fifty-eight consecutive suicides committed between 1984 and 1987 by adolescents and young adults (age 15-29 years) in an urban community were the subject of retrospective investigations by means of interviews with survivors. The outcome of the survivors' crisis reactions and the interviewees' capacity to participate in the interviews were evaluated. Two weeks after a main interview, a follow-up interview dealing with the interviewee's reactions to the investigation was performed. The cautious interview procedure seemed very acceptable to the survivors. An initial contact about 2 months after the suicide is recommended. Tape-recording was generally tolerated. There was a relationship between a satisfactory outcome of the crisis and good quality of the information given by the interviewee, but survivors in severe crisis may also cooperate well and give information with good trustworthiness and precision. An unsatisfactory crisis outcome was significantly more common in interview subjects with post-traumatic stress disorder according to DSM-III-R. Many interviewees benefit from the single interview.

Hahn, W. K., & Marks, L. I. (1996). Client receptiveness to the routine assessment of past suicide attempts. *Professional Psychology: Research and Practice, 27*, 592-594. doi:10.1037/0735-7028.27.6.592

Approximately 14% of male and 22% of female college students participating in individual therapy reported having had a suicide attempt at some point in their lives, and 50% of the individuals with a history of suicide attempt discussed the attempt during the intake interview. Approximately 77% of all clients were receptive to the routine evaluation of past suicide attempts, whereas approximately 20% were undecided. Only 3% of all respondents reported it was not a good idea to assess past suicide attempts routinely. The authors recommend including the routine assessment of suicide risk factors into intake protocols.

Gould M. S., Marrocco F. A., Kleinman M., Thomas J. G., Mostkoff, K., Cote J., & Davies M. (2005). Evaluating iatrogenic risk of youth suicide screening programs: A randomized controlled trial. *Journal of American Medical Association*, 293, 1635-1643. doi:10.1001/jama.293.13.1635

Context: Universal screening for mental health problems and suicide risk is at the forefront of the national agenda for youth suicide prevention, yet no study has directly addressed the potential harm of suicide screening.

Objective: To examine whether asking about suicidal ideation or behavior during a screening program creates distress or increases suicidal ideation among high school students generally or among high-risk students reporting depressive symptoms, substance use problems, or suicide attempts. **Design, Setting, and Participants** A randomized controlled study conducted within the context of a 2-day screening strategy. Participants were 2342 students in 6 high schools in New York State in 2002-2004. Classes were randomized to an experimental group (n = 1172), which received the first survey with suicide questions, or to a control group (n = 1170), which did not receive suicide questions.

Main Outcome Measures: Distress measured at the end of the first survey and at the beginning of the second survey 2 days after the first measured on the Profile of Mood States adolescent version (POMS-A) instrument. Suicidal ideation assessed in the second survey.

Results: Experimental and control groups did not differ on distress levels immediately after the first survey (mean [SD] POMS-A score, 5.5 [9.7] in the experimental group and 5.1 [10.0] in the control group; $P = .66$) or 2 days later (mean [SD] POMS-A score, 4.3 [9.0] in the experimental group and 3.9 [9.4] in the control group; $P = .41$), nor did rates of depressive feelings differ (13.3% and 11.0%, respectively; $P = .19$). Students exposed to suicide questions were no more likely to report suicidal ideation after the survey than unexposed students (4.7% and 3.9%, respectively; $P = .49$). High-risk students (defined as those with depression symptoms, substance use problems, or any previous suicide attempt) in the experimental group were neither more suicidal nor distressed than high-risk youth in the control group; on the contrary, depressed students and previous suicide attempters in the experimental group appeared less distressed ($p = .01$) and suicidal ($p = .02$), respectively, than high-risk control students.

Conclusions: No evidence of iatrogenic effects of suicide screening emerged. Screening in high schools is a safe component of youth suicide prevention efforts.

Reynolds, S. K., Lindenboim, N., Comtois, K. A., Murray, A., & Linehan, M. M. (2006). Risky assessments: Participant suicidality and distress associated with research assessments in a treatment study of suicidal behavior. *Suicide and Life-threatening Behavior*, 36, 19-34.

The purpose of this study was to examine patterns of self-reported suicidality and distress during research assessments in a sample of 63 women meeting criteria for borderline personality disorder and current and chronic suicidality. The risk management protocol we used during the two-year study period (University of Washington Risk Assessment Protocol; UWRAP) is described. Results indicated that changes in suicidality following assessments were small and relatively infrequent, and were just as likely to reflect decreases in suicidality as increases (17.5% versus 16.4% of sessions, respectively). Further, longitudinal analyses indicated that changes in suicidality became increasingly rare over the course of the 2-year study. Ratings of distress were more changeable than suicidality, underscoring the need for separate measurement of these constructs when assessing risk. With the aid of the UWRAP, our assessors judged 15 participants as high-risk status in 28 assessment sessions (3.7% of all sessions). In comparison to the rest of the sample, these individuals were of significantly greater clinical severity as measured by the HRSD 17-item, GAF scores, number and severity of previous suicide attempts, and number of previous psychiatric hospitalizations. Low-intensity risk intervention strategies (e.g., validating participant's feelings) were typically sufficient to reduce risk in these participants. Overall, our findings indicate that research with highly suicidal individuals can be done safely with the use of well-trained assessors

and an appropriate crisis management protocol.

Runeson, B., & Beskow, J. (1991). Reactions of survivors of suicide victims to interviews. *Acta Psychiatrica Scandinavica*, 83, 169-173.

Fifty-eight consecutive suicides committed between 1984 and 1987 by adolescents and young adults (age 15-29 years) in an urban community were the subject of retrospective investigations by means of interviews with survivors. The outcome of the survivors' crisis reactions and the interviewees' capacity to participate in the interviews were evaluated. Two weeks after a main interview, a follow-up interview dealing with the interviewee's reactions to the investigation was performed. The cautious interview procedure seemed very acceptable to the survivors. An initial contact about 2 months after the suicide is recommended. Tape-recording was generally tolerated. There was a relationship between a satisfactory outcome of the crisis and good quality of the information given by the interviewee, but survivors in severe crisis may also cooperate well and give information with good trustworthiness and precision. An unsatisfactory crisis outcome was significantly more common in interview subjects with post-traumatic stress disorder according to DSM-III-R. Many interviewees benefit from the single interview.

Smith, P., & Poindexter, E., & Cukrowicz, K. (2010). The effect of participating in suicide research: Does participating in a research protocol on suicide and psychiatric symptoms increase suicide ideation and attempts? *Suicide and Life-threatening Behavior*, 40, 535-543.

The effect of engaging in an intensive research protocol that inquired extensively about psychiatric and suicide symptoms and exposed participants to a number of images, including suicide-related content was explored. Individuals experiencing a major depressive episode were called at 1 and 3 months after the initial protocol. Participants were asked about changes in suicide ideation and the occurrence of self-harm or suicide attempts following participation. Participants reported experiencing reductions in suicide ideation at the first follow-up and no changes at the second follow-up. No participant reported having engaged in self-harm or having attempted suicide at either follow-up. Results suggest that basic science/nontreatment research can be conducted safely with suicidal participants and in a manner that does not increase suicide symptoms or suicide risk.

Trauma

Reviews

Newman, E., & Kaloupek, D. G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17, 383-394. Retrieved from EBSCOhost.

Concern about minimizing harm and maximizing benefit has been particularly acute with regard to the scientific study of individuals exposed to potentially traumatic events such as terrorist attack or disaster. This review outlines conceptual and practical issues and summarizes available evidence regarding potential risks and benefits of participation in trauma-related research. Current, limited evidence suggests that most individuals make favorable cost-benefit appraisals regarding their participation. Although a subset of participants report strong negative emotions or unanticipated distress, the majority of these do not regret or negatively evaluate the overall experience. Continuing efforts are needed to identify individuals at risk for unfavorable reactions to research participation. A systematic empirical approach to evaluating participant experience in all human research is recommended.

Newman, E., & Risch, E. (2006). Ethical issues in trauma-related research: A review. *Journal of*

Ethical decision-making about trauma-related studies requires a flexible approach that counters assumptions and biases about victims, assures a favorable ethical cost-benefit ratio, and promotes advancement of knowledge that can benefit survivors of traumatic stress. This paper reviews several ethical issues in the field of traumatic stress: benefit and risks in trauma-related research, whether trauma-related research poses unique risks and if so what those might be, informed consent and mandatory reporting, and supervision of trauma-related research. For each topic, we review potential ethical issues, summarize the research conducted thus far to inform ethical practice, and recommend future practice, research questions and policies to advance the field so that research on trauma can continue to be a win-win situation for all stakeholders in the research enterprise.

Newman, E., Willard, T., Sinclair, R., & Kaloupek, D. (2001). The costs and benefits of research from the participants' view: The path to empirically informed research practice. *Accountability in Research*, 8, 27-47. Retrieved from EBSCOhost.

Concern about minimizing harm and maximizing benefit has been particularly acute with regard to the scientific study of individuals exposed to potentially traumatic events such as terrorist attack or disaster. This review outlines conceptual and practical issues and summarizes available evidence regarding potential risks and benefits of participation in trauma-related research. Current, limited evidence suggests that most individuals make favorable cost-benefit appraisals regarding their participation. Although a subset of participants report strong negative emotions or unanticipated distress, the majority of these do not regret or negatively evaluate the overall experience. Continuing efforts are needed to identify individuals at risk for unfavorable reactions to research participation. A systematic empirical approach to evaluating participant experience in all human research is recommended.

Primary literature

Brabin, P. J., & Berah, E. F. (1995). Dredging up past traumas: Harmful or helpful? *Psychiatry, Psychology and Law*, 2, 165-171. doi:10.1080/13218719509524863

Describing traumatic experiences is a routine feature of mental health assessment and treatment; it is accepted that, in the clinical context this will be distressing to some patients. Research on the experience and sequelae of *trauma* is also a situation where people may be asked for detailed accounts of traumatic experiences. A common concern voiced by ethics committees is whether the process of reviving memories of *past traumas* may adversely affect the research participant. The study to be described here attempts to shed some light on this issue. At the conclusion of intensive interviews with 257 mothers and 160 fathers who had a stillborn baby some years earlier, parents were asked about the extent to which they found the interview distressing and the extent to which they found it helpful or unhelpful. We found that of the small proportion of parents who found the interview distressing, nearly all reported that it had also been helpful to them. These data suggest that, in evaluating research which involves the evocation of painful memories, ethics committees should not focus on whether participants will become distressed by the research, but rather on whether the study is designed in such a way that the final outcome will be a positive one for participants.

Carlson, E. B., Newman, E., Daniels, J. W., Armstrong, J., Roth, D., & Loewenstein, R. (2003). Distress in response to and perceived usefulness of trauma research interviews. *Journal of Trauma and Dissociation*, 4, 131-142. doi:10.1300/J229v04n02_08

Because studying trauma often involves asking about upsetting experiences, it is important for researchers to study the effects of such interviews on research participants, particularly those who may be more vulnerable. In a study of psychiatric inpatients that included a structured interviews for PTSD and childhood physical and sexual assault experiences, participants rated how upsetting and how helpful or useful they found the interview. Of the 223 participants for whom we knew level of distress, 70% experienced relatively low levels of distress, and 51% found participation to be useful in some way. Level of upset was moderately to strongly related to levels of past trauma and current symptoms, while perceived usefulness was not significantly related to any experiences or symptoms.

Dean, K. L., Stein, B. D., Jaycox, L. H., Kataoka, S. H., & Wong, M. (2004). Acceptability of asking parents about their children's traumatic symptoms. *Psychiatric Services*, 55, 866.

Providing trauma screening and services did not appear to induce distress among parents of children who had been traumatized by violence. The positive parental response has important implications for trauma-based services and research in the community and schools.

DePrince, A. P. & Chu, A. (2008). Perceived benefits in trauma research: Examining methodological and individual difference factors in responses to research participation. *Journal of Empirical Research on Human Research Ethics*, 3, 35-47. doi:10.1525/jer.2008.3.1.35

This study examined methodological and individual difference factors in relation to perceived benefits and cost-benefit ratios among adult participants in trauma-related research. In two samples (N's = 72 and 118), ethnically-diverse community participants completed trauma-related questionnaires plus an in-depth interview. In separate community (N = 213) and undergraduate (N = 130) samples, participants completed trauma-related questionnaires, but no interviews. Participants rated their perceptions of the research process using the Response to Research Participation Questionnaire (RRPQ). Cost-benefit ratios were favorable in all samples. The research procedures (questionnaires only versus questionnaires plus interviews) explained unique variance in RRPQ scale scores and cost-benefit ratios, as did trauma-related distress. Implications of these findings for developing trauma research protocols are discussed.

DePrince, A. P., & Freyd, J. J. (2004). Costs and benefits of being asked about trauma history. *Journal of Trauma Practice*, 4, 23-35.

How do participants feel about trauma history questions in research? We asked 528 undergraduate and community participants to answer three questions about their experience of completing the Brief Betrayal Trauma Survey (BBTS; Goldberg & Freyd, 2004), a self-report trauma measure. The questions tapped (1) participants' experience of whether the trauma history questions were more or less distressing than things encountered in day-to-day life, (2) how important participants believe it is for psychologists to ask about these events, and (3) how good of an idea, according to participants, it is to include such a measure in psychology research. Participants indicated that, on average, questions about trauma are neutral compared to day-to-day experiences. Further, participants reported that research asking about stressful life events is more than "somewhat important," and that including such measures is more than "somewhat good." These results do not support the assumption that trauma history questions are harmful to participants and suggest that participants, on average, appreciate the inclusion of trauma questions in psychological research.
© 2004 by The Haworth Press, Inc. All rights reserved.]

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science and Medicine*, 58, 391-400. doi:10.1016/S0277-9536(03)00205-3

Despite the ethical codes guiding bereavement research, few studies have been conducted to evaluate the perceived stress experienced by the bereaved, and to explore which methodologies cause least distress. This article investigates how bereaved and traumatised populations experience research participation, and they voice their recommendations for future research. The data are from a nationwide three-phase study in Norway among parents who had lost their child by suicide, SIDS, and accidents between July 1, 1997 and December 31, 1998. Whereas the first phase reported quantitative results of perceived psychosocial health and focused on offered and ideal support (N = 262), the second phase investigated the same issues through in-depth interviews of a sub sample (N = 69). Phase three, reported here, included the responses of 64 parents to a short questionnaire evaluating research participation in the two previous phases. The results show that 100% of the parents experienced participation as "positive"/"very positive", and none regretted participating. In order to protect bereaved and vulnerable populations from harm, already existing ethical codes must be strictly applied, and the researchers must listen respectfully to recommendations from bereaved parents.

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. Retrieved from EBSCOhost.

Few studies have examined the impact of trauma research participation upon trauma survivors. Empirical data regarding reactions to research participation would be very useful to address the question of whether it is harmful for trauma survivors to participate in trauma studies. We examined participant reactions to different trauma assessment procedures in 260 domestic violence, 108 rape, and 62 physical assault samples. Results indicated that participation was very well tolerated by the vast majority of the trauma survivors. Participants generally found that the assessment experience was not distressing and was, in fact, viewed as an interesting and valuable experience. The findings suggest that trauma survivors are not too fragile to participate in trauma research even in the acute aftermath of a traumatic experience.

Johnson, L. E., & Benight, C. C. (2003). Effects of Trauma-Focused Research on Recent Domestic Violence Survivors. *Journal of Traumatic Stress*, 16, 567-571. Retrieved from EBSCOhost.

This study investigated the impact of trauma-focused research on domestic violence survivors. At the end of a survey assessing psychological distress, abuse severity, coping self-efficacy (CSE), and cognitions, questionnaire items were utilized to assess participants' levels of gain, unexpected upset, and regret of participation. Participants were 55 women who had recently experienced abuse by a partner. Forty-five percent reported positive gain from participation, 25% reported they were more upset than anticipated, and a minority of women (6%) expressed regret for participation. Results indicated that women who were more upset than expected scored significantly higher on depression, posttraumatic stress disorder (PTSD), and number of lifetime traumas, and significantly lower on CSE. Implications for enhancement of consent form documents and debriefing procedures are addressed.

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. doi:10.1016/S0163-8343(02)00200-1

Systematic assessment of the effect of clinical research studies on child and parent participants has been limited. Such assessment could provide an empirical basis for the ethical conduct of research, assisting investigators and institutional review boards in balancing the need for sound research with

the need to protect study participants. The Reactions to Research Participation Questionnaire for Children (RRPQ-C) and the RRPQ for Parents (RRPQ-P) are brief measures designed to assess child or parent views of clinical research studies. Both measures were piloted and then administered as part of an interview-based study of traumatically injured children (aged 5-17 yrs) and their parents, to assess their psychometric properties and potential usefulness as addenda to future study protocols. The RRPQ-C and RRPQ-P each demonstrated acceptable internal consistency. Both were easily administered and well-accepted by respondents. There is evidence that children and adults were willing to answer honestly, even about negative responses. Brief measures such as the RRPQ-C and RRPQ-P may provide a practical and empirically informed method for assessing children's and parents' responses to research participation.

Newman, E., Walker, E. A. & Gefland, A. (1999). Assessing the ethical costs and benefits of trauma-focused research. *General Hospital Psychiatry*, 21, 187-196. doi:10.1016/S0163-8343(99)00011-0

This study examines the frequency and correlates of adverse reactions and adequacy of informed consent among 1,174 women in an HMO who completed a trauma-focused health survey, and a subset of 252 women who later completed a trauma-focused research interview. The majority of women found participation in the interview and the questionnaire study to be a positive experience. Although a small number of women, particularly those with a history of maltreatment, underestimated the level of upset they would subsequently experience, the majority still did not regret participating, indicating that informed consent procedures were adequate, with a large proportion reporting immediate perceptions of personal gain. The cost-benefit ratio appears stable 48 hrs post-interview. Results suggest that research on childhood victimization is well tolerated by women who participate. In general, adverse reactions appear less common than previously anticipated.

Schwerdtfeger, K. L. (2009). The appraisal of quantitative and qualitative trauma-focused research procedures among pregnant participants. *Journal of Empirical Research on Human Research Ethics*, 4, 39-51. doi:10.1525/jer.2009.4.4.39

Despite the importance of studying the dynamics and consequences of trauma, there has been concern that trauma-focused questionnaires and interviews could further harm vulnerable participants, such as pregnant women who have suffered prior sexual trauma (e.g., rape, incest, sexual abuse). There has also been concern that employing personal interviews, rather than anonymous written questionnaires in trauma-focused research procedures may compromise participants' confidentiality. This exploratory study examined the methodological differences associated with perceived discomforts and benefits among pregnant women participants in a two-phase, trauma-focused research study. In Phase I, pregnant women (N = 109) completed anonymous, trauma-related questionnaires. In Phase II, a subsample of Phase I participants (N = 10) who reported a previous history of sexual trauma completed in-depth, personal interviews. Participants in both phases of the study rated their reaction to research participation using the Response to Research Participation Questionnaire Revised (RRPQ-R). Results suggest that both written survey and personal interview methods are well tolerated by pregnant women. Specific findings indicated that pregnant women with a sexual trauma history reported significantly higher "personal benefit" from participating in personal interview procedures compared to written questionnaires. Recommendations for conducting trauma-focused research with potentially high-risk or vulnerable populations are provided. In addition, recommendations for future research are outlined in an effort to further extend the ethical understanding of the benefits and costs of trauma-focused research.

Schwerdtfeger, K. L., & Nelson Goff, B. S. (2008). The effects of trauma-focused research on pregnant female participants. *Journal of Empirical Research on Human Research Ethics*, 3, 59-67. doi:10.1525/jer.2008.3.1.59

Recent emphasis on the ethical conduct of researchers has resulted in a growing body of literature exploring the impact of trauma-focused research on participants. To date, pregnant women have not been widely included in trauma-focused research, possibly because they are considered a vulnerable population in research. The current research investigated how 41 expectant mothers responded to participation in a trauma-focused study. Overall, the results of this study suggest that trauma-focused research is well tolerated by pregnant women. Specific findings indicated that pregnant women considered more traumatized perceived greater benefits from participation. Best practices for conducting ethical trauma-focused research with pregnant women are provided. As well, recommendations for future research are outlined in an effort to further extend the ethical understanding of the benefits and costs of trauma-focused research with potentially vulnerable populations.

Willebrand, M., Wikehult, B., & Ekselius, L. (2004). Acceptance of a trauma-focused survey: Do personality and health matter? *General Hospital Psychiatry, 26*, 70-77.

Health evaluations after trauma are often performed by postal surveys, although previous studies show that some participants experience distress reactions afterwards. The aim was to explore how former burn patients react to filling in a trauma-related survey and whether the reactions are related to individual factors. The survey contained 307 questions, of which one was an open question to elicit reactions to participation. Personality was measured with the Swedish universities Scales of Personality, health with the Burn Specific Health Scale-Brief, and psychological health with the Hospital Anxiety and Depression Scale and Impact of Event Scale-Revised. Participants were 78 (67%) adult burn patients, injured on average 3.9 years previously. Three groups of reactions were identified: positive/beneficial (55%), effort/time-consuming (32%), and negative/intrusive (13%). Only four participants expressed that the survey had been intrusive. Negative reactions were associated with maladaptive personality traits, poorer relationships, and more stress symptomatology, but not with burn severity or sociodemographic variables. Patients with self-inflicted injuries were evenly spread across the groups, but those with negative reactions were responsible for most of the group differences in individual factors. While a small subgroup reacted negatively, the majority accepted the trauma-focused survey and even found it beneficial.

Measure

Kassam-Adams, N., & Newman, E. (2005). Child and parent reactions to participation in clinical research. *General Hospital Psychiatry, 27*, 29-35. doi:10.1016/j.genhosppsych.2004.08.007

Background: Psychological and psychiatric research studies in medical settings often enroll children who are ill, injured, coping with pain or undergoing stressful medical procedures. Yet empirical evidence to date regarding the effects of research on these participants is scarce. This study assessed reactions of injured children and their parents to research participation and examined associations with demographic, injury and acute stress variables. Methods: Administered standard research reactions questionnaires to 203 injured children (5-17) and 200 parents participating in a study of acute posttraumatic stress. Results: Fifty-two percent of children and 74% of parents were glad they had participated; 77% of children and 90% of parents felt good about helping others. Self-reported distress from study participation was uncommon (5% of children and parents). Child age was associated with more positive appraisals of the research process and with greater trust in and information about elements of informed consent. Conclusions: Participation in a research interview following traumatic injury had little risk of generating distress for children or parents. The most commonly reported positive aspect of research participation was feeling good about helping others. This study supports the feasibility of incorporating standardized assessment of participant reactions in clinical research protocols.

fMRI work and Incidental Findings

Overview

Deslauriers, C., Bell, E., Palmour, N., Pike, B., Doyon, J., & Racine, E. (2010). Perspectives of Canadian researchers on ethics review of neuroimaging research. *Journal of Empirical Research on Human Research Ethics*, 5, 49-66. doi:10.1525/jer.2010.5.1.49

The current and potential uses of neuroimaging in healthcare and beyond have spurred discussion about the ethical issues related to neuroimaging and neuroimaging research. This study examined the perspectives of neuroimagers on ethical issues in their research and on the ethics review process. One hundred neuroimagers from 13 Canadian neuroscience centers completed an online survey and 35 semi-structured interviews were conducted. Neuroimagers felt that most ethical and social issues identified in the literature were dealt with adequately, well, and even very well by research ethics boards (REBs), but some issues such as incidental findings and transfer of knowledge were problematic. Neuroimagers reported a range of practical problems in the ethics review process. We aimed to gather perspectives from REB on the ethics review process, but insufficient participation by REBs prevented us from reporting their perspectives. Given shortcomings identified by neuroimagers as well as longstanding issues in Canadian ethics governance, we believe that substantial challenges exist in Canadian research ethics governance that jeopardize trust, communication, and the overall soundness of research ethics governance. Neuroimagers and REBs should consider their shared responsibilities in developing guidance to handle issues such as incidental findings, risk assessment, and knowledge transfer.

Illes, J., & Chinn, V. N. (2008). Bridging philosophical and practical implications of incidental findings in brain research. *The Journal of Law, Medicine & Ethics*, 36, 298-304. doi:10.1111/j.1748-720x.2008.00273.x

Empirical studies and ethical-legal analyses have demonstrated that incidental findings in the brain, most commonly vascular in origin, must be addressed in the current era of imaging research. The challenges, however, are substantial. The discovery and management of incidental findings vary, at minimum, by institutional setting, professional background of investigators, and the inherent differences between research and clinical protocols. In the context of human subjects protections, the challenges of disclosure of unexpected and potentially meaningful clinical information concern privacy and confidentiality, communication, and responsibility for follow-up. Risks, including a blurring of boundaries between research and clinical practice, must be weighed against the possible benefit to subjects and a moral duty to inform. Identification and examination of these challenges have been met by scientific interest and a robust, interdisciplinary response resulting in the pragmatic recommendations discussed here.

Keane, M. A. (2008). Institutional Review Board approaches to the incidental findings problem. *The Journal of Law, Medicine & Ethics*, 36, 352-355. doi:10.1111/j.1748-720x.2008.00279.x

Institutional Review Boards (IRBs) are confronted with new challenges in the face of expanding technologies while fulfilling their existing regulatory mandate to ensure that plans are in place to protect subjects and to inform them of risks and benefits of research participation. Existing regulations and guidance do not address the issue of incidental findings (IFs), thus leaving awareness of the issue and the application of ethical principles to IRB judgment alone. In order to assure that researchers are aware of the potential for IFs, IRBs must identify which studies are likely to identify IFs and establish what plans should be put into place prior to study initiation to assure the subjects are appropriately informed of the likelihood of IFs, how IFs will be communicated to subjects, and whether the burden of follow-up falls on the researchers or is the subject's responsibility.

Lawrenz, F, & Sobotka, S. (2008). Empirical analysis of current approaches to incidental findings. *The Journal of Law, Medicine & Ethics*, 36, 249-255. doi:10.1111/j.1748-720x.2008.00267.x

This paper presents results found through searching publicly available U.S. data sources for information about how to handle incidental findings (IF) in human subjects research, especially in genetics and genomics research, neuroimaging research, and CT colonography research. We searched the Web sites of 14 federal agencies, 22 professional societies, and 100 universities, as well as used the search engine Google for actual consent forms that had been posted on the Internet. Our analysis of these documents showed that there is very little public guidance available for researchers as to how to deal with incidental findings. Moreover, the guidance available is not consistent.

Marshall, J., Martin, T., Downie, J., & Malisza, K. (2007). A comprehensive analysis of MRI research risks: In support of full disclosure. *Canadian Journal of Neurological Sciences*, 34, 11-17. Retrieved from EBSCOhost.

Magnetic resonance imaging (MRI) procedures have been used for over 20 years. This modality is considered relatively safe and holds great promise. Yet, MRI has a number of risks. In order for MRI research to meet the Canadian standard of disclosure, the investigator must communicate and make note of all risks in their research protocols and consent forms. Those creating and reviewing research protocols and consent forms must take notice of the different circumstances under which MRI poses a risk. First, this paper will describe the current standard of disclosure in Canada for research participants. Second, the paper will provide a comprehensive synthesis of the known physical and psychological risks associated with MRI. Third, the paper will provide recommendations concerning areas for further investigation and risk reduction strategies. This information will thus equip researchers and research ethics boards (REBs) with the criteria needed for the composition of research protocols that meet the Canadian disclosure standard.

Miller, F. G., Mello, M. M., & Joffe, S. (2008). Incidental findings in human subjects research: What do investigators owe research participants? *The Journal of Law, Medicine & Ethics*, 36, 271-279. doi:10.1111/j.1748-720x.2008.00269.x

The use of brain imaging technology as a common tool of research has spawned concern and debate over how investigators should respond to incidental findings discovered in the course of research. In this article, we argue that investigators have an obligation to respond to incidental findings in view of their entering into a professional relationship with research participants in which they are granted privileged access to private information with potential relevance to participants' health. We discuss the scope and limits of this professional obligation to respond to incidental findings, bearing in mind that the relationship between investigators and research participants differs fundamentally from the doctor-patient relationship.

Milstein, A. C. (2008). Research malpractice and the issue of incidental findings. *The Journal of Law, Medicine & Ethics*, 36, 356-360. doi:10.1111/j.1748-720x.2008.00280.x

Human subject research involving brain imaging is likely to reveal significant incidental findings of abnormal brain morphology. Because of this fact and because of the fiduciary relationship between researcher and subject, board-certified or board-eligible radiologists should review the scans to look for any abnormality, the scans should be conducted in accordance with standard medical practice for reviewing the clinical status of the whole brain, and the informed consent process should disclose the possibility that incidental findings may be revealed and what consequences will follow. In the event such findings are revealed, qualified physicians should explain to the subject the significance of the findings and the alternatives available.

Nelson, C. A. (2008). Incidental findings in magnetic resonance imaging (MRI) brain research. *The Journal of Law, Medicine & Ethics*, 36, 315-319. doi:10.1111/j.1748-720x.2008.00275.x

The use of magnetic resonance imaging (MRI) to investigate brain structure (“structural MRI”) and function (so-called “functional MRI”) has become increasingly common among neuroscientists, psychologists, and even economists in recent years. Yet, despite this increase in use, relatively little attention has been paid to the issue of incidental findings. The current paper discusses these issues, and anticipates the future of incidental findings in the context of other neuroimaging tools currently being used to investigate the living brain.

Parker, L. S. (2008). The future of incidental findings: should they be viewed as benefits? *The Journal of Law, Medicine & Ethics*, 36, 341-351. doi:10.1111/j.1748-720x.2008.00278x

This paper argues against considering incidental findings (IFs) as potential benefits of research when assessing the social value of proposed research, determining the appropriateness of a study's risk/benefit ratio, and identifying and disclosing the risks and benefits of participation during informed consent. The possibility of generating IFs should be disclosed during informed consent as neither a risk nor benefit, but as a possible outcome collateral to participation. Whether specific IFs will be disclosed when identified is a separate question whose answer is material to determining whether IFs constitute a risk or a potential indirect benefit of participation. Finally, three types of IF should be distinguished and treated differently during informed consent: those that will be routinely generated (e.g., results of testing to determine study eligibility), those that can reasonably be characterized in terms of their nature and frequency of generation (e.g., misattributed parentage), and those of unpredictable nature and frequency that can be characterized only in general terms. Research protocols should provide a rationale for sharing or not sharing IFs of these three types with participants. Regulatory review of such plans should not, however, be confused with regarding IFs as potential benefits when assessing the study's risk/benefit ratio or merit.

Racine, E., Bar-Ilan, O., & Illes, J. (2005). fMRI in the public eye. *Nature Reviews Neuroscience*, 6, 159-164. Retrieved from EBSCOhost.

The wide dissemination and expanding applications of functional MRI have not escaped the attention of the media or discussion in the wider public arena. From the bench to the bedside, this technology has introduced substantial ethical challenges. Are the boundaries of what it can and cannot achieve being communicated to the public? Are its limitations understood? And given the complexities that are inherent to neuroscience, are current avenues for communication adequate?

Royal, J. M., & Peterson, B. S. (2008). The risks and benefits of searching for incidental findings in MRI research scans. *The Journal of Law, Medicine & Ethics*, 36, 305-314. doi:10.1111/j.1748-720x.2008.00274.x

We weigh the presumed benefits of routinely searching all research scans for incidental findings (IFs) against its substantial risks, including false-positive and false-negative findings, and the possibility of triggering unnecessary, costly evaluations and perhaps harmful treatments. We argue that routinely searching for IFs may not maximize benefits and minimize risks to participants.

Wolf, S. M. (2008). Introduction: The challenge of incidental findings. *The Journal of Law, Medicine & Ethics*, 36, 216-218. doi:10.1111/j.1748-720x.2008.00265.x

The article discusses the problems posed by incidental findings given the importance of health or reproductive decisions of research participants. One of the problems is the consensus on how to handle incidental findings in human subjects. Another problem is

the confusion over whether to offer research participants individual research results.

Wolf, S. M., Lawrenz, F. P., Nelson, C. A., Kahn, J. P., Cho, M. K., Clayton, E., ... Van Ness, B. (2008). Managing incidental findings in human subjects research: Analysis and recommendations. *Journal of Law, Medicine & Ethics*, 36, 219-248. doi:10.1111/j.1748-720X.2008.00266.x

No consensus yet exists on how to handle incidental findings (IFs) in human subjects research. Yet empirical studies document IFs in a wide range of research studies, where IFs are findings beyond the aims of the study that are of potential health or reproductive importance to the individual research participant. This paper reports recommendations of a two-year project group funded by NIH to study how to manage IFs in genetic and genomic research, as well as imaging research. We conclude that researchers have an obligation to address the possibility of discovering IFs in their protocol and communications with the IRB, and in their consent forms and communications with research participants. Researchers should establish a pathway for handling IFs and communicate that to the IRB and research participants. We recommend a pathway and categorize IFs into those that must be disclosed to research participants, those that may be disclosed, and those that should not be disclosed.

Wolf, S. M., Paradise, J., & Caga-anan, C. (2008). The law of incidental findings in human subjects research: Establishing researchers' duties. *The Journal of Law, Medicine & Ethics*, 36, 361-383. doi:10.1111/j.1748-720x.2008.00281.x

Research technologies can now produce so much information that there is significant potential for incidental findings (IFs). These are findings generated in research that are beyond the aims of the study. Current law and federal regulations offer no direct guidance on how to deal with IFs in research, nor is there adequate professional or institutional guidance. We advocate a defined set of researcher duties based on law and ethics and recommend a pathway to be followed in handling IFs in research. This article traces the underlying ethical and legal theories supporting researcher duties to manage IFs, including duties to develop a plan for management in the research protocol, to discuss the possibility of and management plan for IFs in the informed consent process, and to address, evaluate, and ultimately offer to disclose IFs of potential clinical or reproductive significance to research participants when they arise.

Primary Literature

Kirschen, M. P., Jaworska, A., & Illes, J. (2006). Subjects' expectations in neuroimaging research. *Journal of Magnetic Resonance Imaging*, 23, 205-209. doi:10.1002/jmri.20499

Purpose: To explore subjects' attitudes and expectations concerning the detection and management of incidental findings in neuroimaging research.

Materials and Methods: Healthy control subjects (N = 105) who previously participated in neuroimaging studies in medical and nonmedical settings were surveyed about their expectations and attitudes toward unexpected clinical findings on their research brain scans. We hypothesized that even though the participants consented to a scanning procedure for research purposes alone, they would still expect pathology, if present, to be detected and reported to them.

Results: Fifty-four percent of participants reported that they expected research scans to detect abnormalities if they existed. Nearly all subjects (> 90%) reported that they would want findings communicated to them, and many (59%) preferred this to be done by a physician affiliated with the research team. The participants responded in similar ways whether they were scanned in medical or nonmedical settings.

Conclusion: Clarity about procedures for handling incidental findings when obtaining written and verbal informed consent is essential to ensure that the subjects' expectations are consistent with the

purpose and scope of the research.

McGlynn, F. D., Karg, R., & Lawyer, S. R. (2003). Fear responses to mock magnetic resonance imaging among college students toward a prototype experiment. *Journal of Anxiety Disorders, 17*, 335-347.

Two hundred randomly selected student participants (139 females, 61 males) responded initially to questionnaires that quantified variables such as state and trait anxiety, anxiety sensitivity, claustrophobia, and panic/agoraphobia. Later they were informed that a mock magnetic resonance imaging (MRI) procedure was upcoming, and were prompted to provide self-efficacy ratings vis-à-vis completing the procedure. Finally, the participants' behavioral reactions to a mock MRI procedure were characterized; their heart beats were recorded and ratings of fearfulness were acquired. One purpose of the research was simply to tally numbers of participants who responded fearfully in various ways: 7 failed the procedure behaviorally, 7 others completed the procedure but did so fearfully, 17 others completed the procedure but manifested excessive heart-rate responsivity. A second purpose of the research was to "predict" subjects' fear-response categorization psychometrically and/or with self-efficacy ratings: psychometric data related to claustrophobia predicted subjects' fear-response categorization as did self-efficacy ratings. According to these results mock MRI assessment among college students provides a promising context for research on claustrophobia.

Szameitat, A. J., Shen, S., & Sterr, A. (2009). The functional magnetic resonance imaging (fMRI) procedure as experienced by healthy participants and stroke patients – A pilot study. *BMC Medical Imaging, 9*, 9-14. doi:10.1186/1471-2342-9-14

Background: An important aspect in functional imaging research employing magnetic resonance imaging (MRI) is how participants perceive the MRI scanning itself. For instance, the knowledge of how (un)comfortable MRI scanning is perceived may help institutional review boards (IRBs) or ethics committees to decide on the approval of a study, or researchers to design their experiments. **Methods:** We provide empirical data from our lab gained from 70 neurologically healthy mainly student subjects and from 22 mainly elderly patients suffering from motor deficits after brain damage. All participants took part in various basic research fMRI studies using a 3T MRI scanner. Directly after the scanning, all participants completed a questionnaire assessing their experience with the fMRI procedure.

Results: 87.2% of the healthy subjects and 77.3% of the patients rated the MRI procedure as acceptable to comfortable. In healthy subjects, males found the procedure more comfortable, while the opposite was true for patients. 12.1% of healthy subjects considered scanning durations between 30 and 60 min as too long, while no patient considered their 30 min scanning interval as too long. 93.4% of the healthy subjects would like to participate in an fMRI study again, with a significantly lower rate for the subjects who considered the scanning as too long. Further factors, such as inclusion of a diffusion tensor imaging (DTI) scan, age, and study duration had no effect on the questionnaire responses. Of the few negative comments, the main issues were noise, the restriction to keep still for the whole time, and occasional feelings of dizziness.

Conclusion: MRI scanning in the basic research setting is an acceptable procedure for elderly and patient participants as well as young healthy subjects.

References

1. Asgard, U., & Carlsson-Bergstrom, M. (1991). Interviews with survivors of suicide: Procedures and follow-up of interview subjects. *Crisis, 12*, 21-33.
2. Becker-Blease, K. A., & Freyd, J. J. (2006). Research participants telling the truth about their lives: The ethics of asking and not asking about abuse. *American Psychologist, 61*, 218-226. doi:10.1037/0003-066X.61.3.218
3. Beskow, R. B. (1991). Reactions of survivors of suicide victims to interviews. *Acta Psychiatrica Scandinavica, 83*, 169-173.
4. Black, M. C., Kresnow, M., Simon, T. R., Arias, I., & Shelley, G. (2006). Telephone survey respondents' reactions to questions regarding interpersonal violence. *Violence and Victims, 21*, 445-459.
5. Boothroyd, R. A. (2000). The impact of research participation on adults with severe mental illness. *Mental Health Services Research, 2*, 213-231.
6. Boscarino, J. A., Figley, C. R., Adams, R. E., Galea, S., Resnick, H., Fleischman, A. R., Bucuvalas, M., & Gold, J. (2004). Adverse reactions associated with studying persons recently exposed to mass urban disaster. *Journal of Nervous and Mental Disease, 192*, 515-524. Adverse reactions associated with studying persons recently exposed to mass urban disaster. Retrieved from EBSCOhost.
7. Boothroyd, R. A., & Best, K. A. (2003) Emotional reactions to research participation and the relationship to understanding of informed consent disclosure. *Social Work Research, 27*, 242-251.
8. Brabin, P. J., & Berah, E. F. (1995). Dredging up past traumas: Harmful or helpful? *Psychiatry, Psychology and Law, 2*, 165-171. doi:10.1080/13218719509524863
9. Campbell, R., & Adams, A. E. (2009). Why do rape survivors volunteer for face-to-face interviews? A meta-study of victims' reasons for and concerns about research participation. *Journal of Interpersonal Violence, 24*, 395-405. doi:10.1177/0886260508317192
10. Carlson, E. B., Newman, E., Daniels, J. W., Armstrong, J., Roth, D., & Loewenstein, R. (2003). Distress in response to and perceived usefulness of trauma research interviews. *Journal of Trauma and Dissociation, 4*, 131-142. doi:10.1300/J229v04n02
11. Celio, A. A., Bryson, S., Killen, J. D., & Taylor, C. B. (2003). Are adolescents harmed when asked risky weight control behavior and attitude questions? Implications for consent procedures. *International Journal of Eating disorders, 34*, 251-254.
12. Clements, K., & Holtzworth-Munroe, A. (2009). Participation in laboratory research result in emotional distress with one's partner: Comparing violent and nonviolent couples. *Journal of Family Violence, 24*, 283-295. doi:10.1177/ 1077801210397756
13. Cook, A. S., & Bosley, G. (1995). The experience of participants in bereavement research: Stressful or therapeutic? *Death Studies, 19*, 157-170.
14. Daugherty, T. K., & Lawrence, J. W. (1996). Short-term effects of research participation on college men. *Journal of Psychology, 130*, 71-77.

15. Dean, K. L., Stein, B. D., Jaycox, L. H., Kataoka, S. H., & Wong, M. (2004). Acceptability of asking parents about their children's traumatic symptoms. *Psychiatric Services, 55*, 866.
16. Decker, S. E., Naugle, A. E., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of Empirical Research on Human Research Ethics, 6*, 55-64.
17. deGraaf, R., ten Have, M. van Dorsselaer, S., Schoemaker, C., & Vollebergh, W. A. M. (2004). Negative and positive participant responses to the Composite International Diagnostic Interview: Results of the Netherlands Mental Health Survey and Incidence Study. *Social Psychiatry and Psychiatric Epidemiology, 39*, 521-527.
18. DePrince, A. P. & Chu, A. (2008). Perceived benefits in trauma research: Examining methodological and individual difference factors in responses to research participation. *Journal of Empirical Research on Human Research Ethics, 3*, 35-47. doi:10.1525/jer.2008.3.1.35
19. DePrince, A. P., & Freyd, J. J. (2004). Costs and benefits of being asked about trauma history. *Journal of Trauma Practice, 4*, 23-35.
20. Deslauriers, C., Bell, E., Palmour, N., Pike, B., Doyon, J., & Racine, E. (2010). Perspectives of Canadian researchers on ethics review of neuroimaging research. *Journal of Empirical Research on Human Research Ethics, 5*, 49-66. doi:10.1525/jer.2010.5.1.49
21. DiLillo, D., DeGue, S., Kras, A., Di Lorento-Colgan, A. R., & Nash, C. (2006). Participant responses to retrospective surveys of child maltreatment: Does mode of assessment matter? *Violence and Victims, 21*, 410-424. Retrieved from EBSCOhost.
22. Disch, E. (2001). Research as clinical practice: Creating a positive research experience for survivors of sexual abuse by professionals. *Sociological Practice: A Journal of clinical and Applied Sociology, 3*, 221-239.
23. Dunn, L. B. (2006). Capacity to consent to research in schizophrenia: The expanding evidence base. *Behavioral Sciences and the Law, 24*, 431-445. doi:10.1002/bsl.698
24. Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science and Medicine, 58*, 391-400. doi:10.1016/S0277-9536(03)00205-3
25. Dyregrov, K., Dyregrov, A., & Raundalen, M. (2000). Refugee families experience of research participation. *Journal of Traumatic Stress, 13*, 413-426. Retrieved from EBSCOhost.
26. Edwards, V. J., Dube, S. R., Felitti, V. J., & Anda, R. F. (2007). It's OK to ask about past abuse. *American Psychologist, 62*, 327-328. doi:10.1037/0003-066X62.4.327
27. Edwards, K. M., Kearns, M. C., Calhoun, K. S., Gidycz C. Z. (2009). College women's reaction to sexual assault research participation: Is it distressing? *Psychology of Women Quarterly, 33*, 225-234. Retrieved from EBSCOhost.
28. Epley, N., & Huff, C. (1998). Suspicion, affective response, and educational benefit as a result of deception in psychology research. *Personality and Social Psychology Bulletin, 24*, 759-869. doi:10.1177/0146167298247008

29. Fendrich, M., Lippert, A. M., & Johnson, T. P. (2007). Respondent reactions to sensitive questions. *Journal of Empirical Research on Human Research Ethics*, 2, 31-37. doi:10.1525/jer.2007.2.3.31
30. Ferrier-Auerbach, A. G., Erbes, C. R., & Polusny, M. A. (2009). Does trauma survey research cause more distress than other types of survey research? *Journal of Traumatic Stress*, 22, 320-323. Retrieved from EBSCOhost.
31. Galea, S. Nandi, A., Stuber, J., Gould, J., Acierno, R., Best, C. L., Bucuvalas, M., Rudenstine, S., Boscarino, J. A. & Resnick, H. (2005). Participant reactions to survey research in the general population after terrorist attacks. *Journal of Traumatic Stress*, 18, 461-465. doi:10.1002/jts.20053
32. Gould M. S., Marrocco F. A., Kleinman M., Thomas J. G., Mostkoff, K., Cote J., & Davies M. (2005). Evaluating iatrogenic risk of youth suicide screening programs: A randomized controlled
33. 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. Retrieved from EBSCOhost.
34. Hahn, W. K., & Marks, L. I. (1996). Client receptiveness to the routine assessment of past suicide attempts. *Professional Psychology: Research and Practice*, 27, 592-594. doi:10.1037/0735-7028.27.6.592
35. Halek, K., Murdoch, M. and Fortier, L. (2005). Spontaneous reports of emotional upset and health care utilization among Veterans with posttraumatic stress disorder after receiving a potentially upsetting survey. *American Journal of Orthopsychiatry*, 75, 142–151. doi:10.1037/0002-9432.75.1.142
36. Henderson, A. S., & Jorm, A. F. (1990). Do mental health surveys disturb? *Psychological Medicine*, 20, 721-724.
37. Herjanic, B., Hudson, R., & Kotloff, K. (1976). Does interviewing harm children? *Research Communications in Psychology, Psychiatry and Behavior*, 1, 523-531.
38. Illes, J., & Chinn, V. N. (2008). Bridging philosophical and practical implications of incidental findings in brain research. *The Journal of Law, Medicine & Ethics*, 36, 298-304. doi:10.1111/j.1748-720x.2008.00273.x
39. Jacomb, P. A., Jorm, A. F., Rodgers, B., Korten, A. E., Henderson, A. S., & Christensen, H. (1999). Emotional response of participants to a mental health survey. *Social Psychiatry and Psychiatric Epidemiology*, 34, 80-84.
40. Johnson, L. E., & Benight, C. C. (2003). Effects of Trauma-Focused Research on Recent Domestic Violence Survivors. *Journal of Traumatic Stress*, 16, 567-571. Retrieved from EBSCOhost.
41. Jorm, A. F., Henderson, A. S., Scott, R., Mackinnon, A. J., Korten, A. E., & Christensen, H. (1994). Do mental health surveys disturb? Further evidence. *Psychological Medicine*, 24, 233-237.
42. Jorm, A. F., Kelly, C. M., & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 27, 917-926. doi:10.1017/S0033291706009779
43. Kassam-Adams, N., & Newman, E. (2005). Child and parent reactions to participation in clinical research. *General Hospital Psychiatry*, 27, 29-35. doi:10.1016/j.genhosppsy.2004.08.007

44. 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. doi:10.1016/S0163-8343(02)00200-1
45. Keane, M. A. (2008). Institutional Review Board approaches to the incidental findings problem. *The Journal of Law, Medicine & Ethics, 36*, 352-355. doi:10.1111/j.1748-720x.2008.00279.x
46. Kelman, H.C. (1967). Human use of human subjects: The problem of deception in social psychological experiments. *Psychological Bulletin, 67*, 1-11. doi:10.1037/h0024072
47. Kirschen, M. P. Jaworska, A., & Illes, J. (2006). Subjects' expectations in neuroimaging research. *Journal of Magnetic Resonance Imaging, 23*, 205-209. doi:10.1002/jmri.20499.
48. Kreicbergs, U., Valdimarsdottir, U., Steineck, G., & Henter, J.-I. (2004). A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer. *Lancet, 364*, 787.
49. Langhinrichsen-Rohling, J., Arata, C., O'Brien, N., Bowers, D., & Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyway? *Violence and Victims, 21*, 425-444.
50. Lawrenz, F., & Sobotka, S. (2008). Empirical analysis of current approaches to incidental findings. *The Journal of Law, Medicine & Ethics, 36*, 249-255. doi:10.1111/j.1748-720x.2008.00267.x
51. McFarland, C., Cheam, A., & Buehler, R. (2007). The perseverance effect in the debriefing paradigm: Replication and extension. *Journal of Experimental Psychology, 43*, 233-240. doi:10.1016/j.jesp.2006.01.010
52. McGlynn, F. D., Karg, R., & Lawyer, S. R. (2003). Fear responses to mock magnetic resonance imaging among college students toward a prototype experiment. *Journal of Anxiety Disorders, 17*, 335-347.
53. Marshall, J., Martin, T., Downie, J., & Malisza, K. (2007). A comprehensive analysis of MRI research risks: In support of full disclosure. *Canadian Journal of Neurological Sciences, 34*, 11-17. Retrieved from EBSCOhost.
54. Marshall, R. D., Spitzer, R. L., Vaughan, S. C., Vaughan, R., Mellman, L. A., MacKinnon, R. A., & Roose, S. P. (2001). Assessing the subjective experience of being a participant in psychiatric research. *American Journal of Psychiatry, 158*, 319-321. doi:10.1176/appi.ajp.158.2.319
55. Martin, J. L., Perrott, K., Morris, E. M., & Romans, S. E. (2001). Participation in retrospective child sexual abuse research: Beneficial or harmful? What women think six years later. In L. M. Williams & V. L. Banyard (Eds.), *Trauma and memory* (pp. 149-159). Thousand oaks, CA: Sage.
56. Miller, F. G., Mello, M. M., & Joffe, S. (2008). Incidental findings in human subjects research: What do investigators owe research participants? *The Journal of Law, Medicine & Ethics, 36*, 271-279. doi:10.1111/j.1748-720x.2008.00269.x
57. Milstein, A. C. (2008). Research malpractice and the issue of incidental findings. *The Journal of Law, Medicine & Ethics, 36*, 356-360. doi:10.1111/j.1748-720x.2008.00280.x

58. Mosher, D. J., Schultz, S. K., Arndt, S., Benjamin, M. L., Fleming, F. W., Brems, C. S., Paulsen, J. S., Applebaum, P. S., & Andreasen, N. C. (2002). Capacity to provide informed consent for participation in schizophrenia and HIV research. *American Journal of Psychiatry*, *159*, 1201-1207.
59. Nelson, C. A. (2008). Incidental findings in magnetic resonance imaging (MRI) brain research. *The Journal of Law, Medicine & Ethics*, *36*, 315-319. doi:10.1111/j.1748-720x.2008.00275.x
60. Newman, E., & Kaloupek, D. G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, *17*, 383-394. Retrieved from EBSCOhost.
61. Newman, E., & Risch, E. (2006). Ethical issues in trauma-related research: A review. *Journal of Empirical Research on Human Research Ethics*, *2*, 29-46. doi:10.1525/jer.2006.1.3.29
62. Newman, E., Walker, E. A. & Gefland, A. (1999). Assessing the ethical costs and benefits of trauma-focused research. *General Hospital Psychiatry*, *21*, 187-196. doi:10.1016/S0163-8343(99)00011-0
63. Newman, E., Willard, T., Sinclair, R., & Kaloupek, D. (2001). The costs and benefits of research from the participants' view: The path to empirically informed research practice. *Accountability in Research*, *8*, 27-47. Retrieved from EBSCOhost.
64. Owen, D. J., Heyman, R. E., & Smith Slep, A. M. (2006). The risk of partner aggression research: Impact of laboratory couples conflict protocols on participants. *Violence and Victims*, *21*, 483-497. doi:10.1891/vivi.21.4.483
65. Parker, L. S. (2008). The future of incidental findings: should they be viewed as benefits? *The Journal of Law, Medicine & Ethics*, *36*, 341-351. doi:10.1111/j.1748-720x.2008.00278x
66. Parslow, R. A., Jorm, A. F., O'Toole, B.I., Marshall, R. P. & Grayson, D. A. (2000). Distress experienced by participants during an epidemiological survey of posttraumatic stress disorder. *Journal of Traumatic Stress*, *13*, 465-471. doi:10.1023/A:1007785308422
67. Pittenger, D.J. (2002). Deception in research: Distinctions and solutions from the perspective of utilitarianism. *Ethics & Behavior*, *12*, 117-142. doi:10.1207/S15327019EB1202_1
68. Rabenhorst, M. M. (2006). Sexual assault survivors' reactions to a thought suppression paradigm. *Violence and Victims*, *21*, 473-481.
69. Racine, E., Bar-Ilan, O., & Illes, J. (2005). fMRI in the public eye. *Nature Reviews Neuroscience*, *6*, 159-164. Retrieved from EBSCOhost.
70. Reynolds, S. K., Lindenboim, N., Comtois, K. A., Murray, A., & Linehan, M. M. (2006). Risky assessments: Participant suicidality and distress associated with research assessments in a treatment study of suicidal behavior. *Suicide and Life-threatening Behavior*, *36*, 19-34.
71. Rojas, A., & Kinder, B. N. (2007). Effects of completing sexual questionnaires in males and females with histories of childhood sexual abuse: Implications for Institutional Review Boards. *Journal of Sex & Marital Therapy*, *33*, 193-201. doi:10.1080/00926230701267795
72. Ross, L., Lepper, M. R., & Hubbard, M. (1975). Perseverance in self-perception and social perception: Biased attributional processes in the debriefing paradigm. *Journal of Personality and Social Psychology*, *32*, 880-892. doi:10.1037/0022-3514.32.5.880

73. Royal, J. M., & Peterson, B. S. (2008). The risks and benefits of searching for incidental findings in MRI research scans. *The Journal of Law, Medicine & Ethics*, *36*, 305-314. doi:10.1111/j.1748-720x.2008.00274.x
74. Runeson, B., & Beskow, J. (1991). Reactions of survivors of suicide victims to interviews. *Acta Psychiatrica Scandanavica*, *83*, 169-173.
75. Savell, J. K., Kinder, B. N., & Young, M. S. (2006). Effects of administering sexually explicit questionnaires on anger, anxiety, and depression in sexually abused and non-abused females: Implications for risk assessment. *Journal of Sex & Marital Therapy*, *32*, 161-172. Retrieved from EBSCOhost.
76. Schwerdtfeger, K. L. (2009). The appraisal of quantitative and qualitative trauma-focused research procedures among pregnant participants. *Journal of Empirical Research on Human Research Ethics*, *4*, 39-51. doi:10.1525/jer.2009.4.4.39
77. Schwerdtfeger, K. L., & Nelson Goff, B. S. (2008). The effects of trauma-focused research on pregnant female participants. *Journal of Empirical Research on Human Research Ethics*, *3*, 59-67. doi:10.1525/jer.2008.3.1.59
78. Shorey, R. C., Cornelius, T. L., & Bell, K. M. (2011). Reactions to participating in dating violence research: Are our questions distressing participants? *Journal of Interpersonal Violence*, *26*, 2890-2907.
79. Smith, P., & Poindexter, E., & Cukrowicz, K. (2010). The effect of participating in suicide research: Does participating in a research protocol on suicide and psychiatric symptoms increase suicide ideation and attempts? *Suicide and life-threatening behavior*, *40*, 535-543.
80. Smith, S. S., & Richardson, D. (1983). Amelioration of deception and harm in psychological research: The importance of debriefing. *Journal of Personality and Social Psychology*, *44*, 1075-1082. doi:10.1037/0022-3514.44.5.1075
81. Szameitat, A. J., Shen, S., & Sterr, A. (2009). The functional magnetic resonance imaging (fMRI) procedure as experienced by healthy participants and stroke patients – A pilot study. *BMC Medical Imaging*, *9*, 9-14. doi:10.1186/1471-2342-9-14
82. Turnbull, J. E., McLeod, J. D., Callahan, J. M., & Kessie, R. C. (1988). Who should ask? Ethical interviewing in psychiatric epidemiologic studies. *American Journal of Orthopsychiatry*, *58*, 228-239.
83. Wager, N. (2011). Researching sexual revictimisation: Associated ethical and methodological issues, and possible solutions. *Child Abuse Review*, *20*. Online Preview. doi:10.1002/car.1152
84. Walker, E. A., Newman, E., Koss, M., & Bernstein, D. (1997). Does the study of victimization revictimize the victims? *General Hospital Psychiatry*, *19*, 403-410. Retrieved from EBSCOhost.
85. Widom, C. S., & Czaja, S. J. (2005). Reactions to research participation in vulnerable subgroups. *Accountability in Research*, *12*, 115-138.
86. Willebrand, M., Wikehult, B., & Ekselius, L. (2004). Acceptance of a trauma-focused survey: Do personality and health matter? *General Hospital Psychiatry*, *26*, 70-77.

87. Wolf, S. M. (2008). Introduction: The challenge of incidental findings. *The Journal of Law, Medicine & Ethics*, 36, 216-218. doi:10.1111/j.1748-720x.2008.00265.x
88. Wolf, S. M., Lawrenz, F. P., Nelson, C. A., Kahn, J. P., Cho, M. K., Clayton, E., ... Van Ness, B. (2008). Managing incidental findings in human subjects research: Analysis and recommendations. *Journal of Law, Medicine & Ethics*, 36, 219-248. doi:10.1111/j.1748-720X.2008.00266.x
89. Wolf, S. M., Paradise, J., & Caga-anan, C. (2008). The law of incidental findings in human subjects research: Establishing researchers' duties. *The Journal of Law, Medicine & Ethics*, 36, 361-383. doi:10.1111/j.1748-720x.2008.00281.x
90. Yanos, P. T., Stanley, B. S., & Greene, C. S. (2009). Research risk for persons with psychiatric disorders: A decisional framework to meet the ethical challenge. *Psychiatric Services*, 60, 374-383. doi:10.1176/appi.ps.60.3.374
91. Zimmerman, M., Farber, N. J., Hartung, J., Lush, D. T., & Kuzma, M. A. (1994). Screening for psychiatric disorders in medical patients: A feasibility and patient acceptance study. *Medical Care*, 32, 603-608.
92. Zimmerman, M., Lush, D. T., Farber, N. J., Hartung, J., Plescia, G., Kuzma, M. A., & Lish, J. (1996). Primary care patients' reactions to mental health screening. *International Journal of Psychiatry in Medicine*, 26, 431-441.