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Title: The benefits and harms of surveying adolescents about intimate partner violence and verbal, physical and sexual abuse.

by

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DECLARATION

I, Tracy McClinton Appollis, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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University of Cape Town

Abstract

Background: In many studies participants are asked to disclose sensitive information, and little is known about the participants' experiences of disclosing this information. In particular, very few studies have been conducted on adolescents' experiences of participating in research on sensitive topics. Ethics review committees, therefore, have little information to inform and guide their decision making on this topic.

Aims:

- i.** To conduct a systematic literature review on the literature describing adolescents' and adults' experiences of participating in a survey that included sensitive questions regarding abuse and intimate partner violence, and to compare the experiences of those who had been victims of violence with those who had not.
- ii.** To conduct primary research to describe adolescents' experiences of participating in a survey that included sensitive questions regarding abuse and intimate partner violence in Cape Town, South Africa, and to compare the experiences of those who had been victims of these forms of violence with those who had not.

Methods:

- i.** An electronic database search of three data bases was conducted between February and May 2012 for published peer-review journal articles. Specific research terms and inclusion criteria related to the aim and objectives of this paper were used to identify relevant articles. The titles of the studies and then the abstracts were assessed for possible inclusion. The full manuscripts were obtained for those articles deemed relevant and those that met the inclusion criteria were included in the review. A "related article search" was conducted for each of the articles deemed relevant.

ii. We asked adolescents in Grade 8 in three high schools in the Cape Town Metropole area to complete two different surveys, one focusing on condom use and intimate partner violence (sub-group A), and the other on delayed sexual debut and physical and sexual abuse within the home and school (sub-group B) as part of a pilot phase of a bigger study. Participants were asked to complete the same survey two weeks later as part of a test-retest study.

Results:

i. We identified 5 studies among adolescents and 22 studies among adults (12 of which also included adolescents in their samples). The findings of the systematic review indicate that whether adolescents or adults are victims of violence/abuse or not, they report small to moderate levels of distress. Most studies reported a greater prevalence of reports of benefit than distress. The percentage of participants reporting distress ranged between 2.5% to 37% for adolescents (median: 5.7%) and 11.4% to 50% for adults (median: 25%). The percentage of participants reporting benefit in the only adolescent study that measured benefit was 84%. The percentage of adult participants who reported benefits ranged from 25% to 100% (median of 92.4%). In 2 studies in which a high proportion (above 70%) of participants reported distress, a high proportion also reported benefit (above 51%) and there were few expressed regrets about participation. Twenty (5 adolescent and 15 adult) studies compared the prevalence of reports of distress of those who were victims of abuse or intimate partner violence with those who were not, and in 11 (3 adolescent and 8 adults) of them, those exposed were more likely to report distress. 8 studies (1 adolescent and 7 adult) compared the prevalence of reports of benefit of those who were victims of violence and those who were not and , 3 adult studies found victims more likely to find participation beneficial and a positive experience, and 6 (2 adolescent and 4 adult) studies found no difference. Of the 11 (3 adolescent and 8 adult) studies measuring the gender difference, 5 (2 adolescent and 3 adult) studies found

females more likely to report distress, 3 adult studies found males more likely and 3 (1 adolescent and 2 adult) found no difference. Of the 4 (1 adolescent and 3 adult) studies measuring the age difference, all 3 of the adult studies found older participants to be more likely to report that they were more upset than they had expected, compared with younger participants. However, the one adolescent study found that younger participants experience more distress than older adolescents.

ii. More than half the young adolescents participating in the primary research answered the questions about their experience of the research (78.5% in sub-group A and 67.3% in sub-group B). We found participants in both sub-groups were more likely to report positive experiences related to research participation than negative ones. Only two participants (1.1%) in sub-group A and none in sub-group B reported feeling distressed by the research. Many participants reported experiencing the research as beneficial (73.7% in sub-group A and 67% in sub-group B). Adolescents who reported prior IPV or abuse were no more or less likely to report the research to be beneficial compared with those with no history of violence and abuse. None of the victims of abuse reported the research to be distressing.

Conclusion: The findings of our primary research suggest that adolescents, including victims of violence and abuse, do not experience research about their exposure to violence and abuse as distressing, and many experience it as beneficial. However, these findings are at risk of selection bias: we know nothing about the experiences of the participants who did not answer the questions. These findings are not altogether consistent with the findings of the systematic review in which most of the studies (3 adolescent and 8 adult studies) found that victims of violence and abuse report experiencing more distress than non-victims. This suggests that most often victims are more distressed than non-victims. However, whether adolescents or adults are victims of violence/abuse or not, they report a low to moderate prevalence of distress, and those

that do report high levels of distress and low levels of benefit also report no regrets. Our primary study results are consistent with the literature showing that the benefits far outweigh the distress.

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List of abbreviations

CBT	Cognitive Behavioral Therapy
EPHPP	Effective Public Health Practice Project
FCS	Family, Child and Sexual Violence Unit
HMO	Health Maintenance Organization
IPV	Intimate Partner Violence
IRB	Institutional Review Board
PANAS-X	Positive and Negative Affect Schedule
PTSD	Posttraumatic Stress Disorder
RCT	Randomized Controlled Trial
RRPQR	Reactions to Research Participation Questionnaire Revised
SPSS	Statistical Package for the Social Sciences
STPI	State-Trait Personality Inventory

CHAPTER 1-LITERATURE REVIEW

1. INTRODUCTION

1.1. The implications of conducting research with participants about sensitive issues

Sensitive research topics include those that are highly private and sometimes illegal (Rosenbaum and Langhinrichsen-Rohling, 2006), addressing subjects such as substance use, sexual practices, violence and abuse. They also include psychologically traumatic experiences such as death, accidents, combat (including war) and natural disasters. Since the 1930s and 1940s, research has increasingly focused on sensitive topics (Tourangeau and Smith, 1996). This is because of the increased use of illicit drugs, the onset of the AIDS epidemic, and teenage pregnancies (Tourangeau and Smith, 1996). Efforts to combat such problems need to be informed by accurate information about their prevalence, as well as risk and protective factors. Often the most efficient data collection method is self-report, necessitating asking research participants to respond to sensitive questions (Tourangeau and Smith, 1996).

In such research, the experiences of the participants to being asked and responding to sensitive questions are important to understand. Rosenbaum and Langhinrichsen-Rohling (2006) state that too often researchers and reviewers focus on the results of the study and whether they were significant, losing sight of the fact that these numbers reflect people with feelings. One of the concerns with such research is that participants who have experienced traumatic events might experience re-victimisation upon being asked about the events. A further ethical concern in trauma research is the possibility of increased distress in participants, who are suffering from post-traumatic stress disorder (PTSD) (Johnson and Benight, 2003). PTSD is a reaction to traumatic events characterized by increased emotional reactivity, particularly when individuals are

exposed to reminders of the traumatic event (Ferrier-Auerbach, Erbes, & Polusny, 2009).

The main goal of ethical committees and institutional review boards (IRBs) is to ensure the safety of participants by evaluating the likely risks and benefits of research participation. When applying for ethical clearance, the researcher needs to state his or her beliefs about the possible risks and benefits for participants, and how the risks will be minimized. There has been considerable debate as to whether recalling and answering questions about past abuse has negative or positive consequences for the participants of such research (Newman and Kaloupek, 2004; Black and Black, 2007; Becker-Blease and Freyd, 2006; Ahern, 2012; Ullman, 2007; Draucker, 1999).

Black and Black (2007) have questioned commonly held beliefs and assumptions that asking about abuse is upsetting, harmful, and stigmatizing; that survivors are not emotionally stable enough to assess risk or seek help; and that researchers have an obligation to protect survivors from questions about their experiences. These beliefs have led to the assumption that those who have been affected by abuse require special protection because it can be distressing to disclose trauma-related information (Newman and Kaloupek, 2004). Contrary to these assumptions, many have argued that such disclosure is regularly followed by emotional relief, that many participants identify such disclosure as beneficial, and that the majority of participants do not regret or negatively appraise their research participation (Black, Kresnow, Simon, Arias, & Shelley, 2006; Carlson, et al., 2003; Decker, Naugle, Carter-Visscher, Bell & Seifert, 2011; Geskoki, Gray & Adler, 2009; Griffin, Resick, Waldrop, & Mechanic, 2003; Kuyper, de Wit, Adam, & Woertman, 2010; Newman, Walker & Gefland, 1999; Walker, Newman, Koss & Bernstein, 1997). Newman and Kaloupek (2004) have suggested that emotional

distress can be understood as an indicator of emotional engagement with a research project rather than as an indicator of harm.

Becker-Blease and Freyd (2006) and Ahern (2012) have debated as to whether distress experienced during research participation is in fact harmful. Becker-Blease and Freyd (2006) reviewed evidence that suggests it is not direct questions about abuse that usually trigger traumatic memories. Instead, survivors often report that memories of abuse surface when they are in environments or experience emotions similar to those in the original traumatic event. Research shows that even if questions remind survivors of upsetting events, the feelings that come up are not necessarily overwhelming or even completely undesirable (Becker-Blease and Freyd, 2006). Those who have experienced deeply upsetting events may continue to experience negative emotions about the event and at the same time find discussing the events to be manageable and even helpful (Becker-Blease and Freyd, 2006). When the negative feelings evoked by research are more closely associated with the experience of abuse (e.g., feelings of betrayal or grief), this is not necessarily an indication of psychological harm. Feelings like grief, anger, and fear in response to remembering a trauma may be a transitory negative state that is understandable and not harmful (Becker-Blease and Freyd, 2006).

In her study exploring the benefit and harm health professionals experienced from participation in qualitative research about potentially distressing personal and professional issues, Ahern (2012) found that despite most participants reporting varying degrees of distress during participation, they did not consider this harmful. One of the participants who 'went through a box of tissues' during her interview, later described how 'the upset was already there and would have come out' at some point. Ahern (2012) posits that the research itself was not the cause of distress: it merely presented the

opportunity for its expression. Becker-Blease and Freyd (2006) raise a concern about participants' longer-term reactions to research participation. They speculate that the intense feelings that the research might evoke might not be able to be resolved before the end of the participation in the research and might lead to long-term harms or benefits. For instance, the participant may seek help and may subsequently heal from a traumatic experience. Feelings that are so intense that they lead to behaviors that are harmful to the self or others are obviously of great concern.

Black and Black (2007) strongly agree with Becker-Blease and Freyd's (2006) statement that decisions not to ask about abuse play directly into the social forces that perpetuate intimate partner violence (IPV) and other forms of violence as pervasive and pernicious social and public health problems. IPV is when two people are involved in an intimate or dating relationship and there is a pattern of assaultive and coercive behaviours such as physical injury, sexual assault, psychological abuse progressive social isolation, stalking, deprivation, intimidation or threats (National Resource Center on Violence, 2 March 2012). From a public health perspective, the question is not "whether" to ask but "how" to ask about participants' experiences with abuse (Black and Black, 2007). Becker-Blease and Freyd (2006) and Edwards, Dube, Felitti, & Anda (2007) state that researchers studying health outcomes who fail to ask study subjects about traumatic childhood experiences (such as child abuse, family violence, and other interpersonal violence) are overlooking an important risk factor for many major health issues as well as social problems such as poverty, divorce, HIV risk, school performance, criminality, learning disorders, and mental and physical illness. Becker-Blease and Freyd (2006) state that when we do not ask, we withhold child protective services' responses that prevent future harm; and we deprive participants of the opportunity to learn about normal reactions to abuse and about community resources that could help. Studies that

ask about child abuse help break the taboo against speaking about abuse, helping survivors to know that talking about their experiences is important. If we do not ask, we will not be as able to prevent victimization and help survivors. When research is set up with a “don’t ask, don’t tell” policy in which researchers ask about many aspects of participants’ lives (sexual behavior, illegal behavior, etc.) but not about abuse, they may convey to participants that abuse is unimportant or that it makes researchers uncomfortable.

Ullman (2007) states that research has shown that trauma disclosure has physical and psychological health benefits in experimental studies in which participants are randomly assigned to write about traumatic experiences or neutral events. Draucker (1999) argues that reflecting on traumatic experiences in a research context may be a positive cathartic experience; an initial step in seeking mental health, or an empowering opportunity to help other victims.

Another interesting aspect of the benefit versus harm debate is how being asked about abuse affects perpetrators of violence. This question will be addressed in the literature review.

For all of the above reasons, it is important to know whether asking research participants sensitive questions, including questions about traumatic experiences is beneficial or harmful.

1.2. Theoretical Framework

Experiential avoidance has been broadly defined as the attempt to avoid thoughts, feelings, memories, physical sensations, and other internal experiences (Kashdan,

Barrios, Forsyth & Steger, 2005). An individual with experiential avoidance avoids stimuli that serve as reminders of the traumatic event in an attempt to protect themselves from reliving the event (Rosenbaum and Langhinrichsen, 2006). Therefore, asking victims to talk about personal traumatic experiences (or asking them to fill out a questionnaire about this topic) might cause more distress for them as they have chosen to avoid this trauma in an act of self-protection.

The problem with avoidance behavior is that it only offers short-term relief of discomfort that increases the likelihood that the behavior will persist. This behavior often disrupts and interferes with important, valued aspects of an individual's life and prevents the victim from leading a normal, psychologically healthy life.

In counselling victims of abuse, victims are encouraged to talk about traumatic experiences face-to-face, in a safe non-judgemental environment where everything they say is kept confidential within the counselling room (Help2HealUK, 2011).

Therapeutic approaches such as Client-Centred Therapy and Cognitive Behavioural Therapy (CBT) are suitable for people who have suffered abuse (Chouliara et al., 2011). Client-centred therapy, also known as person-centred therapy, places emphasis on the relationship between client and therapist. It is believed that if the client feels that he/she can trust the therapist, constructive change will naturally follow. In a recent study Chouliara et al. (2011) found survivors of childhood sexual abuse to report the following benefits in talk therapy: a trusting therapeutic relationship, feeling safe to disclose, breaking isolation, enhancing self-esteem and self-worth, contextualizing the abuse, and moving toward recovery. The therapist provides the client with acceptance and a sense of value, and encourages them to find their own solutions by listening and empathising with their problems (Corey, 2005).

CBT therapists typically help patients identify and evaluate disruptive cognitions by exposing them to the traumatic material, letting them write down the details of their traumatic experience and reading them. The disruptive thoughts about the traumatic experience are then challenged and modified, and patients are asked to rewrite the experience with a more positive perspective (The Journal of Family Practice, 2005).

The conditions under which research participants disclose abuse (during interviews or through completing anonymous questionnaires or surveys) is clearly very different to the conditions of therapy. Interviewers or data collectors can create a safe environment, convey a non-judgmental approach, and contain and refer participants who appear to be distressed. However, it is not clear whether this is enough to prevent the distress associated with being reminded of traumatic events. It is also not clear whether such research could hold any therapeutic benefits.

The purpose of this systematic review is to fill this current knowledge gap by reviewing the research literature that investigated adolescent and adult participants' experiences of being asked sensitive questions in research.

2. AIM

The aim of this review is to evaluate the literature describing adolescents' and adults' experiences of participating in a survey that included sensitive questions regarding abuse and IPV, and comparing the experiences of those who had been victims of violence with those who had not.

3. OBJECTIVES

- To conduct a systematic review of the literature on the impact of research that asked adolescent participants (aged 10-19 years) and adult participants sensitive

questions about their past emotional, physical or sexual abuse or other traumatizing events they may have experienced.

- To describe participants' experience of participating in the research studies and the extent to which they found it distressing and/or beneficial.
- To compare the experiences of research participation of those participants who had been victims of abuse with those who had not.
- To compare the experiences of research participation of those participants who were perpetrators of abuse with those who were victims.
- To assess whether there are gender and age differences in responses to survey participation.
- To compare the experiences of research participation of those participants who were suffering from PTSD symptoms at the time of participation and those who were not.

4. LITERATURE REVIEW

4.1. Search method

I conducted an electronic database search of PubMed, Academic Search Premier, and PsycARTICLES was conducted between February and May 2012 for published peer-review journal articles. The following search terms were used: (1) "ethics" AND "sensitive topics" OR "sensitive questions" AND "research" AND "adolescents" AND "trauma" AND "intimate partner violence" OR "childhood abuse"; (2) "sensitive topics" AND "research experience"; (3) "sensitive research" AND "ethics" AND research experience"; (4) "violence" AND "trauma research". Restrictions for language (English) and species (humans) were made.

The following inclusion criteria were utilized: (1) studies that examined adult and/or adolescent participants' experience of harms and benefits of participation in research, (2) were published in academic peer reviewed journal articles, (3) in English, (4) without restrictions for date, and (5) the sample must have either included participants who had been victims of violence/abuse or the measures used must have asked about experiences of traumatic events especially abuse or violence, or asked about PTSD symptoms. The exclusion criteria were: (1) study reported in a language other than English.

4.2. Number of studies located

Using the search methods specified above, I identified 1050 articles across all three data bases (Appendix 1: PRIMSA Flow Diagram). The titles of all 1050 articles were assessed for relevance. Of these, 28 were found to be potentially relevant, for which the abstract was assessed for possible inclusion. Nineteen of these abstracts were regarded as possibly relevant, for which the full manuscripts were obtained. After reviewing the 19 full manuscripts, 14 of these met the inclusion criteria and were included in the review.

A search was then conducted for articles related to the 14 articles included in the review and 571 articles were found (Recorded in appendix 1: PRIMSA Flow Diagram under heading "Additional records identified through other sources"). The titles of all 571 articles were assessed for relevance. Of these, 46 were found to be potentially relevant, for which the abstract was assessed for possible inclusion, and 20 of these full articles were read. Thirteen articles were included in the study. Therefore in total 27 articles were decided by my supervisors and myself to be included in the final review.

4.3. What is already known about this topic?

4.3.1. Risk of bias

Assessments of risk of bias of all of the included studies were conducted. Different methods of assessment were used for quantitative and qualitative papers. All studies were assessed by myself, and a random sample of five quantitative studies and two qualitative studies were assessed by Dr. Mathews (Supervisor) and A/Prof Lund (Co-supervisor) to check whether my assessments were correct. There were some disagreements with the quantitative studies reviewed by Dr. Mathews and changes were made accordingly. No disagreements were found when A/Prof Lund reviewed the qualitative studies.

4.3.1.1. Quantitative studies

We assessed risk of bias in the five quantitative adolescent and the 19 adult studies with an amended version of the assessment tool developed by the Effective Public Health Practice Project (EPHPP), which is a quality assessment tool for quantitative studies (Appendix 2 and 3, the original version can be found at <http://www.ephpp.ca/Tools.html>). In this tool, there are six criteria against which risk of bias is assessed, namely (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection method (6) withdrawals and dropouts. Between two and four questions measure potential sources of bias for each criterion. For example, to measure the potential for selection bias, the relevant questions are: (1) Are the individuals selected to participate in the study likely to be representative of the target population?, and (2) What percentage of selected individuals agreed to participate?

Most of the quantitative studies (70%) included in this review were cross-sectional.

Therefore, we amended the instrument by excluding the criteria that related

predominantly to experimental studies, namely the assessments of “Blinding” and “Withdrawal and Drop-Out”. The amended instrument included five criteria and two to four questions for each (Appendices 4 and 5). The “blinding” and “withdrawal and drop-out” criteria for the five quantitative studies that used experimental or longitudinal studies were assessed separately. We made further amendments to the criteria, “Confounders” and “Data Collection Tools”:

(1) Confounders

Two potential confounders we believe are relevant are age and sex. Therefore we rated the adequacy with which these potential confounders were taken into account as follows:

Strong – when both age **and** sex were controlled for

Moderate – when either age **or** sex was controlled for

Weak – when both age **and** sex were not controlled for **or** when confounders were not described

(2) Data Collection Methods

The studies in this review included measures of exposure (prior trauma and/or abuse) and measures of outcomes (distress and/or benefit). We believed it was important for our assessment to reflect the risk of bias for each of these measures. Therefore we created two components for data collection methods, one for measures of exposure and one for measures of outcome.

The global rating of the papers was as follows:

Strong – when there are no weak ratings for any of the components

Moderate – when there is one weak rating on any one of the components

Weak – when there are two or more weak ratings

With regards to the data collection methods component, we have applied the following:

(1) when both the exposure and outcome measures were rated as weak, then this counted as one (not two) weak rating towards the global rating; (2) when either the exposure or outcome measure had a weak rating, this weak rating did not count as a weak rating towards the global rating (see Tables 2 and 3, below).

4.3.1.2. Qualitative studies

The three adult studies were assessed using a quality assessment instrument containing criteria described by Walsh and Downe (2006). This instrument refers to seven stages that included nine essential criteria that each included several specific items:

1. Scope and purpose: a clear statement of and rationale for research question(s)/ aim(s)/purpose(s) of the study thoroughly contextualized by existing literature
2. Design: method/design clear and consistent with research intent, data collection strategy clear and appropriate
3. Sampling strategy: sample and sampling method appropriate
4. Analysis: analytic approach appropriate
5. Interpretation: data used to support interpretation
6. Ethical dimensions: demonstration of sensitivity to ethical concerns
7. Relevance and transferability: relevance and transferability evident (Walsh and Downe, 2006).

Articles were rated as 'A', 'B' or 'C' as follows:

A – when there were no or few flaws, and the study credibility, transferability, dependability, and confirmability is high

B - when there were some flaws that were unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study

C – when there were some flaws that may affect the credibility, transferability, dependability, and/or confirmability of the study

D – when there were significant flaws that were likely to affect the credibility, transferability, dependability, and/or confirmability of the study (Table 4).

4.3.2. Results

Of the 27 studies included in this review, 22 were conducted in America, two in England one in the Netherlands, one conducted in Sweden and Estonia, and one in South Africa.

They were published between 1997 and 2012, with most studies published in 2003, 2007, and 2008. Five of the studies were conducted among adolescents and 22 were conducted among adults (Table 1).

Table 1: Studies looking at adolescents' as well as adults' experiences of participation in sensitive research, 1997 – 2012.

Author Year Country	Sample type N Study Design Age Gender	Instrument Type of questions	Results-Descriptive Reported feelings about research participation	Results – Group comparisons
ADOLESCENT STUDIES				
Langhinrichsen-Rohling, Arata, O'Brien, Bowers, Klibert 2006 America	<p><u>Subgroup 1:</u> School students</p> <p><u>Subgroup 2:</u> Juvenile justice institution</p> <p><u>Subgroup 1:</u> N = 880</p> <p><u>Subgroup 2:</u> N = 660</p> <p>Cross-sectional 13-18 yrs Males & females</p>	<p>Instrument Interviewer-administered questionnaires.</p> <p>Type of questions Suicidal behavior, physical & sexual abuse, drug use.</p>	<p>Prevalence of reported distress Between 2.5% to 7.5% of adolescents from both settings reported feelings of being upset while completing the survey.</p>	<p>Differences by history of violence/abuse (Participants were asked how often they were upset while completing this survey. Responses ranged from “not at all” to “rarely”, “sometimes”, “often”). Participants reporting physical abuse (Mean=0.81) felt more upset than participants who did not (Mean=0.39), p = .000. Similarly, participants reporting sexual abuse (Mean=0.82) felt more upset during the survey than those who did not report (Mean=0.44), p = .000.</p> <p>Gender differences Girls reported more frequent interest in the survey than boys (t = 2.77, p=.006).</p>
Chu, DePrince, & Weinzierl 2008 America	<p>School-aged children with & without trauma histories. N = 181 Cross-sectional Males & females</p>	<p>Instrument <u>Both sub-groups:</u> Info. obtained from parents about their children's trauma history</p> <p><u>Sub-Group 1:</u> 1.Interviewer-administered questionnaire 2.Emotion-understanding tasks 3.IQ estimated test</p> <p><u>Sub-group 2:</u> 1.Lab. tasks 2.Interviewer-administered questionnaire</p> <p><u>Both studies:</u> After completion of all tasks, parents & children completed questionnaires</p> <p>Type of questions <u>Both sub-groups:</u> Experienced or witnessed physical</p>	<p>Prevalence of reported distress 1.6% children made negative appraisals of participation.</p> <p>Prevalence of reported benefit Cost-benefit ratio was positive for the vast majority of participants.</p>	<p>Differences by history of violence/abuse (Questions were asked on 12 items where participants rated their responses on a 3-point scale ranging from 1=no, 3=maybe, and 5=yes). There were no significant differences between those with & those without a history across all 3 trauma exposure groups: no-trauma: Mean = 1.12, non-interpersonal trauma: Mean = 1.05, interpersonal trauma: Mean = 1.12, p < .05. NB: children were not asked about abuse history!</p>

& sexual abuse, depression, anxiety

Sub-Group 1:

1. Their own behaviours & their parent's parenting practices.
2. Children & parents looked at pictures of babies & had to label emotions.
3. Subscales of the Wechsler Intelligence Scales for Children - 4th edition.

Sub-group 2:

1. Designed to assess cognitive (including attention, memory, estimated IQ) & academic performance (e.g., achievement tests).
2. Their own feelings & behaviour.

Both studies:

Questions about their research experience.

Ybarra, Langhinrichsen-Rohling, Friend, & Diener-West 2009 America	Youth N = 1588 Longitudinal 10-15 yrs Males & females	Instrument Respondent-administered questionnaires. Type of questions Victimization, perpetration, exposure to all types of violence (physical, verbal, sexual).	Prevalence of reported distress 23% upset by the questions. 10 themes related to distress emerged: specific types of questions; general denial; emotional reaction; personal intrusiveness; too young; don't know/nonresponsive; brought up bad memories; everything; against religion or moral code; or nothing.	Differences by history of violence/abuse There were no significant differences between victims & non-victims & level of upset. Perpetrators of violence were no more likely to report being upset by the survey than non-perpetrators. Gender differences Females were significantly more likely to report being upset than were boys. Age differences Younger youth were significantly more likely to report being upset than were older youth.
Priebe, Backstrom, & Ainsaar 2010 Europe	Adolescents in their final year of high school Subgroup 1: Estonia N=1334 Subgroup 2: Sweden N=3401 Cross-sectional 17-18 yrs Males & females	Instrument Respondent-administered questionnaires. Type of questions Consensual sexuality, sexual abuse victimization & perpetration, sexual attitudes, experiences with pornography & experiences with sexual exploitation.	Prevalence of reported distress Majority of participants did not feel discomfort based on the results of the following statements: 1. Questions were unpleasant to answer (11.9% agreed; 5.5% strongly agreed). 2. One should not ask people such questions (3.7% agreed; 6.0% strongly agreed). 3. Questions can have unfortunate impacts (7.2% agreed; 3.8% strongly agreed). 4. Questions were too private (9.5% agreed; 8.2% strongly agreed).	Differences by history of violence/abuse (Mean scores for the 4 questions of discomfort asked ranged from 1= "strongly disagree" to 5= "strongly agree"). Participants who had a history of abuse & were sexually experienced reported more discomfort than those without a history & who were sexually inexperienced. 1. Sexually abused: 2.14; 1.72; 1.99; 2.10 (p >.001). 2. Not sexually abused: 2.39; 1.67; 2.04; 2.31 3. Sexually Inexperienced: 2.49; 1.93; 2.13; 2.57 (p<.001). 4. Sexually experienced: 2.11; 1.70; 1.98; 2.15.

Zajac, Ruggeriero, Smith, Saunders, & Kilpatrick 2011 America	Youth who had completed the National Survey of Adolescents-Replication. N = 3614 Cross-sectional & part longitudinal 12-17 yrs Males & females	Instrument Telephonic interviews. Type of questions Physical assault & abuse, sexual assault, witnessed community & parental violence, & other traumatic events experienced, PTSD, major depression, alcohol abuse.	Prevalence of reported distress 5.7% found some questions distressing & of these only 0.2% remained upset at the end of the interview. Prevalence of reported need for help Less than 0.1% wished to speak to a counselor.	Differences by history of violence/abuse Adolescents who reported a history of sexual abuse 20.6%; physical assault 12.5%; physical abuse 16.1% were significantly more likely to report distress than those without a history (sexual abuse 4.4%, $p < .001$; physical assault 4.4%, $p < .001$; physical abuse 4.2%, $p < .001$). Gender differences Girls were significantly more likely (7.5%) to report distress than boys (3.9%; $p = .001$). Baseline & follow-up differences Adolescents who were upset at baseline (6.2%) were no more likely than those who were not upset (5.5%) to drop out of the study.
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Studies are arranged by date in ascending order

ADULT STUDIES

Walker, Newman, Koss & Bernstein 1997 America	HMO members N = 330 Cross-sectional 18-45yrs Females	Instrument Respondent-administered mailed questionnaires. Type of questions Early childhood & adult forms of sexual, physical, emotional abuse & neglect victimization.	Prevalence of reported distress 13% more upset than expected Prevalence of reported benefit More than 25% gained something positive. 13% felt they did not gain anything positive Prevalence of reported regret 76% would participate again. 5% would not participate again.	Differences by history of violence/abuse Participants who were distressed reported a significantly higher degree of exposure to traumatic events during childhood (One-way Anova=2.00), than those who experienced no abuse (One-way Anova = 1.68) $p < 0.05$.
Newman, Walker & Gefland 1999 America	HMO members N = 1174 Longitudinal (Cohort) 18 – 65 yrs Females	Instrument Respondent-administered mailed questionnaires & those with history of child abuse were administered a follow-up interview 3-12mths later & a 48hr follow-up telephone call. Type of questions Child maltreatment, physical & mental health.	<u>Questionnaire (baseline):</u> Prevalence of reported benefit 24% of participants reported benefit. <u>Interview 3-12 months later:</u> Prevalence of reported benefit 86% reported benefit. 1 reported no benefit. Prevalence of reported regret 1 reported regret. <u>48 hour follow up:</u> Prevalence of reported distress 7% increase in unexpected upset from the previous interview. 3% decrease in unexpected upset from the previous interview. Prevalence of reported benefit	Differences by history of violence/abuse (Questions were asked on 3 items where participants rated on a 5-point Likert scale from 1= “strongly disagree” to 5= “strongly agree”, where 3= “neutral”). Participants with histories of sexual abuse (Questionnaire: Mean=2.40; Interview: Mean=2.30; Interview + 48 hrs: Mean=2.52) were more likely to underestimate their level of upset from research participation on questionnaires & interviews than those without a history of sexual abuse (Questionnaire: Mean=2.10; Interview: Mean=2.39; Interview + 48hrs: Mean=2.22) $p < 0.001$. PTSD symptoms Participants who reported unexpected upset over the questionnaire had significantly higher levels of PTSD symptoms (Mean= 34.90, SD=12.5) than those who

			<p>74% reported benefit. Prevalence of reported regret 0% reported regret</p>	<p>were not unexpectedly upset (Mean=26.38, SD=9.68 p< 0.0001). Participants who were unexpectedly upset over the interview (Mean=33.27, SD= SD=11.7) reported significantly higher levels of PTSD symptoms (Mean=25.95, SD=11.73, p<.0001) than those who were not unexpectedly upset. (Mean=4.31, SD=0.94, p<0.0001). Participants who were regretful about the survey (Mean=24.40, SD=8.08) experienced lower levels of PTSD symptoms (Mean=27.40, SD=10.41, p<0.033).</p>
Ruzek & Zatzick 2000 America	Hospitalized physically injured motor vehicle & assault survivors, N=117 Cross-sectional 14-61 yrs Males & Females	<p>Instrument Interviews.</p> <p>Type of questions Traumatic history such as combat (e.g. war), life-threatening accident, witnessing injury, rape, molestation physical assault/abuse, child neglect, psychological symptoms, physical health.</p>	<p>Prevalence of reported distress 12% unexpected emotional upset. 32% negative reactions. 30% had unwanted thoughts as a result of research participation.</p> <p>Prevalence of reported benefit 95% reported the benefits outweighed costs & they had no regrets. 75% positive experiences.</p>	<p>Differences by history of violence/abuse (Questions were asked on 10 items where participants rated on a 5-point Likert scale ranging from False to True (3=uncertain). There were no statistically significant differences between negative & positive responders on any of the RRPQ items with regard to lifetime trauma.</p> <p>Gender differences There were no statistically significant differences between negative & positive responders on any of the items with regard to gender.</p> <p>Age differences Older participants were significantly more likely (Mean = 39.9; SD = 13.3) to report that they were more upset than they had expected than those who were younger (Mean = 32.7; SD=11.5; p < 0.05).</p> <p>PTSD symptoms Participants who reported negative reactions, were significantly more likely to have higher PTSD (Mean=44.7; SD=12.1) & depressive symptom levels (Mean=29.7; SD =8.9) than those who did not report negative reactions (PTSD: Mean=35.4, SD = 13.6 p <0.01; Depressive symptoms: Mean = 23.1, SD = 12.0; p < 0.01).</p>
Johnson & Benight 2003 America	Domestic violence survivors N=55 Cross-sectional 18-65 yrs Females	<p>Instrument Respondent-administered questionnaires.</p> <p>Type of questions Domestic violence, PTSD symptoms, depression.</p>	<p>Prevalence of reported distress 25% more upset than expected.</p> <p>Prevalence of reported benefit 45% reported positive gain.</p> <p>Prevalence of reported regret 6% reported regret.</p>	<p>Differences by history of violence/abuse (Mean scores ranged on a 5-point scale where 1=strongly disagree and 5=strongly agree (3=neutral). Participants expressing upset had experienced a greater number of lifetime traumas (Mean=6.21) than those who were not upset (Mean=3.44; p < .01).</p>

Griffin, Resick, Waldrop, & Mechanic 2003 America	<p><u>Subgroup 1:</u> Acute physical / sexual assault survivors</p> <p><u>Subgroup 2:</u> Domestic violence survivors</p> <p><u>Subgroup 1:</u> N=170</p> <p><u>Subgroup 2:</u> N=260</p> <p>Cross-sectional 18-62yrs Females</p>	<p>Instrument Computer & paper respondent-administered questionnaires, interviews, psycho-physiological laboratory assessment in which heart rate & skin conductance monitors are placed on participants while talking about the traumatic event, & video-records for non-verbal behaviour.</p> <p>Type of questions Rape, physical assault & domestic violence victimization.</p>	<p><u>Subgroup 1:</u> Prevalence of reported distress Assessment process was largely viewed as interesting & not very distressing. (Prevalences were not reported)</p> <p>Prevalence of reported regret 5% would not be willing to participate again.</p> <p><u>Subgroup 2:</u> Prevalence of reported distress 42% reported they felt strong or very strong emotions during the assessment process.</p> <p>Prevalence of reported regret 2% would not be willing to participate again if they had known what participation would be like.</p>	<p><u>Subgroup 1:</u> PTSD symptoms Participants who met PTSD criteria reported greater difficulty in speaking about the traumatic event during the psycho-physiological assessment (Mean=4.7, SD=2.1) than those who did not meet PTSD criteria (Mean=3.7, SD=2.1; $p<.05$) (scoring: 1=easy, 7=very difficult).</p> <p>Participants who met PTSD criteria reported more distress in speaking about the traumatic event during the psycho-physiological assessment (Mean=5.4, SD=1.5) than those who did not meet PTSD criteria (Mean=3.7, SD=1.9, $p<.01$) (scoring: 1=not distressing, 7=very distressing).</p> <p><u>Subgroup 2:</u> There were no significant differences in reported distress between those who met PTSD criteria (Mean=39.3, SD=9.9) & those who did not (Mean=19.1, SD = 10.0). (scoring: 1=not distressing, 7=very distressing).</p>
Carlson, Newman, Daniels, Armstrong, Roth & Loewenstein 2003 London	<p>Psychiatric inpatients N = 223</p> <p>Cross-sectional Average age 37.7 Males & Females</p>	<p>Instrument Interviews.</p> <p>Type of questions PTSD & childhood sexual & physical abuse.</p>	<p>Prevalence of reported distress 70% reported low levels of distress. 24% very much or extremely upset. 6.6% stopped interview because upset. For example: Having to remember painful suppressed memories& the fact that it brought up a lot of suppressed memories).</p> <p>Prevalence of reported benefit 51% reported it was somewhat useful. Of the 24% highly upset, 37% found it somewhat useful. (Examples of what they found useful: Participation made them want to help stop abuse by giving researchers an understanding of their experiences)</p>	<p>Differences by history of violence/abuse Participants with a higher level of past trauma & current symptoms experienced more upset than those with lower levels of past trauma.</p> <p>PTSD symptoms Participants with PTSD symptoms were significantly more likely than those without to be upset by participation. Those that reported that participation was useful were not significantly correlated with any experience or symptom variables.</p>
DePrince & Freyd 2004 America	<p>N = 528</p> <p>Cross-sectional Males & females</p> <p><u>Subgroup 1:</u> Undergrad. students Mean age: 20.4 yrs</p> <p><u>Subgroup 2:</u> Community</p>	<p>Instrument Respondent-administered questionnaire.</p> <p>Type of questions Exposure to non-interpersonal trauma (e.g., natural disaster), witnessing violence being done to others & direct interpersonal trauma (e.g., physical, sexual abuse). Participants were asked if they</p>	<p>Prevalence of reported distress The mean (SD) response to whether participants found participation more distressing than day-to-day encounters was 2.9 (1.0) & 3.0 (1.1) for community & undergrad. responses respectively, where scores ranged from 1-5 with lower scores indicating more distress & 3 neutral.</p> <p>Prevalence of reported benefit The mean (SD) response to whether participants thought this type of research is important was</p>	<p>Differences by history of violence/abuse Among both subgroups, the interpersonal violence group reported that it was more important that psychologists study trauma (Community: Mean=4.5; Undergrad: Mean=4.4) than the no interpersonal violence group (Community: Mean=4.2; Undergrad: Mean=4.2). Scores ranged from 1-5 with higher scores indicating more importance & 3 neutral responses.</p> <p><u>Community participants:</u> Gender differences</p>

members
Mean age:
38.7 yrs

experienced the event before or
after age 18.

4.5 (.9) & 4.3 (1.0) for community &
undergrad. responses respectively, where scores
ranged from 1-5 with lower scores indicating a
bad idea & 3 a neutral response.
Both subgroups rated the importance of the
research significantly higher than the distress
(community: $t(147)=15.1, p<.001$, Cohen's $d=$
1.7; undergrad: $t(467)=19.1, p<.001$,
Cohen's $d=1.2$).

When asked how good an idea it would be to include
such a measure in psych. research, women gave higher
ratings (Mean=4.5) than men (Mean=4.2), $p<.0$.
Scores ranged from 1-5 with lower scores indicating a bad
idea & 3 a neutral response.

Undergrad. participants:

Gender differences

Men were more likely to report the questions were less distressing
than things encountered in daily life (Mean=3.2)
than women (Mean=3.0), $p<.05$.

However, women were more likely to report they believed it was
more important for psychologists to study this issue
(Mean=4.4) than men (Mean=4.1), $p<.05$.

Women made were more likely to report that this research is a
good idea (Mean=4.4) than men (Mean=4.2), $p < .05$.

Savell, Kinder
Young
2006
America

College undergrad.
students
N = 207
Cross-sectional
18-25 yrs
Females

Instrument
Respondent-administered
questionnaires.
Type of questions
Childhood sexual abuse, sexual
experience, sexual attitudes & sexual,
behaviour.

No results reported

Differences by history of violence/abuse

There were no significant differences between abused
and non-abused participants on scale 1 ("state" anxiety,
anger, depression, curiosity) and scale 2 ("trait" anxiety,
anxiety, anger, depression, curiosity). Suggesting that
participation in the survey did not cause distress.

Black, Kresnow,
Simon, Arias, &
Shelley
2006
America

Cross-sectional
Age not reported
Males & females
Subgroup 1:
ICARIS-2 survey
(a national
cross-sectional
list-assisted RDD
telephone survey
of English- &
Spanish-speaking
Adults)
N = 9,684
Subgroup 2:
SIPV pilot study
(a annual
telephone survey)
N = 7,698

Instrument
Interviews
Type of questions
Subgroup 1:
Family & sexual violence, stalking,
interpersonal violence, participants'
relationship to the perpetrator.
Subgroup 2:
IPV, sexual violence, violence in
past 12 months.

Subgroup 1:
Prevalence of reported distress
15.9% reported being upset because the
questions reminded them of a past
victimization experience.
Prevalence of reported benefit
More than 95% of participants said such
questions about violence should be asked.
Among the 269 victims who reported
being upset or afraid, 246 (96.4%) responded
that the questions should be asked.
Subgroup 2:
Prevalence of reported distress
11.4% of participants reported being upset
because the questions reminded them of a past
victimization experience.
Prevalence of reported benefit
92.4% of participants responded that such
questions about violence should be asked.

Subgroup 1:
Differences by history of violence/abuse
Victims were no more likely than non-victims to report
that questions about violence should be asked (96.1% and
95.3% respectively).
Victims of IPV (95.1%) reported that such questions
should be asked, compared to 96.9% of victims of other
types of violence.
Victims of sexual violence more frequently reported
being upset (21.7%) than did victims of stalking
(9.2%).
Victims of IPV were significantly more likely (25.9%)
to report being upset than victims of other types of
violence (13.5%) $p < .001$.
Gender differences
Men (96%) & women (96.3%) were equally likely to
respond that such questions should be asked.
Women were significantly more likely than men to
report being upset (13.6% and 6.1% respectively).

Among the 221 victims who reported being upset/afraid, 189 (89.1%) responded that the questions should be asked.

Subgroup 2:

Differences by history of violence/abuse

Victims were no more likely than non-victims to report that questions about violence should be asked (93.7% and 92.2% respectively).

Gender differences

Men were no more likely than women to report that questions about violence should be asked (94.1% and 92.7% respectively). Women were significantly more likely to report being upset (13.6%) than were men (6.1%), $p = .0001$.

Rojas & Kinder 2007 America	Undergrad psych. students with a history of childhood sexual abuse. N = 250 Cross-sectional 18 - 36 yrs Males & Females	<p>Instrument Respondent-administered questionnaires.</p> <p>Type of questions Child sexual experiences, reasons for not using condoms, & feelings & thoughts about genitals.</p>	No results reported	<p>Differences by history of violence/abuse There were no significant differences in states of anxiety, anger & depression between before and immediately after survey completion between non-abused, abused, & severely abused participants.</p> <p>Gender differences Males did not appear to suffer any greater adverse effects than females.</p>
Carter-Visscher, Naugle, Bell, & Suvak 2007 America	Undergrad. students N = 79 Longitudinal (Cohort) 18 - 44 yrs Females	<p>Instrument</p> <p><u>Session 1:</u> Respondent-administered questionnaire & interview</p> <p><u>Session 2:</u> Exposure to visual stimuli in which participants were presented with photographs of different facial expressions & asked to label the emotions depicted. Participants were also asked to look at violent pictures of murder & sexually arousing pictures. They also had to listen to auditory stimuli of car crashes, sirens & alarms while wearing a heart rate monitor.</p> <p><u>Session 3:</u> Follow-up questionnaire about research experience one week later.</p> <p>Type of questions <u>Session 1:</u> PTSD & childhood physical &</p>	<p>Prevalence of reported distress Those upset at Session 2 had a mean rating of 3.13 while all other ratings for upset (1=not at all upsetting, 6=very upsetting) difficulty (1=not at all difficult, 6=very difficult) & bother (1=not at all bothered, 6=very bothered) had ratings of less than 3. Overall, low levels of distress were reported.</p> <p>Prevalence of reported benefit 100% in Session 1 & over 95% in Session 2 & 3 rated sessions as somewhat interesting or more. Over 75% rated all three sessions as somewhat beneficial & enjoyable or more.</p> <p>Prevalence of reported regret No participants in Session 1, 4% in Session 2 & 6% in Session 3 indicated that they would be unwilling to participate again.</p>	<p>Differences by history of violence/abuse Participants with a history of childhood abuse exhibited a stronger, positive association with Session 1 distress than Session 2 ($B = -0.09, p < .05$) or Session 3 ($B = -0.09, p < .05$) suggesting that individuals reporting higher levels of childhood abuse were impacted more by Session 1 than individuals reporting lower levels of childhood abuse.</p> <p>No significant relationship trauma history & between willingness & beneficial report ratings were found.</p> <p>PTSD symptoms Similarly, the relationship between PTSD & distress was strongest in response to Session 1 compared to Session 2 & Session 3 (B interaction = 0.04, $p < .05$; $B = 0.04, p < .05$).</p>

sexual abuse.

Session 2:

Stimuli unrelated to childhood trauma.

Session 3:

Research experience.

Hlavka, Kruttschnitt, & Carbone-Lopez 2007 America	Incarcerated women N = 142 Cross-sectional with a small qualitative component. Average age: 34.85yrs Females	<p>Instrument Interviews.</p> <p>Type of questions Verbal, psychological, physical, sexual, childhood, adulthood victimization, stress.</p>	<p>Prevalence of reported distress Of participants who experienced childhood sexual abuse, 44% did not complete the interview & only 12% did ($\chi^2 = 10.31, p < .01$). More than one half (56%) of participants who experienced both child & adult victimization, did not complete the interview, whereas just one third (33%) with similar traumatic experiences did so. Non-completers displayed varying ranges of emotional regulation & management in the form of blocking, burying, avoidance, & self-reflection within three categories: (a) some women chose not to talk about their victimization at all; (b) some women would talk around their experiences, avoiding narrative description but focusing on another aspect of their violent encounter; & (c) most women, while refusing to give interviewers a narrative of the event, chose to talk about these experiences during debriefing sessions.</p>
Newman, Willard, Sinclair & Kaloupek 2008 America	College students N=613 Cross-sectional Average age 22.7yrs Males & Females	<p>Instrument Respondent-administered questionnaires.</p> <p>Type of questions Amount of times experienced</p>	<p>No results reported.</p> <p>Differences by history of violence/abuse (Questions were asked on 60 items where participants rated their responses on a 5-point scale ranging from 1= "strongly agree" to 5= "strongly disagree"). Participants with & without a history of trauma exposure did not differ significantly on any of the scales below traumatic events & PTSD.</p> <p>Gender differences Men rated the overall experience as significantly more positively than women: Personal satisfaction: Men (Mean = 2.22; SD = .64) Women (Mean = 2.11; SD = .58) Personal Benefits: Men (Mean = 2.68; SD = .69) Women (Mean = 2.73; SD = .72)</p>

				<p>Emotional Reactions: Men (Mean = 2.38; SD = .79) Women (Mean = 2.25; SD = .84) Perceived Drawbacks: Men (Mean = 2.60; SD = .78) Women (Mean = 2.36; SD = .70) Global evaluation: Men (Mean = 1.95; SD = .50) Women (Mean = 1.72; SD = .49) PTSD symptoms Participants with & without PTSD did not differ significantly on any of the scales.</p>
Schwerdtfeger & Goff 2008 America	Pregnant females N = 41 Cross-sectional 18–33 years Females	<p>Instrument Respondent-administered questionnaire or interview. Participants could choose between questionnaire & interview. 92.7% chose to be interviewed. Participants were also observed for behavioural signs of distress. Type of questions Traumatic events experience (accidents, natural disasters, crime, child abuse, rape, adult abuse, witnessing death/murder, being in a dangerous/life threatening situation, news of the unexpected or sudden death of a loved one), trauma symptoms (anxiety, depression, dissociation, sexual problems, sleep disturbances), research experience.</p>	No important results for this review.	<p>Differences by history of violence/abuse (Questions were asked on 24 items where participants rated their responses on a 5-point scale ranging from 1= “strongly agree” to 5= “strongly disagree”). The 36 pregnant female participants with previous trauma histories indicated favourable reactions to participation (M=99.86, SD=7.53). No differences in lifetime trauma exposure were found when comparing pregnant women based on their report of emotionality (unexpected emotionality: Mean = 3.54, no unexpected emotionality: Mean= 2.71), insight (insight gained: Mean =2.71, no insight gained: Mean=5.00), or discomfort (comfort participating: Mean = 3.50, discomfort participating: Mean = 4.20). Participants with greater lifetime trauma exposure perceived research participation as more beneficial & meaningful (Mean=3.62) than those who did not perceive participation as beneficial & meaningful (Mean=2.33). PTSD symptoms Similarly, participants with higher trauma symptoms perceived participation as more beneficial & meaningful (Mean=22.00) than those who perceived participation as not personally meaningful (Mean=19.00).</p>
DePrince & Chu 2008 America	<p><u>Subgroup 1:</u> Community members <u>Subgroup 2:</u> Undergrad. psych. students <u>Subgroup 3:</u></p>	<p>Instrument <u>All participants:</u> Respondent-administered questionnaire. <u>Subgroup 1 & 4:</u> Interviews. Type of questions</p>	<p>Prevalence of reported distress & benefit (Questions were asked on 24 items where participants rated their responses on a 5-point scale ranging from 1= “strongly disagree” to 5= “strongly agree”). Participants in all samples reported that Personal Benefits (Subgroup 1: Mean=4.03; Subgroup 2:</p>	<p>Gender differences Multiple regression analyses showed that males were more likely to have regrets & report negative experiences of participation ($p < .05$), whereas females were more likely to say that they thought research is important ($p < .001$). Age differences Multiple regression analyses show that older participants ($p < .05$)</p>

<p>Community members <u>Subgroup 4:</u> Community members N = 529 Experimental (Non-randomized Controlled Trial) Age not reported Males & females</p>	<p><u>Questionnaire:</u> Brief Betrayal Trauma Survey (interpersonal trauma & non-interpersonal trauma (e.g. natural disasters), dissociation scale, PTSD, research participation. <u>Interviews:</u> Questions regarding cognitive & emotion themes (e.g. shame, fear, rage, betrayal) experienced in response to various forms of trauma exposure.</p>	<p>Mean=3.15; Subgroup 3: Mean=3.47; Subgroup 4: Mean=3.97) were greater than Emotional Reactions (Subgroup 1: Mean=2.82; Subgroup 2: Mean=2.56; Subgroup 3: Mean=3.09; Subgroup 4: Mean=3.17). Participants in all subgroups also reported that Personal Benefits (same scores represented above) outweighed Perceived Drawbacks (Subgroup 1: Mean=1.76; Subgroup 2: Mean=2.56; Subgroup 3: Mean=2.43; Subgroup 4: 1.82). Prevalence of reported benefit The interview procedures were associated with more positive appraisals than the questionnaire only procedures.</p>	<p>were more likely to experience greater unexpected & negative emotions, but also reported greater perceived benefits. Younger participants ($p < .01$), were uniquely associated with better global evaluations (beliefs about importance of research). PTSD symptoms Those who experienced greater trauma-related symptoms ($p < .001$) were more likely to experience greater unexpected & negative emotions, but also reported greater perceived benefits. Effect of instrument Those administered questionnaires ($p < .001$) were more likely to report regret & negative experiences, whereas those administered interviews ($p < .001$) were more likely to report that this type of research is important.</p>
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<p>Gekoski, Gray & Adler 2009 London</p>	<p>Bereaved by homicide N = 14 Cross-sectional 40 - 89yrs Females</p>	<p>Instrument Interviews. Type of questions Experiences of secondary victimization by various criminal justice agencies & media.</p>	<p>Prevalence of reported distress 50% reported having experienced upset/distress (E.g. brought back memories). Prevalence of reported benefit All participants gained something positive (E.g. being heard; hope that their participation would help others). Prevalence of reported regret None regretted participation.</p>	<p>No group comparisons were made.</p>
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<p>Ferrier-Auerbach, Erbes, & Polusny 2009 America</p>	<p>Out-patient PTSD patients. N = 127 Experimental (RCT) 22 - 82 yrs Males & females</p>	<p>Instrument Respondent-administered questionnaire & emotional reactions to a two-item picture measure in which participants rate their current affect & arousal. Type of questions <u>Subgroup 1:</u> Trauma-related survey: combat/war exposure, PTSD & beliefs following trauma. <u>Subgroup 2:</u> Non-trauma-related survey: personality, care satisfaction & values.</p>	<p>No results reported</p>	<p>Effect of instrument (Participants were asked to rate their experience on a 5-point Likert scale with lower scores indicating strong disagreement). Participants who were administered the trauma-related survey reported significantly more sadness & tension (Mean=27.23, SD=6.89), than those administered the non-trauma survey (Mean=24.49, SD=7.51), $p < .05$. Participants administered the trauma survey were more likely to report that they were more upset (Mean=2.79; SD=.15) than expected after completing the questionnaire than those administered the non-trauma survey (Mean=2.29; SD=.15), $p < .05$. However, there were no differences between the two groups in ratings of perceived gain from participating in the study or willingness to complete the research if they had known ahead of time what completion of the questionnaire would be like (Trauma survey: Mean=2.76, SD=.13;</p>
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Non trauma survey: Mean=2.90, SD=.13, F (1,131) <1.)

Kuyper, de Wit, Adam, & Woertman 2010 Netherlands	Sexually experienced young people N = 899 Cross-sectional 14-26yrs Males & females	Instrument Respondent-administered on-line questionnaire. Type of questions Sexual victimization, & sexual risk behaviour.	Prevalence of reported distress One in four participants reported distress (e.g. feeling down 16.5% or sad 7.8%). Prevalence of reported benefit The majority (96.5%) of participants reported positive feelings. Prevalence of reported need for help 3.5% expressed a need for help. (Questions were about research experience were given on a 5-point scale ranging from 1=totally disagree to 5=totally agree).	Differences by history of violence/abuse (Questions were asked on 3 items where participants rated their responses on a 5-point scale ranging from 1= "totally disagree" to 5= "totally agree"). <u>Trauma & distress</u> Victims of sexual coercion felt more distress & were likely to report a need for help due to participation, but also had positive feelings about the questionnaire. Verbal manipulation: Mean = 2.18; SD = .98 No verbal manipulation: Mean = 1.67; SD = .80, p < .001. Situational abuse: Mean = 2.17; SD = 1.01 No situational abuse: Mean = 1.88; SD = .91; p < .001. Sexual violence: Mean = 2.51; SD = 1.14 No sexual violence: Mean = 1.86; SD = .87; p < .001. Any form of sexual victimization: Mean = 2.16; SD = .98 No form of sexual victimization: Mean = 1.61; SD = .77; p < .001. <u>Trauma & positive feelings:</u> Verbal manipulation: Mean = 3.97; SD = .67 No verbal manipulation: Mean = 3.84; SD = .65; p = .01. Situational abuse: Mean = 3.99; SD = .66 No situational abuse: Mean = 3.89; SD = .66. Sexual violence: Mean = 4.16; SD = .75 No sexual violence: Mean = 3.86; SD = .64; p < .001. Any form of sexual victimization: Mean = 3.96; SD = .67 No form of sexual victimization: Mean = 3.83; SD = .65; p = .01. Gender differences More women (Mean=2.01) than men (Mean=1.76) were distressed by the questions (p<.01). Age differences Younger participants reported more positive feelings (Mean=3.97) from participation than older participants (Mean=3.83).
Campbell, Adams,	Rape survivors	Instrument	Prevalence of reported distress	No results reported

Wasco, Ahrens & Sefl 2010 America	N = 92 Cross-sectional Average age: 34.79 yrs Females	Interviews. Type of questions Rape assault, physical health, social support, psych. well-being.	4.3% of the women expressed participation as a negative experience, stating that reopening the wounds from the assault was painful & the interview brought those negative memories back. Prevalence of reported benefit Vast majority of participants described participation as positive, stating it was a supportive environment in which to talk about the assault, & for some that was instrumental in creating new ways of interpreting their experiences as survivors. (Prevalences were not reported).	
Decker, Naugle, Carter-Visscher, Bell & Seifert 2011 America	Undergrad students N = 79 Longitudinal (Cohort) & quantitative 18-44yrs Females	<u>Session 1:</u> Respondent-administered questionnaires, interviews. <u>Session 2:</u> Visual/audio stimuli: participants must identify emotions while exposed to emotionally evocative photographs & sounds <u>Session 3:</u> 1 week later participants asked to report distress. Childhood victimization, dating & sexual practices, emotionally evocative photographs & sounds.	Prevalence of reported distress 8.9%-25.3% reported no bother at all. Responses coded for bother due to specific factors were low overall (1.3–27.8%), with some reporting bother due to an emotional reaction to experimental stimuli. Prevalence of reported benefit 3.8% reported no benefit at all across sessions. The following benefits were reported: having increased insight into the self (26.6 – 30.4% across sessions), being able to help others through participation (session 1 – 30.4%, session 2 – 12.7%, session 3 – 10.1%); & having an interest in psychology or research. (Prevalences were not reported).	Differences by history of violence/abuse <u>Session 1:</u> Significantly more participants with an abuse history (47.2%) reported bother than those without an abuse history (11.6%), $p = 0.001$. <u>Session 2 & 3:</u> Participants without an abuse history reported being significantly more (20.9%) bothered by gaining painful insights about others than those with an abuse history (5.5%), $p = 0.058$. Also, participants who reported that research did not bother them were significantly less likely (25.5%) to have an abuse history than those without an abuse history (5.5%), $p = 0.03$. <u>Over all sessions</u> More participants with an abuse history commented that participation in the study was helpful, both during Session 1 (36.1% vs. 9.3% of those without an abuse history ($p = 0.006$) and during Session 3 (30.1% vs. 6.9% of those without an abuse history, $p = 0.008$). Overall, the results demonstrated that participants with a history of childhood abuse were more likely to report distress due to remembering the past, but were also more likely to report participation as being helpful.
Cook, Darnell, Anthony, Tusher, Zimmerman, Enkhtor & Hipp 2011 America	Undergrad. students N = 219 Experimental (RCT) 18 - 45 yrs Males & females	Instrument Respondent-administered questionnaires. Type of questions <u>Subgroup 1 (control):</u> Personality attributes to birth rank questionnaire	Prevalence of reported distress Participants reported a few drawbacks such as the study: taking too long, being boring, inconvenient, or too personal. Prevalence of reported benefit Control condition participants reported higher	No results reported

<p><u>Subgroup 2 (exposure):</u> Stressful events</p> <p><u>Subgroup 3 (exposure):</u> Stressful & stigmatizing events</p> <p><u>Subgroup 4 (exposure):</u> Stressful, non-stigmatizing & potentially traumatizing events</p> <p><u>Subgroup 5 (exposure):</u> Stressful, stigmatizing, & potentially traumatizing events</p> <p><u>Subgroup 6 (exposure):</u> Sexually violating events</p>	<p>levels of positive affect than those in other conditions. They agreed more strongly that the study did not raise emotional issues for them. They disagreed that participation was stressful & that they were upset more than they expected from participating.</p> <p>Prevalence of reported regret Participants responded that they would engage in the study again after knowing what it was like to participate.</p> <p>Overall, regardless of exposure condition, participants reported low levels of negative effect & generally positive reactions immediately after participation. The exposure conditions that brought the most negative & least positive responses, were those that contained questions about stressful life events & sexual violation.</p>
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<p>Sikweyiya & Jewkes 2012 South Africa</p>	<p>Participants who had participated in a household-based survey. N = 23 Quantitative with longitudinal qualitative 22 - 67yrs Males & females</p>	<p>Instrument Questionnaire & Interviews</p> <p>Type of questions <u>Questionnaire:</u> Childhood trauma (emotional neglect & abuse, physical hardship & abuse, sexual abuse), gender relations, sexual harassment, sexual relations, domestic violence, rape, emotional, physical & sexual IPV perpetration (men) & victimization (women).</p> <p><u>Interviews (4-6 weeks later):</u> Victimization & perpetration (males), victimization (females), participants experience of the questionnaire in a larger study.</p>	<p>Prevalence of reported distress Some participants reported that the survey caused them pain by reminding them of past painful Experiences. However, the pain was short-lived & not overwhelming.</p> <p>Prevalence of reported benefit & regret While a number of informants had emotional reactions to some survey questions, the vast majority thought the survey had a positive effect on them & did not regret participation.</p>	<p>Differences by history of violence/abuse A number of informants, in particular those who had major adversities in their lives (e.g. sexual assault, IPV, HIV), mentioned that they do not often get a safe space to talk about their traumatic event. Therefore those with trauma histories felt talking about their experiences to be a positive experience.</p> <p>Gender differences Men felt discomfort by the type of questions asked, whereas women felt empowered. 5 of the men reported feeling discomfort with some of the questions. They viewed the questions as sensitive & personal. For them it was taboo to be asked about sex, condoms, HIV, intimate relationships & IPV. Some women reported feeling empowered by participation, & some felt fearful after disclosing abuse fearing that their partners will find out & become violent.</p>
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Studies are arranged by date in ascending order
HMO - Health Maintenance Organization

4.3.2.1. Types of studies

4.3.2.1.1. Description of adolescent studies

All five of the studies among adolescents described the prevalence of distress/benefit related to research participation and also made comparisons between participants who had been victims of abuse and those who had not. Two of these studies compared males and females and one study compared older adolescents with the younger ones in terms of the prevalence reporting distress or benefit. None of the adolescent studies compared participants who reported PTSD symptoms with those who did not or with those who reported less severe symptoms, in terms of their experiences of distress and benefit.

a. Study designs

a.1. Quantitative studies

Three of the five adolescent studies used a cross-sectional study design. One of these cross-sectional studies also included a longitudinal aspect with a 12-month follow-up (Zajac, Ruggeriero, Smith, Saunders, & Kilpatrick, 2011). However, the longitudinal data was not reported and therefore it was classified as cross-sectional. One study used a longitudinal design with a 13-month follow-up (Ybarra, Langhinrichsen-Rohling, Friend, & Diener-West, 2009).

b. Measures

In these studies, the variables of interest can be categorized into measures of exposure and outcome. Exposure variables were measures of the abuse/traumatic events or symptoms of traumatic events such as PTSD. Outcome variables were measures of participants' research experience.

b.1. Exposure measures

Three of the adolescent studies made use of respondent-administered questionnaires (Chu, DePrince, & Weinzierl, 2008; Priebe, Backstrom, and Ainsaar, 2010; Ybarra, et al., 2009), one made use of interview-administered questionnaires (Langhinrichsen-Rohling, Arata, O'Brien, Bowers & Klibert, 2006), and the other made use of telephonic interviews (Zajac, et al., 2011) to measure exposure to abuse.

b.1.(i) Questions asked to measure exposure

Three of the five adolescent studies questioned participants about their experience of verbal, physical, and/or sexual victimization (Langhinrichsen-Rohling, et al., 2006; Ybarra, et al., 2009; Zajac, et al., 2011). Two studies examined perpetration of abuse (Priebe, et al., 2010; Ybarra, et al., 2009). Priebe, et al. (2010) focussed on questions regarding sexual attitudes, pornography, sexual abuse victimization and perpetration. Two studies asked questions about drug abuse (Langhinrichsen-Rohling, et al., 2006) and alcohol abuse (Zajac, et al., 2011). Zajac, et al. (2011) went further to question participants about community and parental violence, and other traumatic events experienced. During the Chu, et al. (2008) study, children completed non-trauma related tasks to assess emotional understanding and cognitive ability, while their parents reported on children's interpersonal (e.g., sexual abuse, physical abuse, witnessing domestic violence, witnessing community violence) and non-interpersonal (e.g., motor vehicle accidents, medical traumas, natural disasters) trauma exposure.

b.2. Outcome measures

Three of the five adolescent studies made use of respondent-administered questionnaires (Chu, et al., 2008; Priebe, et al., 2010; Ybarra, et al., 2009;), one made use of interview-administered questionnaires (Langhinrichsen-Rohling, et al., 2006), and the other made

use of telephonic interviews (Zajac, et al., 2011) to measure outcome of their research participants' research participation experience.

As mentioned above Chu, et al. (2008) made use of respondent-administered questionnaires to measure the outcome of participants' research experience where data was obtained from two larger studies in which a combination of instruments were used. The one study consisted of: (1) an interviewer-administered questionnaire where adolescents were asked to report their own behaviours and their parents' parenting practices, (2) emotion-understanding tasks where participants and their parents were asked to look at pictures of babies and label emotions in the pictures, and (3) IQ estimated test. The other study consisted of: (1) Laboratory tasks designed to assess cognitive (including attention, memory, estimated IQ) and academic performance, and (2) administered interviewer-administered questionnaire about their own behaviours and feelings.

b.2.(i) Questions asked to measure outcome (research experience)

Questions to measure distress

Each of the five studies made use of a different set of questions to assess distress. In Langhinrichsen-Rohling, et al.'s (2006) study, participants were asked to rate how often they felt upset while answering the questions in the survey (not at all, rarely, sometimes, often). Ybarra, et al. (2009) asked participants if any of the questions about abuse made them upset, and if yes, to describe in their own words what was upsetting. Priebe, et al. (2010) asked participants to rate the following questions on a 5-point Likert-type scale from 1 = "strongly disagree" to 5 = "strongly agree" to assess distress: "The questions were unpleasant to answer"; "One should not ask people such questions"; "The questions can have unfortunate impacts"; "I think the questions were too private." Zajac,

et al. (2011) asked participants whether any of the survey questions were emotionally upsetting to them, and whether they felt they needed to talk with a counsellor. Chu, et al. (2008) asked participants whether the study made them feel upset or sad.

Questions to measure benefit

Langhinrichsen-Rohling, et al. (2006) asked participants one question to rate how often they were interested while completing the survey (not at all, rarely, sometimes, often). Ybarra, et al. (2009) asked participants to rate on a 5-point Likert scale how strongly they agreed or disagreed with the statement, “A survey like this should ask these questions about violence.” Chu, et al. (2008) asked participants two questions to assess benefit: (1) whether they were glad they were in the study, and (2) whether the study made them feel good about themselves. Priebe, et al. (2010) and Zajac, et al. (2011) did not measure benefit.

Questions to measure regret

The only study to ask whether participants were sorry they were in the study was Chu, et al. (2008).

Questions to measure other aspects of the research experience

Chu, et al. (2008) went further to ask the following eight questions: (1) “Was the study boring?”, (2) “Was it your choice to be in the study?”, (3) “Do you feel that things you said will be kept private?”, (4) “Did you tell the truth in the study?”, (5) “Did participation make you feel good about helping others?”, (6) “Did you feel you could skip questions or part of the study?”, (7) “Did you feel you could stop at any time?”, and (8) “Did you feel you could take a break?”.

4.3.2.1.2. Description of adult studies

Of the 22 adult studies, five described the prevalence of distress/benefit related to research participation without comparing participants who had and had not experienced abuse, and 15 compared participants with and without a history of abuse. One of the studies examined completion rates as an indicator of distress and another compared reactions to research participation by administering a trauma survey to half of the participants and a non-trauma survey to the other half. Seven of the studies compared males and females and two studies compared adults of different ages in terms of the prevalence of reporting distress or benefit. Six of the studies made a comparison between participants who reported PTSD symptoms and those who did not or scored lower on PTSD symptoms, in terms of their experiences of distress and benefit. Of the 15 adult studies that reported participants' age ranges, 12 included adolescents between the ages of 18 and 19 years. Two of these included adolescents who were as young as 14 to 19 years. Unfortunately the proportion of the sample that comprised adolescents was not reported in any of these 12 studies.

a. Study design

a.1. Quantitative studies

There were 19 quantitative adult studies. Of the 19 quantitative studies, 14 used a cross-sectional study design; one of these also included a small qualitative component (Hlavka, Kruttschnitt, and Carbone-Lopez, 2007). Three of the 19 adult quantitative studies used an experimental design, one of which was a non-randomized controlled trial (DePrince and Chu, 2008) and the other two were randomized controlled trials (RCTs) (Cook, et al., 2011; Ferrier-Auerbach, Erbes, & Polusny, 2009). Two of the 19 adult quantitative studies used longitudinal observational designs, one of which measured participants' research experience a week after completion of the questionnaire (Carter-

Visscher, Naugle, Bell, & Suvak, 2007). The other longitudinal study had a 48 hour follow-up from the time of questionnaire completion (Newman, et al., 1999).

a.2. Qualitative studies

Two of the adult qualitative studies made use of in-depth interviews (Black, et al., 2006; Gekoski, et al., 2009) and one made use of open-ended as well as closed ended questions (Campbell, Adams, Wasco, Ahrens & Sefl, 2010). All three of these studies made use of qualitative research for both the exposure and outcome measures.

a.3. A combination of qualitative and quantitative study designs

Of all the adult studies two used a combination of qualitative and quantitative study designs. One study made use of a combination of qualitative interviews and quantitative respondent-administered questionnaires to measure the exposure of abuse and they also conducted a short longitudinal study in which a questionnaire was administered one week after data collection (Decker, et al., 2011). Another study made use of a quantitative responded-administered questionnaire to measure the exposure of abuse and a qualitative interview 4-12 weeks later to measure the outcome of the participants' experiences of participation in the questionnaire (Sikweyiya and Jewkes, 2012).

b. Measures

b.1. Exposure measures

Twelve of the 22 adult studies used respondent-administered questionnaires, seven used interviews, and three used respondent-administered questionnaires as well as interviews (Decker, et al., 2011, Carter-Visscher, et al., 2007, Schwerdtfeger and Goff, 2008) to assess exposure to abuse.

Two of the above studies made use of a combination of instruments as part of their research. Decker, et al. (2011) conducted three sessions with the first session included respondent-administered questionnaires and interviews, session two consisted of visual/audio stimuli in which participants were asked to identify emotions while being exposed to emotionally evocative photographs and sounds, during the third session participants were asked a week later about their research experience. Ferrier-Auerbach, et al. (2009) administered respondent-administered questionnaires and visual stimuli that monitored emotional reactions to a two-item picture measure in which participants rate their current affect and arousal.

b.1.(i). Questions asked to measure exposure

Twenty of the studies' research questions focused on participants' history of abuse such as emotional, physical and sexual abuse, rape and PTSD symptoms. Four studies asked participants about their sexual experience and practices (Decker, et al., 2011; Kuyper, et al., 2010; Sikweyiya and Jewkes, 2012). Two of the studies asked about IPV (Black, et al., 2006; Sikweyiya and Jewkes, 2012). Only one study asked about IPV perpetration by men (Sikweyiya and Jewkes, 2012).

b.2. Outcome measures

Thirteen of the 22 adult studies used respondent-administered questionnaires, six used interviews, one used respondent-administered questionnaires as well as interviews (Newman, et al., 1999), one study administered interviews as well as recorded participants' observed behaviour during the interview (Hlavka, et al., 2007), and another allowed participants to choose between questionnaires and interviews, as well as recorded observational signs of distress (Schwerdtfeger and Goff, 2008) to measure the outcome of their research participation experience.

Two of the above studies made use of a combination of instruments to measure the outcome of participants' research experience. Griffin, et al. (2008) administered respondent-administered questionnaires, psycho-physiological laboratory assessments in which heart rate and skin conductance monitors were placed on participants while talking about the abuse, and video-records for non-verbal behaviour. Carter-Visscher, et al. (2007) conducted three sessions. The first session included respondent-administered questionnaires and interviews. During the second session participants were exposed to visual stimuli in which they were presented with photographs of different facial expressions and asked to label the emotions depicted. Participants were also asked to look at violent pictures of murder and sexually arousing pictures, and they also had to listen to auditory stimuli of car crashes, sirens and alarms while wearing a heart rate monitor. During the third session participants were asked about their research experience a week later.

b.2.(i). Questions asked to measure outcome

Questions to measure distress

In order to assess the participants' research experience, the researchers made use of varying questions to assess distress and benefit. In order to assess distress, six studies asked whether participants were more upset by the questions than they had expected by responding to a 5-point Likert scale ranging from strongly disagree to strongly agree (Ferrier-Auerbach, et al., 2009; Gekoski, et al., 2009; Johnson and Benight, 2003; Newman, et al., 1999; Newman, Willard, Sinclair & Kaloupek, 2008; Walker, et al., 1997,).

One study asked participants whether they were more upset than expected, as well as whether the research made them think of things they did not want to think about, on a 5-point Likert scale ranging from false to true (Ruzek and Zatzick, 2000). Another study asked whether participants found it upsetting to answer questions, and “how much” on a 5-point Likert scale (0 = not at all; 1 = a little bit; 2 = somewhat; 3 = very much; 4 = extremely). They were also asked “What was upsetting about it?” (Carlson, et al., 2003). One study measured distress by asking the following three questions: “The questions gave me bad thoughts about things that happened to me,” “The questions made me feel down,” and “The questions made me sad”, and participants had to rate their response on a 5-point Likert scale (1=totally disagree - 5=totally agree) (Kuyper, et al., 2010). Decker, et al. (2011) examined distress by asking participants whether they were bothered at all, and what in particular they were most bothered by [about participation]?. DePrince and Chu’s (2008) study asked participants to respond to the following statements regarding research participation on a scale of 1 (strongly disagree) to 5 (strongly agree): “The research raised emotional issues for me that I had not expected”; “I experienced intense emotions during the research session”; “The study procedures took too long”; “Participating in this study was inconvenient for me”. DePrince and Freyd (2004) asked participants to rate whether they found answering the questions to be more or less distressing than other things they sometimes encounter in day-to-day life (1–much more distressing; 2–somewhat more distressing; 3–neutral; 4–somewhat less distressing; 5–much less distressing).

During Carter-Visscher, et al.’s (2007) study participants were asked to rate the following four questions: (1) Right now, how upsetting has participating in this study been for you? (1 = not at all upsetting, 6 = very upsetting); (2) Right now, how difficult has participating in this study been for you? (1 = not at all difficult, 6 = very difficult);

(3) Right now, how bothered are you by thoughts about aspects of this study? (1 = not at all bothered, 6 = very bothered); (4) Right now, rate your emotional reactions to participating in this study (1 = did not experience any feelings, 2 = felt minimal feelings, 3 = some feelings but not strong, 4 = some strong feelings, 5 = felt very strong feelings).

Griffin, et al. (2003) asked participants to rate the assessment experience on the following items: distress level (1 = not distressing, 7 = very distressing), interest level (1 = very interesting, 7 = very boring), confusion level (1 = not confusing, 7 = very confusing), difficulty level (1 = easy, 7 = very difficult), level of emotional numbing (1 = did not feel my feelings, 2 = felt minimal feelings, 3 = some feelings but not strong, 4 = some strong feelings, 5 = felt very strong feelings), and whether the participant would be willing to be assessed like this again (1 = I am quite willing, 2 = I might be willing, 3 = I don't think I am willing, or 4 = definitely not willing).

Black, et al. (2006) measured distress by asking the following questions: "Did my asking you any of these violence questions make you feel upset because the questions reminded you of a past victimization experience?" and "Did my asking you any of these violence questions make you feel afraid that someone might hear your answer and hurt you in any way?"

Hlavka, et al. (2007) did not ask participants about their research experience, instead they measured distress by looking at participant completion rates and by observational methods. They referred to two groups as "completers" and "non-completers".

Participants were categorized as non-completers when they: skipped certain sections of the interview, vocalized distress or were observed experiencing distress and had problems completing the interview, and broke off the interview.

Questions to measure benefit

In order to assess benefit, six studies asked participants to rate whether they gained something positive from completing the survey on a 5-point Likert scale ranging from strongly disagree to strongly agree (Ferrier-Auerbach, et al., 2009; Gekoski, et al., 2009; Johnson and Benight, 2003; Newman, et al., 1999; Newman, et al., 2008; Walker, et al., 1997).

Ruzek and Zatzick (2000) asked participants the following questions to assess benefit on a 5-point Likert scale ranging from false to true: “Participating in this project was worth it, despite any inconvenience I experienced;” “I gained something positive from participating;” “Volunteering made me feel good about myself” . One study measured benefit by assessing whether participants gained anything positive from participation by asking the following four questions: “I liked it that I was able to give my opinion,” “I found it a relief to share my experiences,” “I think it is important that surveys like this are carried out,” and “I think it is important that young people can speak up about their opinions on sexuality”, and participants had to rate their response on a 5-point Likert scale (1=totally disagree - 5=totally agree) (Kuyper, et al., 2010). Decker,et al. (2011) assessed benefit by asking participants what in particular they found beneficial about participating in the study.

Black, et al. (2006) measured benefit by asking participants whether they thought a survey like this should or should not ask questions about violence. Carter-Visscher (2007) asked participants to rate the following question, “Right now, how beneficial it has been for you to participate in this study?” (1 = not at all beneficial, 6 = very beneficial). One study asked whether participants found it at all helpful or useful to

answer questions on a 5-point Likert scale (0 = not at all; 1 = a little bit; 2 = somewhat; 3 = very much; 4 = extremely) (Carlson, et al, 2003).

DePrince and Chu (2008) asked participants to respond to the following statements regarding research participation on a scale of 1 (strongly disagree) to 5 (strongly agree): “I gained insight into my experiences through research participation”; “I found participating in this study personally meaningful”. DePrince and Freyd (2004) asked participants to rate how good an idea it was to include a respondent-administered questionnaire about interpersonal and non-interpersonal trauma in psychology research (1–very bad; 2–somewhat bad; 3–neutral; 4–somewhat good; 5–very good).

Questions to measure regret

Nine studies assessed regret by asking participants whether they would still have agreed to participate if they had known in advance what completing this survey would be like (Carter-Visscher, et al., 2007; DePrince and Chu, 2008; Ferrier-Auerbach, et al., 2009; Gekoski, et al., 2009; Johnson and Benight, 2003; Newman, et al., 1999; Newman, et al., 2008; Ruzek and Zatzick, 2000; Walker, et al., 1997;;).

Questions to measure other aspects of the research experience

Three studies went further by looking at other types of research experiences. For example, Kuyper, et al. (2010) assessed need for help with the following questions: “I felt a need for help due to the questions” and “I went looking for help due to the questions”.

DePrince and Chu (2008) asked participants to rate on a scale of 1 (strongly disagree) to 5 (strongly agree) whether they liked the idea they contributed to science; whether they

felt they could stop participating at any time; whether they felt they were treated with respect and dignity; and whether they trusted that their replies would be kept private.

DePrince and Freyd (2004) asked participants to rate how important they believe it was for psychologists to ask about these types of events in order to study the impact of such experiences (1 = definitely not important; 2 = somewhat not important; 3 = neutral; 4 = somewhat important; 5 = very important).

Questions to measure overall research experience

Some studies did not ask directly about distress and benefit, but made use of questions that assessed participants' overall research experience. Rojas and Kinder (2007) and Savell, Kinder & Young (2006) used the State-Trait Personality Inventory (STPI), which is an 80-item, self-report measure that consists of eight, 10-item scales that assess state and trait anxiety, depression, anger, and curiosity. Scores on the state items assess how the participant feels at the present moment (e.g., "I am tense" or "I feel calm").

Participants rated each state item on the following four-point scale: (1) not at all, (2) somewhat, (3) moderately so, or (4) very much so. Trait items report how the participant generally feels (e.g., "I am a steady person" or "I feel nervous and restless").

Participants rated each trait item on the following four-point frequency scale: (1) almost never, (2) sometimes, (3) often, or (4) almost always.

Cook, et al. (2011) measured well-being by assessing positive and negative affect with the Positive and Negative Affect Schedule (PANAS-X) and state anxiety with the STAI. The PANAS-X is a 60-item measure that assesses general and specific positive and negative affect. PANAS-X subscales measure specific emotions such as fear, hostility, guilt, sadness, joviality, self-assurance, and attentiveness. Participants indicated the

extent to which they felt each emotion “at this moment” on a Likert scale (1 = very slightly or not at all, 2 = a little, 3 = moderately, 4 = quite a bit, and 5 = extremely).

Schwerdtfeger and Goff (2008) made use of the Reactions to Research Participation Questionnaire Revised (RRPQR) in order to assess participants’ research experience. The RRPQR consists of 24 items assessing participants’ experience of study participation, reasons for participation, and perceived costs and benefits of participation. The measure contains specific items addressing the experiences of participation, including perceived coercion or undue influence by the investigators and perceptions of the researcher’s respect for the individual, as well as participants’ perceptions of personal gain, meaningfulness, and discomfort associated with research participation. Individual items are rated on a 5- point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

Sikweyiya and Jewkes (2012) assessed research experience by asking participants how the survey had impacted them, how answering the sensitive questions had made them feel, whether the research, directly or indirectly, was harmful or helpful to them and how, and whether they experienced adverse consequences as a result of their participation in the survey. Campbell, et al. (2010) asked participants what it was like to participate in the interview and how they could improve their interviewing.

The results of these types of studies discussed above will now be discussed in detail.

4.3.2.2. Results of studies' findings

4.3.2.2.1. Adolescent studies

a. Descriptive data

a.1. Prevalence of distress/benefit related to research participation

Four of the five studies measured the prevalence of distress only and did not assess whether participants found the research experience beneficial. Of these studies, the percentage of participants reporting distress ranged from low to moderate with percentages ranging from 2.5% (Langhinrichsen-Rohling, et al., 2006) to 37% (Priebe, et al., 2010), with the median being 5.7% (Zajac, et al., 2011). The fifth study assessed “cost-benefit ratios” by comparing the prevalence of reports of distress with reports of benefit (Chu, et al., 2008). The cost-benefit ratio was positive for the vast majority of participants in this study with 1.6% making negative appraisals of participation and the remaining 84% making positive appraisals.

b. Group comparisons

b.1. Differences of history of abuse

All five adolescent studies included a comparison of the research experience of those with and without a history of abuse victimization. Four of the five studies measured distress only (Langhinrichsen-Rohling, et al., 2006; Priebe, et al., 2010; Ybarra, et al., 2009; Chu, et al., 2008) and one measured distress and benefit (Zajac, et al., 2011). In three of the five studies, the participants with a history of abuse reported more distress as a result of research participation than those without such histories (Langhinrichsen-Rohling, et al., 2006; Priebe, et al., 2010; Zajac, et al., 2011). The topics of these three studies were: (1) suicidal behaviour, physical and sexual abuse, and drug use (Langhinrichsen-Rohling, et al., 2006); (2) sexual abuse victimization and perpetration, sexual attitudes, and pornography (Priebe, et al., 2010); (3) physical and sexual

assault/abuse, witnessed community and parental violence, and other traumatic events experienced, PTSD, major depression, and alcohol abuse (Zajac, et al., 2011).

In the other two studies that focussed on victimization and perpetration of verbal, physical and sexual abuse (Ybarra, et al., 2009), and experienced or witnessed physical and sexual abuse, depression, anxiety (Chu, et al., 2008), no significant differences were found between participants with and without an abuse history. The sample in the three studies mentioned above that found those with a history of abuse reported more distress than those without consisted of older adolescents (12 - 18 years), while the sample in the other two studies that reported no significant difference between those with a history and those without consisted of younger adolescents (7 – 15 years).

Two studies asked about perpetration of violence, however, one did not report on the perpetrators' distress separately to the victimization (Priebe, et al., 2010), and the other found perpetrators no more likely to be distressed than victims or non-victims (Ybarra, et al., 2009).

b.2. Gender differences

Two of the three studies measuring gender differences in responses to research participation found that girls experienced more distress than boys (Ybarra, et al., 2009; Zajac, et al., 2011). In one of these studies, 7.5% of girls and 3.9% of boys reported distress ($p = .001$) (Zajac, et al., 2011) and in the other the prevalences were not reported (Ybarra, et al., 2009). The third study found no difference in reports of distress between girls and boys. However, in this third study authors reported that girls were more interested in the survey than boys (Langhinrichsen-Rohling, et al., 2006).

b.3. Age differences

The one adolescent study that investigated whether there were age differences in the reports of distress resulting from study participation found that younger adolescents (aged 10 to 12) were more likely to experience distress than older adolescents (aged 13 to 15) in research focussing on verbal, physical and sexual abuse victimisation and perpetration (Ybarra, et al., 2009). The prevalence of reported distress in the respective age groups was not reported.

4.3.2.2.2. Adult studies

a. Descriptive data

a.1. Prevalence of distress/benefit related to research participation

Of the 22 adult studies, 16 measured both distress and benefits, one measured distress only (Hlavka, et al., 2007), and another compared reactions to research participation by administering half of participants a trauma survey and the other half a non-trauma survey (Ferrier-Auerbach, et al., 2009). In a RCT, Ferrier-Auerbach, et al. (2009) found that those administered the trauma survey reported more distress than those administered the non-trauma survey. They also found no differences between the two groups in ratings of perceived gain from participating in the study or willingness to complete the research if they had known ahead of time what completion of the questionnaire would be like. The other five studies did not report the prevalence of self-reported distress or benefit, but did report on group comparisons, such as differences in history of abuse and gender and age differences.

Of the 16 studies that looked at the prevalence of participant-reported distress and benefit, 15 reported a greater prevalence of benefit than distress with the percentage of participants reporting distress ranging from 11.4% (Black, et al., 2006) to 50% (Geskokki,

et al., 2009), with a median of 25%. The percentage of participants reporting benefit ranged from 25% (Walker, et al., 1997) to 100% (Carter -Visscher, et al., 2007; Geskoki, et al., 2009) with a median of 92.4% .

It is important to note that in the study with the highest prevalence of reports of distress (50%) (Geskoki, et al. 2009), 100% of participants reported benefit. In the study with the lowest prevalence of reports of benefit (25%) (Walker et al. 1997) only 13% of participants reported feeling “more upset than expected” and 76% said they would still have participated knowing in advance what the experience would be like. There was one study in which the prevalence of reports of distress was higher than the prevalence of reports of benefit (Carlson, et al., 2003). Carlson, et al. (2003) found 70% of participants to experience low levels of distress, and 51% found participation to be at least somewhat useful. In the other 15 studies that reported on both distress and benefits, the prevalence of reported benefit was higher than the prevalence of reported distress.

The one study that asked about male IPV perpetration did not report on the perpetration results separately to the victimization results (Sikweyiya and Jewkes, 2012).

b. Group comparisons

b.1. Differences of history of abuse

Of the 22 studies among adults, 15 compared the research experience of participants with and without a history of abuse victimization. Of these 15 studies, 14 measured victimization only and one measured victimization as well as perpetration. All of the 15 studies measured distress, with some measuring distress only (8 studies) and others measuring both distress and benefit (7 studies). Six of the 15 studies that measured distress only, found those with abuse history were more likely to find participation in

research distressing than those without a history (Black, et al., 2006; Carlson, et al., 2003; Carter-Visscher, et al., 2007; Johnson and Benight, 2003; Newman, et al., 1999; Walker, et al., 1997). Two studies that measured distress and benefit found victims of abuse to experience more distress than non-victims, but also to have positive feelings about the experience (Decker, et al., 2011; Kuyper, et al., 2010). These positive feelings outweighed the distress among the victims. Three of the 15 studies that measured distress and benefit, found participants who had a history of abuse to be more likely than those without such a history to find participation beneficial and a positive experience rather than distressing (DePrince and Freyd, 2004; Schwerdtfeger and Goff, 2008; Sikweyiya and Jewkes, 2012). The remaining four of the 15 articles, of which two measured distress only (Rojas and Kinder, 2007; Savell, et al., 2006) and two measured distress and benefit (Newman, et al., 2008; Ruzek and Zatzick, 2000) found no significant differences between abuse history and research experience.

One of the studies made use of interview completion rates as a predictor of distress (Hlavka, et al., 2007). They found participants who reported penetrated childhood sexual abuse were much more likely not to complete the interview compared to those who had not, indicating that these participants were possibly distressed.

b.2. Gender differences

Out of the eight studies investigating gender differences in experiences of research participation, six found differences and two found no significant gender differences in reported levels of distress and benefit. Three of the six studies that found gender differences, found that women were more upset by participation than men (Black, et al., 2006; Kuyper, et al., 2010; Newman, et al., 2008). The other three studies found that

women reported more positive experiences and men reported more negative experiences (DePrince and Freyd, 2004; DePrince and Chu, 2008; Sikweyiya and Jewkes, 2012).

b.3. Age differences

All three studies investigating age and research experience, found older participants to be significantly more likely to report that they were more upset than they had expected, compared with younger participants (DePrince and Chu, 2008; Kuyper, et al., 2010; Ruzek and Zatzick, 2000), with one of these studies reporting benefit as well (DePrince and Chu, 2008).

b.4. PTSD symptoms

Six of the eight articles that assessed the relationship between PTSD symptoms and research experience, found that participants who reported PTSD symptoms found research participation to be more distressing than those who had not reported these symptoms (Carlson, et al., 2003; Carter-Visscher, et al., 2007; DePrince and Chu, 2008; Griffin, et al., 2003; Newman, et al., 1999; Ruzek and Zatzick, 2000). One study found that participants, who indicated that research participation was personally meaningful, reported higher levels of PTSD symptoms than those who indicated that participation was not personally meaningful (Schwerdtfeger and Goff, 2008). The other article found no significant differences in research experiences between those with PTSD and those without (Newman, et al., 2008)

4.3.2.2.3. Risk of Bias

a. Quantitative Studies

Of the five quantitative adolescent studies, two were rated as having ‘moderate’ risk of bias and three were rated as ‘weak’ indicating high risk of bias (Table 2). Of the 19

quantitative adult studies, 13 were rated as 'weak', five as 'moderate' and one as 'strong' (Newman, et al. 1999). Factors contributing to the 'weak' ratings were the absence of adequate descriptions of sampling (20 studies), the absence of evidence for the reliability and validity of the exposure and outcome measures (7 studies), and cross-sectional study designs (17 studies) (Table 3).

There were six studies that were either experimental or longitudinal studies. For these we rated the component for "blinding" and "withdrawal and drop-out". Of the six experimental or longitudinal studies, none described efforts to ensure blinding and therefore received a rating of 2 (moderate). Two of the six studies reported more than 80% completion rate and therefore received a strong rating. The other four studies did not report on their withdrawal and drop-out rate and therefore received a weak rating.

Table 2: Quantitative study analysis – Adolescent Studies

Authors	Selection Bias	Study Design	Confounders	Data Collection Method: Exposure Measure	Data Collection Method: Outcome Measure	Global Rating	Comments (Explanations for low ratings of 3)
Langhinrichsen-Rohling, Arata, O'Brien, Bowers, Klibert (2006)	3	3	1	1	3	3	Selection of participants is not described, however, 60-79% of those recruited, agreed to participate. Cross-sectional design. Reliability & validity were not described for the outcome measure.
Ybarra, Langhinrichsen-Rohling, Friend, & Diener-West (2009)	2	2	1	3	3	2	Reliability & validity were not described for both exposure & outcome measures.
Priebe, Backstrom, & Ainsaar (2010)	2	3	1	3	3	3	Cross-sectional design. Reliability & validity were not described for both exposure & outcome measures.
Zajac, Ruggeriero, Smith, Saunders, & Kilpatrick (2011)	1	2	1	3	3	2	Reliability & validity were not described for both exposure & outcome measures.
Chu, DePrince, & Weinzierl (2008)	3	3	1	1	3	3	The selection of participants was not likely to be representative of the target population as they were self-referred. However, more than 80% agreed to participate. Cross-sectional design. The outcome measures have been shown to be reliable but not valid.

1 – strong

2 – moderate

3 – weak

Table 3: Quantitative study analysis – Adult Studies

Authors	Selection Bias	Study Design	Confounders	Data Collection Method: Exposure Measure	Data Collection Method: Outcome Measure	Global Rating	Comments
Johnson & Benight (2003)	3	3	3	1	1	3	Selection of participants is not described, however, 60-79% of those recruited, agreed to participate. Cross-sectional design. Control of confounders not described.
Ruzek & Zatzick (2000)	3	3	1	1	1	3	Selection of participants is not described, however, 80-100% of those recruited, agreed to participate. Cross-sectional design.
Griffin, Resick, Waldrop & Mechanic (2003)	3	3	2	2	3	3	Cannot assess selection bias. Cross-sectional design. Reliability & validity were not described for the outcome measure.
Walker, Newman, Koss & Bernstein (1997)	2	3	2	1	3	2	Cross-sectional design. Reliability & validity were not described for the outcome measure.
Newman, Walker & Gefland (1999)	2	2	2	1	1	1	Control of confounders not described. Reliability & validity were not described for the outcome measure.
Carlson, Newman, Daniels, Armstrong, Roth & Loewenstein (2003)	3	3	3	1	3	3	Selection of participants was not described. However, 60-79% of those recruited, agreed to participate. Cross-sectional design. Control of confounders not described. Reliability & validity were not described for the outcome measure.
Savell, Kinder & Young (2006)	3	3	2	3	1	3	Selection of participants not described. Cross-sectional design. Reliability & validity were not described for the exposure measure.
Rojas & Kinder (2007)	3	3	2	3	1	3	Selection of participants not described. Cross-sectional design. Reliability & validity were not described for the exposure measure.
Newman, Willard, Sinclair & Kaloupek (2008)	3	3	2	3	1	3	Selection of participants not described. Cross-sectional design. Reliability & validity were not described for the exposure measure.

Kuyper, de Wit, Adam & Woertman (2010)	3	3	1	1	3	3	Selected participants were not likely to be representative of the target population, & it was impossible to tell how many participants invited agreed as they were recruited through advertisements. Cross-sectional design. The outcome measures were shown to be reliable but not valid.
Decker, Naugle, Carter-Visscher, Bell & Seifert (2011)	3	2	2	1	3	2	Selection of participants not described. Reliability & validity were not described for the outcome measure.
Ferrier-Auerbach, Erbes & Polusny (2009)	3	1	3	1	1	2	Selection of participants not described. Control of confounders not described.
Carter-Visscher, Naugle, Bell & Suvak (2007)	3	2	2	1	1	3	Selection of participants not described.
Cook, Darnell, Anthony, Tusher, Zimmerman, Enkhtor & Hipp (2011)	3	1	2	2	1	2	Selection of participants not described However, 80-100% of those recruited, agreed to participate.
Hlavka, Kruttschnitt & Carbone-Lopez (2007)	3	3	2	1	3	2	Selection of participants not described However, 80-100% of those recruited agreed to participate. Cross-sectional design with a small qualitative component. Completion rates were used to determine outcome and no measures.
Black, Kresnow, Simon, Arias, & Shelley (2006)	3	3	1	3	3	3	Selection of participants not described. Cross-sectional design. Reliability & validity were not described for both exposure and outcome measures.
DePrince & Chu (2008)	3	3	1	1	1	3	Selected participants were not likely to be representative of the target population, & it was impossible to tell how many participants invited agreed as they were recruited through advertisements. Experimental (non-randomized control trial).
Schwerdtfeger & Goff (2008)	3	3	2	3	3	3	Selection of participants not described. However, 80-100% of those recruited agreed to participate. Cross-sectional design. Both the exposure & outcome measures were shown to be reliable but not valid.

DePrince & Freyd (2004)	3	3	2	3	3	3	Selected participants were not likely to be representative of the target population, & it was impossible to tell how many participants invited agreed as they were recruited through advertisements. Cross-sectional design. Reliability & validity were not described for both exposure and outcome measures.
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1 – strong

2 – moderate

3 – weak

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b. Qualitative studies

In grading the quality of the three qualitative studies, we found one to be of an 'A' rating (Campbell, et al., 2010) (Table 4). The scope and purpose was well articulated, the authors described the rationale behind their methodological approach clearly (e.g. feminist interviewing methodology), the method was consistent with the intent of the research, the sample and sampling method were appropriate, analysis was conducted very rigorously in four phases (with the approach in each phase clearly articulated) using two independent coders, interpretation was well grounded in the data, the authors built reflexivity into the design of the study (e.g. in checking participants experiences of the qualitative interviews as well as their response to the research topic) and the interpretation, ethical concerns were paramount, and the findings were highly relevant and transferable.

The other two studies received a 'B' rating (Gekoski, et al., 2009; Sikweyiya and Jeweks, 2012). There were some flaws, but these were unlikely to affect the credibility, transferability, dependability and/or confirmability of the study. The main area of weakness was the sampling.

Table 4: Qualitative study analysis

Authors	Scope & Purpose	Design	Sampling Strategy	Analysis	Interpretation	Reflexivity	Ethical Dimensions	Relevance/ Transferability	Quality Rating
Sikweyiya & Jeweks (2012)	Clear aim & link between research and existing knowledge demonstrated.	No rationale for study design & method given. Data collection strategies explained.	Description of sampling procedure (random) given, but no justification for its use. Sampling restricted to one geographical area.	Described in detail.	Clear descriptions.	Researcher reflexivity was not demonstrated.	Demonstration of sensitivity to ethical concerns.	Results linked to previous research findings. Limitations not outlined.	B
Campbell, Adams, Wasco, Ahrens & Sefl (2010)	Clear aim & rationale provided.	Rationale for the study design given. Data collection strategies explained.	Detailed description, selection criteria & justification provided.	Described in detail.	Described in detail.	Researcher reflexivity demonstrated.	Ethical approval not provided. Demonstration of sensitivity to ethical concerns.	Relevance & transferability evident.	A
Gekoski, Gray & Adler (2009)	Clear aim & rationale provided.	Rationale for the study design given. Data collection strategies explained.	No description of how sampling was undertaken.	Described.	Described in detail.	Researcher reflexivity was not demonstrated.	Demonstration of sensitivity to ethical concerns.	Limitations & future directions provided & results linked to previous research findings.	B

4.3.3. Discussion

4.3.3.1. Participants' experience of participating in the studies

a. Adolescent studies

In reviewing the studies conducted with adolescents, we found studies reporting low to moderate levels of distress ranging from 1.6% to 37%. It is interesting to note that in the study with the lowest prevalence of reported distress (Chu, et al., 2008) the parents of the participants, and not the participants themselves, were asked to disclose the abuse history of the children. The fact that children were not asked directly about their abuse history could account for the low distress levels (1.6%). In the study with the highest prevalence (36%) of reported distress (Priebe, et al., 2010) the questions had a stronger focus on sex and sexual abuse compared with the other adolescent studies. The questions covered sexual attitudes, pornography, sexual abuse victimization and perpetration. The combination of these topics might be particularly distressing.

b. Adult studies

The studies conducted with adults found distress levels ranging from 11.4% to 50% with a median of 25%, and benefit levels ranging from 25% to 100%, with a median of 92.4%. These results alone demonstrate that benefit levels outweigh distress levels. In reviewing possible reasons for the distribution of distress and benefit levels, it was found that participant type and prior traumatic experiences had a profound impact on the experience research participation. Studies that reported distress levels above the 25% median were those where the study population was limited to people who had traumatic prior experiences to participation, such as domestic violence survivors (Griffin, et al., 2003; Johnson and Benight, 2003), physically injured hospitalized motor/assault victims (Ruzek and Zatzick, 2000), psychiatric patients (Carlson, et al., 2003), and those bereaved by homicide (Gekoski, et al., 2009). The studies in which the prevalence of

reported distress was below the 25% median were those in which the study population was not limited to people with prior traumatic experiences, but included people from Health Maintenance Organization (HMO) members (Newman, et al., 1999; Walker, et al., 1997), sexually experienced people (Kuyper, et al., (2010), undergraduate students (Carter-Visscher, et al., 2007; Decker, et al., 2011), community members (Black, et al., 2006), with the exception of one study in which participants had been rape survivors (Campbell, et al., 2010).

The studies assessed benefits in different ways: some referred to it as positive experiences/feelings with participation; whether participants found participation interesting, useful, satisfying, important that these type of questions should be asked; whether they stated that the environment in which to talk about the assault was supportive; and whether it was instrumental in creating new ways of interpreting their experiences as survivors. The type of questions participants were asked did not appear to affect the variation in prevalence of distress and benefit by study.

The above results demonstrate that adolescents and adults generally report low to moderate levels of distress, and those that do report high levels of distress and low levels of benefit also report no regrets.

4.3.3.2. Comparing the experiences of research participation between those who had been victims of abuse with those who had not

a. Adolescent studies

As hypothesized, in reviewing the studies consisting of adolescents as participants, three studies found that those with a history of abuse reported more distress than those without

(Langhinrichsen-Rohling, et al., 2006; Priebe, et al., 2010; Zajac, et al., 2011). However, the other two studies found no significant differences between those with a history of abuse and those without (Chu et al., 2008; Ybarra, et al., 2009). In trying to understand the reasons for these results, we found that the three studies in which those with a history of abuse reported more distress consisted of older adolescents (12-18yrs), compared with the two studies in which there were no significant differences according to history of abuse (7-15yrs). This could possibly suggest that younger adolescents do not find talking about their traumatic history distressful because they have not yet realised the magnitude of what had been done to them, and only when they are older do they learn that abuse is wrong. Also, the prevalence of distress in the two studies reporting no significant differences was so small, that it is unlikely that it had the statistical power to detect a difference.

b. Adult studies

Of the 15 studies among adults that measured the difference in distress rates between those with a history of abuse and those without, six studies found those with a history of abuse reported more distress than those without, as hypothesized (Walker, et al., 1997; Newman, et al., 1999; Johnson and Benight, 2003; Carlson, et al., 2003; Black, et al., 2006; Carter-Visscher, et al., 2007). Two found those participants with a history of abuse reported more distress than those without, but also reported positive feelings (Kuyper, et al., 2010; Decker, et al., 2011). Three found those participants with a history of abuse reported more benefits than distress (Sikweyiya and Jewkes, 2012; Schwerdtfeger and Goff, 2008; DePrince and Freyd, 2004). Four reported no significant differences (Ruzek and Zatzick, 2000; Savell, et al., 2006; Rojas and Kinder, 2007; Newman, et al., 2008). One study that used completion rates as a predictor of distress found that those participants with a history of abuse were more likely to drop out of the

study than those without; and one study that administered trauma-focused surveys to half their participants and non-trauma surveys to the other half found that those administered the trauma survey reported more distress than those administered the non-trauma survey.

When reviewing these adult studies for reasons for the differences in research experience, we were not able to detect any major differences in the studies that might have accounted for the differences in findings of those with abuse histories and those without. All studies asked similar questions about past abuse.

4.3.3.3. Gender differences in responses to survey participation

a. Adolescent studies

Of the three studies that did look at gender differences, two found females to report more distress than males, and one study found females to report more benefits than males.

b. Adult studies

Of the eight studies that looked at gender differences, three studies found females to report more benefits and males more distress; three studies found females to report more distress than males; and two studies reported no significant gender differences. These findings do not support our hypothesis: women do not necessarily report more distress than males, and males are also likely to be more distressed by sensitive research than females.

4.3.3.4. Age differences in responses to survey participation

All three of the adult studies investigating age and research experience, found older participants to be significantly more likely to report that they were more upset than they had expected, compared with younger participants. This is different to the findings among the one adolescent study that investigated age and research experience, where the younger adolescents (aged 10 to 12) were found to be more distressed than older adolescents (aged 13 to 15) (Ybarra, et al., 2009). However, it is important to note that most of the younger youth in this study completed the survey while being monitored by their caregivers. The researchers suggest that the younger adolescents therefore might have felt distressed as they might have felt their privacy was violated (Ybarra, et al., 2009). It also may be that younger youth are more likely to think up disturbing images in their minds that they are unable to control and therefore feel more distressed by these types of sensitive questions.

4.3.3.5. Risk of bias assessment

The consensus was that the quality of the quantitative articles was mostly weak (17 articles) with only seven articles found of moderate quality and one of strong quality. The reason for most studies being rated as weak was mainly due to authors not describing their sampling techniques, no mention of whether measures used were valid and reliable, and the study design being cross-sectional. The qualitative studies were found to be of good quality with one receiving an “A” rating and the other two a “B” rating.

4.3.3.6. Limitations

One limitation of this review is that there are other potential confounders, namely the age at which the violence was experienced, the time between the violence and research

participation that we did not include in the risk of bias assessment. These were rarely taken into account in the included studies.

4.4. What we do not know

The findings of this review indicate that whether participants are victims of violence/abuse or not, they report mild to moderate levels of distress. However, as mentioned in the introduction of this thesis, there has been a debate as to whether the distress participants report feeling is in fact harmful (Ahern, 2012; Becker-Blease and Freyd, 2006). The findings of this review show that there is a positive cost-benefit ratio in each of the studies investigating this: the prevalence of reports of distress was lower than reports of benefit. This finding supports the notion that participants do not experience the distress related to their research experience as harmful, and indeed, might experience it as beneficial. The data in the literature reviewed above appears to support this notion. We will investigate whether this is true for our primary study in Chapter 2.

Becker-Blease and Freyd (2006) explain that participants' longer term reactions to research participation would be a more accurate way of assessing whether participation in sensitive research is in fact harmful. Therefore studies should assess long term reactions to research by following participants up over a longer period.

To address this gap in knowledge, we examined the extent to which the studies in this review followed participants after the research and found only two adolescent studies (Ybarra, et al., 2009; Zajac, et al., 2011) and four adult studies (Carter-Visscher, et al., 2007; Decker, et al., 2011; Newman, et al., 1999; Sikweyiya and Jewkes, 2012). We then critically assessed whether there was evidence of longer-term effects.

Three of these studies had a very short follow-up period of 1-12 weeks, while the other three had a 3-13months follow-up. It was found that participants in all three studies that participants did not report more distress at the follow-up period and those who were upset at baseline were no more likely than their counterparts to drop out of the study (Newman, et al., 1999; Zajac, et al., 2011; Ybarra, et al., 2009). These three studies did not show any long term effects of participation, however, three studies are too few to make an assumption that all participants are not harmed by participation after a period of a year. This indicates the need to have studies that follow participants and measure longer term effects of participation in the research.

4.5. Gaps in the literature

It is clear that there is very little research on adolescents' experiences of completing sensitive questionnaires in research. Only two studies were found that looked at the effects of research on IPV (Black, et al., 2006; Sikweyiya and Jewkes, 2012), but none of these were studies conducted with adolescents. During this review only two studies with adolescents and one study with adults asked about perpetration of violence, of which two studies did not report on the perpetrators' distress separately to the victimization (Priebe, et al., 2010; Sikweyiya and Jewkes, 2012), and the other found perpetrators no more likely to be distressed than victims or non-victims (Ybarra, et al., 2009). Further research is needed on perpetrators of violence's experience of participating in research that asks about abuse. Only one study was found that was conducted in South Africa and this was a study conducted with adults. To our knowledge there is therefore no research among South African adolescents on this topic. Our primary study below therefore fills this gap in research and is therefore to our knowledge the only study that has been conducted on adolescents in South Africa on this topic.

CHAPTER 2: The benefits and harms of surveying Cape Town adolescents about intimate partner violence and verbal, physical and sexual abuse

1. INTRODUCTION

This research was based on the pilot phase of the test-retest “Promoting sexual and reproductive health among adolescents in southern and eastern Africa – mobilizing schools, parents and communities” (PREPARE study) that was conducted in 2011. The study population was students in Grade 8 in Cape Town, South Africa.

The PREPARE project is an European Union funded study being conducted in four cities (Cape Town, Polokwane, Dar es Salaam and Kampala) in three African countries (South Africa, Tanzania and Uganda) from 2010-2014. The aim of the Cape Town study is to prevent sexual risk behavior and intimate partner violence amongst young adolescents in the Western Cape. As explored in Chapter 1, sensitive topics can include a broad range of topics such as participating in illegal activities such as substance abuse, sexual attitudes and practices, suicidal behavior, depression, anxiety, sexual attitudes, community and parental violence, psychologically traumatic experiences such as death, accidents, combat (including war) and natural disasters, and much more. However, our focus was on intimate partner violence and verbal, physical and sexual abuse. We felt this topic was important as this type of behaviour often leads to HIV/AIDS transmission through rape/unwanted sexual contact.

A survey including sensitive questions about sexual behavior, intimate partner violence, verbal, physical and sexual abuse was administered to students in three high schools in the Cape Metropole as part of the PREPARE pilot study.

2. AIM

The aim of this study is to describe adolescents' experiences of participating in a survey that included sensitive questions regarding abuse and intimate partner violence and to compare the experiences of those who had been victims of violence with those who had not.

3. HYPOTHESES

1. We hypothesize that adolescents who had been a victim of verbal, physical and sexual violence in the school and at home and/or IPV report more negative feelings such as being emotional when completing a survey on these topics than those without these experiences.
2. We further hypothesize that adolescents who had been a victim of verbal, physical and sexual abuse at the school and home and/or IPV are less likely to report that completing the questionnaire was beneficial compared to adolescents who had not been victims.

4. OBJECTIVES

- To determine the prevalence of verbal, physical and sexual abuse victimization, and of IPV victimization and perpetration amongst young adolescent students in three schools in the Western Cape.
- To describe students' experience of participating in the survey on verbal, physical and sexual abuse victimization and IPV victimization and perpetration

at first time of completion (test survey), and the extent to which they found it distressing or beneficial.

- To assess students' experience of completing the same survey two weeks later (retest survey) and to compare these with their responses to the test survey.
- To compare the experiences of research participation between those who had been victims or perpetrators of violence with those who had not.
- To examine whether adolescents who were distressed by their participation in the test survey were more likely than their counterparts to decline to participate in the retest survey.
- To assess whether there are gender differences in responses to survey participation.

5. METHODS

My role within the primary study was managing and planning implementation and assisting with fieldwork.

5.1. STUDY DESIGN

As part of the PREPARE project, this study was a test-retest reliability study of a self-administered questionnaire on intimate partner violence, verbal, physical and sexual abuse. The reason for using the test-retest reliability was to measure the reliability of the survey instrument. During this pilot phase of the study, the questionnaire was administered among a group of adolescents on two different occasions, in preparation for a randomised controlled trial to be carried out in 2013. The adolescents were given the questionnaire to complete in English and Afrikaans or English and Xhosa (test survey), and again two weeks later (retest survey).

5.2. SAMPLING AND PROCEDURE

5.2.1. SAMPLING

Three schools were selected to participate in the pilot study by means of convenience sampling. Each of the schools that was selected represent a different group in terms of the previous Apartheid government's classification system (which remains an indicator of socioeconomic and health status). Therefore, the majority of students in each of the schools were either "black", "white", or "colored". In addition, each of these schools was located in an area of different socio-economic status: one relatively affluent, one moderately deprived and one extremely deprived.

A random sample of grade 8 classes in each school was drawn, depending on the number of students in the classes/grade, so that we had at least 120 students in each school. In school A, four out of five classes were selected; in school B, three out of the five classes; and in school C, four out of six classes were selected. A total of 438 grade 8 students were sampled (school A: N=148, school B: N=150, school C: N=140). Of the 438 students selected, 345 students (79%) completed the test survey and 328 (95%) of these completed the same survey at retest. The majority of participants were between the ages of 12 and 16 years with one student aged 17 and another aged 20.

5.2.2. PROCEDURE

Ethical approval from the University of Cape Town's ethics department (HREC REF: 268/2010; Appendix 4) as well as permission from the Western Cape Education Department (Appendix 5) was granted for the study. The principal of each school provided written permission for the study to proceed before the research could start, thus ensuring informed consent at the school level.

Before students were asked to complete the questionnaires, information letters concerning the survey and parental consent forms were sent home with students to their parent(s)/guardian(s). These provided parents the opportunity to withdraw their child from the study if they so chose. The information letters were sent in the home language of the parents (English, Afrikaans, or Xhosa). If parents were not literate, students were requested to describe the information form to their parents. In the event that parents chose to withdraw their child, they signed the parental consent form indicating their refusal, which was returned to the school and collected by the research co-coordinator before administering the survey. Parents were also given a list of telephone numbers so that they could contact the teacher, principal or research team to withdraw their child from the study or in case they had questions about the study. If refusal was not indicated, it was assumed that parents had given consent to participation. This consent procedure has been widely utilized by similar studies (e.g. Langhinrichsen-Rohling, Arata, O'Brien, Bowers, & Kilbert, 2006) when it is assumed that the research involves minimal risk to participants.

Once/if the parent(s)/guardian(s) had given consent, the students themselves were allowed the opportunity to complete an assent form to indicate whether or not they would like to participate in the study. In all the selected classes, trained fieldworkers explained the study purpose, the process and consent procedure to the students in the teaching language of the school (English, Afrikaans or Xhosa).

Students completed the questionnaire during a school lesson and took them between 30 minutes and an hour to complete. After completion of the questionnaire, students were asked to drop their questionnaire in a sealed "drop in" box in front of the classroom. They were then given refreshments (a health biscuit and a juice) as well as a support

services card that contained relevant contact numbers of police stations and centers for help in the Western Cape (Appendix 6). These centers offer help with problems such as rape, trauma, teenage pregnancies, drug addiction, and HIV/AIDS. These pamphlets are the size of a bank card so that students can keep them in their pocket in case they are in a crisis and in need of help. Administration of the retest survey followed the same format as that of the test survey.

5.3. MEASURES AND INSTRUMENTS

Two respondent-administered paper questionnaires were developed that formed part of the PREPARE Cape Town test-retest study (Appendix 7). We made use of two different questionnaires because we planned to exclude unreliable items in order to combine these questionnaires to make one questionnaire for the main study. Students were unaware of which survey they would receive before assenting to the study. These questionnaires included items concerning a range of sensitive topics, such as sexuality, IPV, abuse and HIV. One questionnaire focused on attitudes and beliefs related to condom use (we will refer to the group of students receiving this questionnaire as “Sub-group A”). The original questionnaire included 203 questions however we have only presented the questions relevant to our study in Appendix 8. The other focussed on attitudes and beliefs related to sexual debut (we will refer to the group of students received this questionnaire as “Sub-group B”). The original of this questionnaire included 176 questions however we have only presented the questions relevant to our study in Appendix 9. and included 176 questions. A random half of the sampled students in each school were given the one questionnaire (sub-group A) and the other half the other questionnaire (sub-group B). Each questionnaire was designed in English and then translated and back translated into Afrikaans and Xhosa, so that each questionnaire was available in English/Afrikaans and English/Xhosa. Both questionnaires begin with

socio-demographic questions asking about date of birth, gender, “race” (according to Apartheid classifications that still reflect socio-economic status and health), and socio-economic status (based on having household assets such as tap water, electricity, and the type of house they live in). Students were asked a set of questions about their relationship status and their sexual behaviour, including whether they had ever had sex. The dependent variables for the analyses reported in this thesis were derived from students’ responses to three open-ended questions at the end of each of the questionnaires. These open-ended questions aimed to capture students’ perceptions of the questionnaire and their experience of research participation. The questions were: “What did you like about the questionnaire?”, “What did you not like about the questionnaire”, and “Would you like to write anything further?”

Exposure to violence and abuse was measured by the variables described below:

Sub-group A’s questionnaire (Appendix 8):

- Intimate Partner Violence (IPV)
 - experience of verbal, sexual, and physical IPV victimization and perpetration by a girlfriend or boyfriend in the past 6 months (scored on a scale from once to never).

Sub-group B’s questionnaire (Appendix 9):

- Violence/Abuse experienced in the home and at school – how often they have experienced or witnessed verbal, sexual and physical violence at the home and at the school by anyone (scored on a scale from never to more than four times).

5.4. DATA COLLECTION AND MANAGEMENT

It was necessary to link the students' surveys between test and retest times, and each participant was given a unique research code that corresponded to the code written on their questionnaires. At no point did they write their names on their questionnaires. The research team maintained a class list that linked student names with their unique research code. Before data collection, the research coordinator and assistant stapled the individual student's name onto the questionnaire with his or her unique research code. Students were given their questionnaire and before they could begin responding, they were asked to tear off their name from the front cover, and discard it. This procedure made it nearly impossible for anyone other than the researchers to look at a participant's answers and connect them to his/her name. Once data collection was completed, the survey "drop in" box was taken to the PREPARE office, emptied and the questionnaires were stored in a locked cupboard separate from the class lists that linked participants to participant numbers. At no time was anyone else given access to this list. Once the final survey was completed in 2013, this list was destroyed. Parents, teachers, school principals, and school health personnel did not have access to information about individual students or classes. In publications or discussion of the study findings, information that could identify a specific individual or school will not be revealed.

5.5. DATA ANALYSIS

Quantitative data from the questionnaire were analyzed with the use of SPSS (Statistical Package for the Social Sciences (SPSS) 19.0 Command Syntax Reference August 2010, SPSS Inc., Chicago Ill).

5.5.1. Demographic info

Frequency distributions and percentages were used to describe the demographic characteristics of participants (sex, age, race and socio-economic status).

When calculating the socio-economic status of participants, we made use of the following two questions: (1) Do you have any of the following at your home: tap water, a toilet, electricity, a fridge, a telephone, a cell phone, a television, or a car? (Assets); (2) Which of the following best describes your home: a shack, a tent or traditional home, a wendy house or backyard shack, a brick house or flat, or other (Housing). In order to calculate the socio-economic status from the first question the following scores were given: 1 = yes, and 0 = no. The sum of these scores was then calculated to give a cumulative score. The percentages, frequencies, means and standard deviations of these scores comprise the “asset score” reported on below. The second question was reported on with the use of frequencies and percentages under “housing”.

5.5.2. Prevalence of abuse victimization and perpetration

Frequency distributions and percentages were used to describe the prevalence of abuse victimization and perpetration in the sample. Participants’ responses to the questionnaire were sorted into the following identified variables: Sub-group A: abuse victimization from anyone including their intimate partners (injuries related to abuse, unwanted sexual touch), IPV victimization (verbal, physical, sexual), abuse perpetration done by them to anyone including their intimate partners (rape, bullying someone at school), and IPV perpetration (verbal, physical, sexual); and Sub-group B: abuse victimization done to them by anyone including their intimate partners (unwanted sexual touch), victimization in the home (verbal, physical), victimization in the school (verbal, physical, sexual), abuse perpetration done by them to anyone including their intimate partners (bullying someone at school). When participants responded yes to any of the questions regarding

these variables, they were labeled as having been exposed to violence. A variable was derived to indicate any exposure to abuse victimization and any exposure to abuse perpetration. Pearson Chi-square tests were then used to indicate significant differences by sex in the prevalence and percentages of those exposed to violence. The Fisher's Exact tests were used when cell counts were lower than 5.

5.5.3. Research experience

Participants' responses to the open-ended questions asking respondents what they liked and did not like about the questionnaire were read, and emerging themes were identified. The responses were then coded by me, a colleague (Ms. Petra De Koker and my supervisor (Dr. Cathy Mathews) according to these themes, and transformed into categorical variables for quantitative analysis. The prevalence of each of the codes was reported. Pearson Chi-square tests were then used to compare the prevalence of exposure to violence for boys and girls. The Fisher's Exact tests were used when cell counts were less than 5. Responses that indicated that research participation had evoked pain because of past experiences were defined as reports of distress. Responses were defined as reports of benefits if participants indicated any one of the following: they liked the questionnaire because it enabled them to be open and honest, they had learned something new, they had gained self-insight, they had felt a sense of relief or clarity from reviewing past events, that the topics covered were relevant to their life and made them think about life, that the questionnaire had the potential to help others through participation or that they felt more prepared for the future. The responses participants reported as "likes" were then coded and classified into "reports of benefits" and "other positive reports". The responses participants reported as "dislikes" were coded and classified into "reports of distress" and "other negative reports" (see Tables 11-14 below).

Chi-square tests were used to compare the research experience of victims of violence to non-victims, and of perpetrators to non-perpetrators. The outcome/dependent variables were the extent to which students reported distress and/or benefit. These analyses were stratified by sex. A logistic regression analysis was performed to assess the extent to which prior violence exposure was associated with experiencing the research as beneficial or not, adjusting for gender and whether the participant had ever had sex.

5.6. ETHICS

Because of the potential risks that a discussion of sensitive issues such as sexuality and violence may have, a system of referral to assessment and counselling services for participants was built into the project. Participants were advised to respond to questions according to their own comfort level. All students were advised prior to participating in data collection that they had the right to withdraw from the study at any time or refuse to answer any questions or refuse to provide their contact information.

Research staff were trained in all aspects related to confidentiality and their legal responsibilities with regard to child protection. If a learner divulged information about illegal activities, this information was not shared with anyone and no one other than trained research staff would have access to any data collected during the study.

However, in the event that a participant reported to data collectors that he/she had been exposed to violence of a serious nature, they would be assisted in reporting their experience to the appropriate agency (Commissioner for Child Welfare or Child Protection Services). Schools were also provided with referral information to facilitate easier access to services by students. If the participant was unwilling to report it and they remained at high risk, the research staff would report it to Child Protection Services as

per South African law (Criminal Procedure Act). Fortunately, this did not occur during the pilot phase of the PREPARE study. In terms of mandatory reporting procedures, if the participant volunteered information that they had been a victim of a form of less serious violence (hitting, punching), there was no reporting procedure in place.

By carefully training the research staff, we hoped that the students felt comfortable raising any issues or concerns related to the project.

During data collection, educators were asked to leave the classroom and only the trained fieldworkers remained. This allowed for confidentiality and allowed students to feel freer to be honest when completing the questionnaire. Research staff remained in the classroom or school for some time after each collection and made themselves available to students who might wish to speak with them. In addition, students were given a support services pamphlet that contained contact numbers to a system of referral to existing services within the community (i.e. relevant Non-Governmental Organisations, government agencies such as the Family, Child and Sexual Violence Unit (FCS), voluntary counselling and testing services, hotlines).

6. RESULTS

Over the entire sample, 438 learners were invited to participate in the study and given parental consent forms to take home to their parents or guardians. Thirty-seven learners were absent on the day of data collection, 19 learner's parents refused to allow their children to participate, 29 learners refused to participate, and 7 learners had left the school before the data collection date, leaving a total of 332 learners participating in the surveys. The response rate was 76%. The two groups were very similar and had no major differences. Both groups had slightly more females than males, the majority of

participants were female, 14 years of age, colored, lived in a brick house and had all 8 assets. The results for Sub-groups A and B are presented separately.

6.1. Participants

Sub-group A

Of the 186 participants who completed this questionnaire, just over half were female (see Table 5). They ranged in age from 13 to 20 years (*Mean* = 13.94, standard deviation (*SD*) = .80). Almost half of the participants identified themselves as “Colored”, with just over one third “Black”, and the remainder “White”, “Indian” or “Other”. Just over one third of participants had 8 or more items and 2.2% had 3 items on the asset index (*Mean* = 6.67, *SD* = 1.37) (maximum possible score was 8). Most participants (80.1%) reported that they lived in a brick house or flat, with the remainder in other dwelling types.

Table 5: Sub-group A (N=186) Characteristics of the participants

Variable	Freq (%)	Variable	Freq (%)	
Sex	Male	80 (43)	Asset score 3	4 (2.2)
	Female	104 (54.9)	4	12 (6.5)
	No response	2 (1.1)	5	21 (11.3)
Age	13	42 (22.6)	6	31 (16.7)
	14	111 (59.7)	7	46 (24.7)
	15	18 (9.7)	8	66 (35.5)
	16	4 (2.2)	No response	6 (3.2)
	20	1 (0.5)		
	No response	10 (5.4)		
Race	Black	73 (39.2)	Housing Shack	17 (9.1)
	White	9 (4.8)	Wendy house	8 (4.3)
	Indian	2 (1.1)	Brick house	149 (80.1)
	Colored	92 (49.5)	Other	2 (1.1)
	Other	2 (1.1)	No response	14 (7.5)
	I prefer not to answer	3 (1.6)		
	No response	5 (2.7)		

Sub-group B

Of the 165 participants completing this questionnaire, just over half were female (see Table 6). They ranged in age from 12 to 17 (*Mean* = 14.09, *SD* = .89). Just over half of the participants identified themselves as “Colored”, with just over one third “Black”, and the remainder “White”, “Indian” or, “Other”. Just over one third of participants had 8 or more items and 1.2% had 2 items, and 0.6% reported that they had none of the items on the asset index (*Mean* = 6.55, *SD* = 1.55) (maximum possible score was 8). Most participants (74.9%) reported they lived in a brick house or flat, with the remainder in other dwelling types.

Table 6: Sub-group B (N=165) - Characteristics of the participants

Variable		Freq (%)	Variable		Freq (%)
Sex	Male	71 (43)	Asset score	0	1 (0.6)
	Female	88 (53.3)		2	2 (1.2)
	No response	6 (3.6)		3	3 (1.8)
Age	12	1 (0.6)		4	13 (7.8)
	13	36 (21.8)		5	16 (9.6)
	14	80 (48.5)		6	35 (21)
	15	25 (15.2)		7	33 (19.38)
	16	12 (7.3)		8	61 (36.5)
	17	1 (0.6)	No response	1 (0.6)	
	No response	10 (6.1)			
Race	Black	63 (37.5)	Housing	Shack	15 (8.9)
	White	7 (4.2)		Tent	1 (0.6)
	Indian	1 (0.6)		Wendy house	8 (4.2)
	Colored	86 (51.5)		Brick house	125 (74.9)
	Other	4 (2.4)		Other	6 (3.6)
	I prefer not to answer	1 (0.6)		No response	101 (6.1)
	No response	3 (1.8)			

6.2. Prevalence of abuse victimization and perpetration

Sub-group A

Victimization

When looking at the prevalence of abuse victimization, the most reported type of abuse victimization was among those reported they had been touched in a sexual way or had done something sexual to them that they felt uncomfortable about (19.9%), with statistically significantly more females reporting more unwanted sexual touch than males ($p < 0.01$) (Table 7). Verbal IPV victimization was also one of the highest reported abuse victimization (17.7%), with females reporting more victimization than males. The remaining types of victimization ranged between 2.7% (sexual IPV) and 6.5% (physical IPV).

The number of participants who did not respond to any of the questions regarding IPV victimization was four (2.2%). The variables with the highest prevalence of non-response were verbal (34.9%), physical (35.5%) and sexual IPV victimization (36%).

When looking for reasons as to why participants did not respond to any of the IPV victimization questions, we found, 57% of the non-responders reporting they did not have a girlfriend or boyfriend. We looked further and checked whether the remaining three non-responders reported any likes or dislikes about the questionnaire in the open-ended questions (where we asked whether there was anything they liked or disliked about the questionnaire) and found only one reporting likes and dislikes.

Table 7: Sub-group A (N=186) - Prevalence of verbal, physical and sexual abuse victimization among male and female adolescents

Variables	Total	Males	Females	P Value
Injury related to abuse (ever)	6 (3.2%)	3 (4.8%)	3 (3.2%)	0.68
Unwanted sexual touch (ever)	37 (19.9%)	8 (10.5%)	29 (29%)	<0.01
Verbal IPV (past 6 months)*	33 (17.7%)	11 (13.8%)	22 (24.4%)	0.19
Physical IPV (past 6 months)**	12 (6.5%)	6 (20.7%)	6 (6.7%)	0.03
Sexual IPV (past 6 months)***	5 (2.7%)	2 (7.1%)	3 (3.3%)	0.59

*Refers to being insulted, made fun of, intimidated, threatened to be hurt by a boyfriend/girlfriend

** Refers to being slapped, pushed, hit, kicked, dragged, choked, burned by a boyfriend/girlfriend

***Refers to forced sex by a boyfriend/girlfriend

Perpetration

When looking at the prevalence of abuse perpetration, the most frequently reported type of abuse perpetration was among those who reported verbal IPV (19.9%), with remaining perpetration ranging between 0.5% (rape) and 9.1% (physical IPV) (see Table 8). There were no significant differences found between males and females reporting any type of IPV perpetration. All participants at least answered one of the questions regarding perpetration. The variables with the highest prevalence of non-response were verbal (19.9%) and physical IPV perpetration (19.9%).

Table 8: Sub-group A (N=186) - Prevalence of verbal, physical and sexual abuse perpetration among male and female adolescents

Variables	Total	Males	Females	P Value
Rape (ever)	1 (0.5%)	0	1 (1.1%)	1.00
Bullying at school (past month)	15 (8.1%)	4 (5%)	11 (10.8%)	0.19
Verbal IPV (past 6 months)*	37 (19.9%)	19 (32.8%)	18 (20%)	0.08
Physical IPV (past 6 months)**	17 (9.1%)	9 (15.3%)	8 (9%)	0.24
Sexual IPV (6 months)***	7 (3.8%)	5 (8.3%)	2 (2.2%)	0.11
Sexual IPV (ever)****	17 (9.1%)	10 (16.1%)	7 (7.7%)	0.10

*Refers to insulting, making fun of, intimidating, threatening to hurt a boyfriend/girlfriend

** Refers to slapping, pushing, hitting, kicking, dragging, choking, burning a boyfriend/girlfriend

***Refers to forcing a boyfriend/girlfriend to have sex with you

****Refers to ever using force for sex, kissing, touching, anal sex on a boyfriend/girlfriend

*Sub-group B**Victimization*

The prevalence of abuse victimization within the school and home was high with the most reported type of abuse victimization being verbal abuse within the school (37%), with females slightly more likely to report verbal abuse within the school (Table 9). The remaining types of victimization ranged between 21.2% (physical abuse within the home) and 33.3% (verbal abuse within the home).

The number of participants who did not respond to any of the questions regarding victimization was 13 (7.9%). The variables with the highest prevalence of non-response were verbal (21.2%) and sexual (21.8%) victimization at school. When looking for reasons as to why participants did not respond to any of the victimization questions, we found none of them answered the questions regarding likes and dislikes about the questionnaire in the open-ended questions (where we asked whether there was anything they liked or disliked about the questionnaire). This could suggest that they were distressed by the questions and did not want to answer.

Table 9: Sub-group B (N=165) - Prevalence of verbal, physical and sexual abuse victimization among male and female adolescents

Variables	Total	Males	Females	P Value
Unwanted sexual touch (ever)	36 (21.8%)	10 (14.7%)	25 (32.1%)	0.01
Verbal Abuse at Home (ever)*	55 (33.3%)	23 (39%)	30 (42.3%)	0.71
Physical Abuse at Home (ever)**	35 (21.2%)	16 (26.7%)	18 (24.7%)	0.79
Verbal Abuse at School (ever)***	61 (37%)	26 (44.8%)	33 (48.5%)	0.68
Physical Abuse at School (ever)****	39 (23.6%)	21 (34.4%)	18 (25.4%)	0.26
Sexual Abuse at School (ever)*****	46 (27.9%)	13 (22.8%)	32 (47.1%)	<0.01

*Refers to being insulted by family

**Refers to being beaten so hard at home that it left a mark or bruise

***Refers to being humiliated or threatened with a weapon by someone at school

****Refers to being beaten or physically punished by a teacher at school

*****Refers to your thighs, buttocks, breasts or private parts being touched by someone at school when you did not want it

Perpetration

On average 14.5% of participants reported that they had bullied someone at school in the past month, and there was no difference between males and females (See Table 10).

Only one participant did not answer the questions regarding perpetration. The questionnaire for Sub-Group B contained no other perpetration variables.

Table 10: Sub-group B (N=165)- Prevalence of verbal/physical abuse perpetration among male and female adolescents

Variables	Total	Males	Females	P Value
Bullying at school (past month)	24 (14.5%)	14 (20%)	10 (11.4%)	0.13

6.3. Research experience

Participants' responses to the questions about what they liked and disliked about the questionnaire are described in Tables 11 to 14.

Sub-group A

With regards to things participants liked about the questionnaire, 7 participants (3.8%) in sub-group A reported that there was nothing they liked about the questionnaire and 44 participants (23.7%) did not respond to the question (Table 11). With regards to the things participants reported they did not like about the questionnaire, 62 participants (33.5%) reported that there was nothing they did not like about the questionnaire and 78 participants (41.9%) did not respond to the question (Table 12).

Sub-group B

Regarding the things participants identified that they liked about the questionnaire, 7 participants (4.2%) in sub-group B reported that there was nothing they liked about the questionnaire and 58 participants (37.6%) did not respond to the question (Table 13).

When asked what they did not like about the questionnaire, 49 participants (29.7%) reported that there was nothing they did not like about the questionnaire and 88 participants (54.5%) did not respond to the question (Table 14).

Table 11: Sub-group A (N=186) - Learners' reports of what they liked about the questionnaire

	Code	Variable	Total Freq (%)	Male N=80 Freq (%)	Female N=104 Freq (%)
Reports of benefit	1	It gives you the ability to be honest, tell the truth, feel heard, to express myself	36 (19.4)	10 (12.5)	26 (25)
	3	It is educational	38 (20.4)	19 (23.8)	19 (18.3)
	4	It gives you a sense of increased self-awareness, self-insight	4 (2.2)	1 (1.3)	3 (2.9)
	6	It's a preparation for the future, it helped me to prepare for the future, general helpfulness	11 (5.9)	7 (8.8)	4 (3.8)
	8	It made me think about life	5 (2.7)	3 (3.8)	2 (1.9)
	11	It's about me (topics that are relevant to my life)	12 (6.5)	6 (7.5)	6 (5.8)
	16	It made me feel good	1 (0.5)	0 (0)	1 (1)
Other positive reports	2	It is confidential, my privacy is respected	13 (7)	4 (5)	9 (8.7)
	7	I enjoyed it	12 (6.5)	3 (3.8)	9 (8.7)
	10	I liked the layout of the questionnaire (colours, wording, format)	12 (6.5)	4 (5)	8 (7.7)
	13	Everything/All the questions /Most of the questions	21 (11.4)	10 (12.5)	11 (10.6)
	14	Feeling that the research team cares about us	1 (0.5)	0 (0)	1 (1)
	15	It is interesting	4 (2.2)	1 (1.3)	3 (2.9)
	17	Other	22 (11.9)	9 (11.3)	13 (12.5)
Non-response			44 (23.7)*	24 (12.9)*	18 (9.7)*

Participants could give more than one response, therefore the percentages do not total 100%

**Participants who did not state their gender were excluded in these results*

Table 12: Sub-group A (N=186) - Learners' reports of what they did not like about the questionnaire

	Code	Variable	Total Freq (%)	Male N=80 Freq (%)	Female N=104 Freq (%)
Reports of Distress	5	It evoked pain because of past painful experiences	1 (0.5)	1 (1.3)	0 (0)
Other negative reports	1	Questions about condoms	7 (3.8)	3 (3.8)	4 (3.8)
	2	Questions about sex	13 (7)	6 (7.5)	7 (6.7)
	3	Questions about relationships	5 (2.7)	0 (0)	5 (4.8)
	4	Questions about pocket money	1 (0.5)	1 (1.3)	0 (0)
	6	It is too personal	4 (2.2)	1 (1.3)	3 (2.9)
	7	It made me feel uncomfortable	5 (2.7)	3 (3.8)	2 (1.9)
	8	Omissions (no question on a certain topic)	2 (1.1)	0 (0)	2 (1.9)
	9	Questions were difficult to comprehend	5 (2.7)	2 (2.5)	3 (2.9)
	11	Age inappropriate questions	2 (1.1)	1 (1.3)	1 (1)
	13	Everything/All the questions /Most of the questions	2 (1.1)	0 (0)	2 (1.9)
	17	Other	9 (4.9)	4 (5)	5 (4.8)
Non-response			78 (41.9)*	37 (19.9)*	39 (21)*

Participants could give more than one response, therefore the percentages do not total 100%

**Participants who did not state their gender were excluded in these results*

Table 13: Sub-group B (N=165) - Learners' reports of what they liked about the questionnaire

	Code	Variable	Total Freq (%)	Male N=71 Freq (%)	Female N=88 Freq (%)
Reports of Benefit	1	It gives you the ability to be honest, tell the truth, feel heard, to express myself	23 (13.9)	10 (14.1)	11 (12.5)
	3	It is educational	24 (14.5)	6 (8.5)	17 (19.3)
	4	It gives you a sense of increased self-awareness, self-insight	7 (4.2)	1 (1.4)	6 (6.8)
	6	It's a preparation for the future, it helped me to prepare for the future, general helpfulness	9 (5.5)	4 (5.6)	5 (5.7)
	8	It made me think about life	2 (1.2)	1 (1.4)	1 (1.1)
	9	It has the potential to help others	2 (1.2)	1 (1.4)	1 (1.1)
	11	It's about me (topics that are relevant to my life)	9 (5.5)	3 (4.2)	6 (6.8)
Other positive reports	2	It is confidential, my privacy is respected	3 (1.8)	1 (1.4)	1 (1.1)
	7	I enjoyed it	6 (3.6)	2 (2.8)	3 (3.4)
	10	I liked the layout of the questionnaire (colors, wording, format)	8 (4.8)	3 (4.2)	5 (5.7)
	13	Everything/All the questions /Most of the questions	26 (15.8)	10 (14.1)	16 (18.2)
	14	Feeling that the research team cares about us	3 (1.8)	0 (0)	3 (3.4)
	15	It is interesting	1 (0.6)	1 (1.4)	0 (0)
Non-response	17	Other	19 (11.5)	7 (10)	11 (12.5)
			62 (37.6)*	29 (17.6)*	27 (16.4)*

Participants could give more than one response, therefore the percentages do not total 100%

**Participants who did not state their gender were excluded in these results*

Table 14: Sub-group B (N=165) - Learners' reports of what they did not like about the questionnaire

	Code	Variable	Total Freq (%)	Male N=71 Freq (%)	Female N=88 Freq (%)
Reports of Distress	5	It evoked pain because of past painful experiences	0 (0)	0 (0)	0 (0)
Other negative reports	1	Questions about condoms	1 (0.6)	0 (0)	1 (1.1)
	2	Questions about sex	16 (9.7)	4 (5.6)	11 (12.5)
	3	Questions about relationships	2 (1.2)	1 (1.4)	1 (1.1)
	6	It is too personal	2 (1.2)	0 (0)	2 (2.3)
	7	It made me feel uncomfortable	5 (3)	3 (4.2)	2 (2.3)
	8	Omissions (no question on a certain topic)	1 (0.6)	0 (0)	1 (1.1)
	9	Questions were difficult to comprehend	1 (0.6)	0 (0)	1 (1.1)
	11	Age inappropriate questions	1 (0.6)	0 (0)	1 (1.1)
	17	Other	3 (1.8)	2 (2.8)	1 (1.1)
Non-response			90 (54.5)*	39 (23.6)*	45 (27.3)*

Participants could give more than one response, therefore the percentages do not total 100%

**Participants who did not state their gender were excluded in these results*

6.4. Reports of distress and benefit

Sub-group A

Benefit

About 73.7% of participants reported benefit, with slightly more females than males reporting benefit (difference not statistically significant) (See Table 15). A few examples of students' reports of things they liked about the questionnaire that we then coded as benefit were: "I finally could be able to open up and not be afraid that some people are going to laugh at me"; "I've learnt so much while doing the questionnaire"; "They were questions I haven't thought of"; "It was questions that would teach you what to do in the future"; "They asked questions what you never really thought about"; "What I most like about this questionnaire is that it ask me more about myself "; "What I like about this questionnaire is it make me feel happy to answer the questions".

About 18% of participants did not report whether there was anything they liked in either the test or retest questionnaire and of these, five were victims and nine were perpetrators of abuse.

Distress

Two (1.1%) male participants reported that they felt distressed by either the test or retest questionnaire (See Table 15). The two examples that students' reported as things they did not like about the questionnaire that were coded as distress were: "Some of the questions refers to you and talks about something that you have done in this early age and some of the questions is something you have do in your life and that hurts and you will be not able to answer these kind of questions"; and "Is that some of the questions were hurting me and affecting one of my friend and family member and my

neighbours”. Of the two participants that reported distress, one of them reported benefit as well.

Almost a third (31%) of participants did not report whether there was anything they did not like in either the test or retest questionnaire and of these 13 were victims and 18 were perpetrators of abuse. The p values in table 15 indicate that there are no significant difference between males and females in prevalence of distress and benefit.

Table 15: Sub-group A (N=186) - Prevalence of reports of distress and benefit in the test or the re-test survey among male and female adolescents

Variables	Total Freq (%)	Males Freq (%)	Females Freq (%)	P Value
Distress	2 (1.1)	2 (3.7)	0	0.17
Benefit	112 (73.7)	42 (68.9)	70 (76.9)	0.27

A logistic regression analysis was performed to assess the extent to which prior violence exposure was associated with experiencing the research as beneficial or not, adjusting for gender and whether the participant had ever had sex. From the below table (Table 16) we can see that there was no significant relationship between prior violence exposure and benefits from the questionnaire.

Table 16: Sub-group A: Logistic Regression with “benefit” as the dependent variable

Independent Variables	Odd Ratios (ORs)	95% Confidence Intervals (CIs)		P value
		Lower	Upper	
Gender	1.24	0.66	2.32	0.50
Ever had sex	0.99	0.38	2.59	0.99
Any type of victimization	1.27	0.65	2.52	0.49
Any type of perpetration	1.76	0.89	3.49	0.11

*Sub-group B*Benefit

None of the participants that received this questionnaire reported distress, while 67% of those who answered the research experience question reported benefit, with significantly more females than males reporting benefit ($p < 0.01$) (See Table 17). A few examples of students' reports of things they liked about the questionnaire that we then coded as benefit were: "That it made me feel free about things I don't want to talk about to friends or family" ; "The way it teaches you about safe sex" ; "It makes you remember your morals, values and virtues" ; "It asks us everything in life that we need to prepare" ; "It really focuses on questions that are important in life" ; "It could maybe help people that was in these particularly situations, by letting everything OUT!" ; "It's about our generation" . Almost a quarter (22%) of participants did not report whether there was anything they liked in either the test or retest questionnaire and of these 16 were victims and 1 was a perpetrator of abuse.

Table 17: Sub-group B (N=165) - Prevalence of reports of distress and benefit in the test or the re-test survey among male and female adolescents

Variables	Total Freq (%)	Males Freq (%)	Females Freq (%)	P Value
Distress	0	0	0	-
Benefit	89 (67)	29 (21.8)	56 (42.1)	<0.01

A logistic regression analysis was performed to assess the extent to which prior violence exposure was associated with experiencing the research as beneficial or not, adjusting for gender and whether the participant had ever had sex. From the Table 18 we can see that there is no significant relationship between prior violence exposure and benefit from the questionnaire.

Table 18: Sub-group B: Logistic Regression with “benefit” as the dependent variable

Independent Variables	Odd Ratios (ORs)	95% Confidence Intervals (CIs)		P value
		Lower	Upper	
Gender	1.90	0.95	3.80	0.07
Ever had sex	0.43	0.14	1.34	0.15
Any type of victimization	1.94	0.89	4.26	0.10
Any type of perpetration	1.18	0.46	3.03	0.73

6.5. Group comparisons

6.5.1. Reports of distress and benefit at test or retest amongst victims and non-victims

Sub-group A

Both the two male participants who reported being distressed by either the test or retest questionnaire did not report being a victim of any type of abuse. Twenty-two percent of participants who reported being a victim (males: 55.6%; females: 77.5%) and 37.6% who did not report being a victim of any type of abuse (males: 76%; females: 77.3%) either in the last 6 months or ever, expressed benefit from the questionnaire (See Table 19). Those who reported unwanted sexual touch were found to report the most benefit from the questionnaire (13%) (males: 37.5%; females: 81.5%). Among the participants who reported not having been a victim of any type of abuse, injury related to abuse were among those that reported the most benefit from the questionnaire (52.2%) (males: 66.7%; females: 77.4%).

Table 19: Sub-group A (N=186) – Comparison of the prevalence of reports of benefit from the research among victims and non-victims of abuse

Abuse victimisation (time frame)		Reported benefit from research					
		Males		Females		Total	
		Benefit Freq (%)	*P value	Benefit Freq (%)	*P value	Benefit Freq (%)	*P value
Injury related to abuse (ever)	Yes	2 (66.7)	1.00	1 (50.0)	0.41	3 (1.6)	0.61
	No	32 (66.7)		65 (77.4)		97 (52.2)	
Unwanted sexual touch (ever)	Yes	3 (37.5)	0.05	22 (81.5)	0.43	25 (13.4)	0.73
	No	39 (75)		45 (73.8)		84 (45.4)	
Verbal IPV (past 6mnths)	Yes	6 (60.0)	0.65	13 (65.0)	0.13	19 (10.3)	0.10
	No	11 (68.8)		52 (81.2)		63 (34.1)	
Physical IPV (past 6mnths)	Yes	5 (83.3)	0.26	5 (83.3)	0.77	10 (5.4)	0.49
	No	11 (57.9)		61 (78.2)		72 (38.7)	
Sexual IPV (past 6mnths)	Yes	1 (50.0)	1.00	3 (100)	1.00	4 (2.2)	1.00
	No	14 (63.6)		63 (77.8)		77 (41.4)	
Any abuse victimization	Yes	10 (55.6)	0.16	31 (77.5)	0.98	41 (22.0)	0.43
	No	19 (76.0)		34 (77.3)		70 (37.6)	

* P values are derived from chi squared tests of the association between past abuse and whether or not students reported that they benefitted from the research.

Sub-group B

When we analyzed the data for any type of abuse victimization, we found no reports of distress in this sub-group. Thirty-seven percent of participants who reported being a victim and 14.5% of participants who did not report being a victim of any type of abuse (either in the last 6 months or ever), reported that they benefitted from the questionnaire (See Table 20). Those who reported verbal abuse at home (18.8%) and those who reported unwanted sexual touch (35.8%) were found to report the most benefit from the questionnaire.

Table 20: Sub-group B (N=165) – Comparison of the prevalence of reports of benefit from the research among victims and non-victims of abuse

Abuse victimisation (time frame)		Reported benefit from research					
		Males		Females		Total	
		Benefit Freq (%)	*P value	Benefit Freq (%)	*P value	Benefit Freq (%)	P value
Unwanted sexual touch (ever)	Yes	6 (75.0)	0.17	19 (82.6)	0.51	26 (15.8)	0.06
	No	23 (48.9)		34 (75.6)		59 (35.8)	
Verbal Abuse at Home (ever)	Yes	12 (57.1)	0.54	18 (69.2)	0.11	31 (18.8)	0.55
	No	14 (48.3)		31 (86.1)		47 (28.5)	
Physical Abuse at Home (ever)	Yes	10 (71.4)	0.06	15 (83.3)	0.53	25 (15.2)	0.08
	No	15 (41.7)		35 (76.1)		53 (32.1)	
Verbal Abuse at School (ever)	Yes	8 (47.1)	0.69	21 (72.4)	0.26	30 (18.2)	0.53
	No	17 (53.1)		27 (84.4)		46 (27.9)	
Physical Abuse at School (ever)	Yes	13 (72.2)	0.03**	14 (87.5)	0.42	27 (16.4)	0.07
	No	13 (39.4)		36 (78.3)		52 (31.5)	
Sexual Abuse at School (ever)	Yes	8 (66.7)	0.21	20 (69.0)	0.08	29 (17.6)	0.74
	No	17 (45.9)		28 (87.5)		47 (28.5)	
Any abuse victimization	Yes	19 (54.3)	0.76	42 (76.4)	0.45	62 (37.6)	0.75
	No	10 (50.0)		12 (85.7)		24 (14.5)	

* P values are derived from chi squared tests of the association between past abuse and whether or not students reported that they benefitted from the research.

** $p < 0.05$

6.5.2. Reports of distress and benefit at test and retest amongst perpetrators and non-perpetrators

Sub-group A

The one male participant who reported being distressed by either the test or retest questionnaire, reported being a perpetrator of verbal and physical IPV. Twenty-one percent of participants who reported being a perpetrator and 39.2% who did not report being a perpetrator of any type of abuse either in the last month, 6 months or ever, expressed benefit from the questionnaire (See Table 21). Those who reported verbal IPV in the last 6 months were found to report the most benefit from the questionnaire (12.9%) (males: 73.3%; females: 81.2%). Among the participants who reported not having been a perpetrator of any type of abuse, bullying in the past month was among

those that reported the most benefit from the questionnaire (53.2%) (males: 67.2%; females:75.9%).

Table 21: Sub-group A (N=186) – Comparison of the prevalence of reports of benefit from the research among perpetrators and non-perpetrators of abuse

Abuse perpetration (time frame)		Reported benefit from research					
		Males		Females		Total	
		Benefit Freq (%)	*P Value	Benefit Freq (%)	*P value	Benefit Freq (%)	P value
Rape (ever)	Yes	0	1.00	1 (100)	1.00	1 (0.5)	1.00
	No	33 (67.3)		63 (75.9)		90 (48.4)	
Bullying at school (past month)	Yes	3 (100)	0.55	9 (90.0)	0.32	12 (6.5)	0.12
	No	39 (67.2)		60 (75.9)		99 (53.2)	
Verbal IPV (past 6mnths)	Yes	11 (73.3)	0.61	13 (81.2)	0.61	24 (12.9)	0.55
	No	21 (65.6)		51 (75.0)		72 (38.7)	
Physical IPV (past 6mnths)	Yes	5 (71.4)	0.77	4 (57.1)	0.20	9 (4.8)	0.42
	No	27 (65.9)		60 (78.9)		87 (46.8)	
Sexual IPV (6mnths)	Yes	2 (50.0)	0.60	0	0.22	2 (1.1)	0.12
	No	30 (66.7)		66 (78.6)		96 (51.6)	
Sexual IPV (ever)	Yes	4 (57.1)	0.68	5 (71.4)	0.76	9 (4.8)	0.47
	No	29 (67.4)		59 (76.6)		88 (47.3)	
Any abuse perpetration	Yes	16 (76.2)	0.37	23 (79.3)	0.81	39 (21.0)	0.45
	No	26 (65.0)		47 (77.0)		73 (39.2)	

* P values are derived from chi squared tests of the association between past abuse and whether or not students reported that they benefitted from the research.

Sub-group B

When asked whether they had bullied someone in the past month, 8.5% of participants who reported having bullied someone and 44.8% who did not report having bullied someone in the past month, expressed benefit from the questionnaire (See Table 22 below).

Table 22: Sub-group B (N=165) – Comparison of the prevalence of reports of benefit from the research among perpetrators and non-perpetrators of abuse

Abuse perpetration (time frame)		Reported benefit from research					
		Males		Females		Total	
		Benefit Freq (%)	P value	Benefit Freq (%)	P value	Benefit Freq (%)	P value
Bullying at school (past month)	Yes	8 (57.1)	0.59	6 (66.7)	0.31	14 (8.5)	0.56
	No	20 (48.8)		50 (79.4)		74 (44.8)	

6.5.3. Change in experience two weeks later

Sub-group A

Eighty-nine participants (47.8%) reported benefit at the test survey and 81 participants (43.5%) at the retest survey. Fifty-eight participants (25 males; 33 females) reported benefit in both the test and retest survey and one male participant reported distress in both the test and retest survey. Another male participant reported distress in the retest questionnaire but not in the test questionnaire.

Sub-group B

Sixty-seven participants (40.6%) reported benefit at the test survey and 57 participants (34.5%) at the retest survey. Thirty-two participants (9 males; 23 females) reported benefit in both the test and retest questionnaire and no participants reported distress in either the test or retest questionnaire.

6.5.4. Dropout rates of distressed participants

Subgroup A

The one participant that reported distress in the test survey did not dropout in the retest survey.

7. DISCUSSION

7.1. Summary of the main findings

This study described the experience of adolescents from 3 high schools in Cape Town when completing questionnaires regarding IPV and verbal, physical and sexual abuse. It was found that verbal victimization was the highest form of victimization reported across both sub-groups. The highest form of perpetration was verbal IPV amongst sub-group A, with females reporting more victimization and surprisingly more perpetration as well. Within sub-group B, the only question asked about perpetration was whether they had bullied someone and males were found to report more perpetration than females. When asked whether they had ever raped someone, one female participant answered yes. Even though very unusual, it is possible that older girls in a group sometimes force younger boys to have sex. It is also possible that this participant misunderstood the question and thought it was asking whether she herself had been raped.

The prevalence of non-responders to questions regarding victimization was highest among sub-group B (7.9%), while all of participants answered at least one of the questions related to perpetration. When looking for reasons as to why participants did not respond to any of the victimization questions in sub-group B, we found none of them answered the questions regarding likes and dislikes about the questionnaire. These findings could suggest that the non-responders found these questions too distressing to answer.

When looking at the open-ended questions about what participants liked and did not like about the questionnaire, we found the “likes” to be reported more often than the “dislikes”. The features that participants reported they liked most about the

questionnaire was that it was educational, that they liked that they could be honest and open and tell the truth, and that there was nothing they did not like about the questionnaire. The most common feature of the questionnaire that participants did not like was that it included questions about sex. It is possible that they felt distressed about these questions; however, in our analyses, we did not regard this response as an indication of distress.

Only two participants in sub-group A, and no participants in sub-group B reported dislikes that we identified as eliciting distress, and of these, one also said it was beneficial. Of the two participants who reported distress in sub-group A, one was neither a victim nor a perpetrator of abuse, while the other was a perpetrator of verbal and physical IPV.

Although abuse victimization and perpetration was high among both sub-groups, it was found that victims and perpetrators were equally as likely to report benefit from this type of study as their counterparts. This finding suggests our hypothesis that victims will report more distress and less benefit than non-victims is not correct.

There were no significant differences in reports of benefits and distress between the test and retest survey two weeks later, with only one participant reporting distress at retest and not at test in sub-group A. Amongst the two participants that were distressed, none dropped out.

7.2. Limitations

There are a number of limitations to our primary research study, which need to be acknowledged. Firstly, the literature review was conducted after the primary research and therefore did not inform the design and methodology of the primary research.

However, it did inform the main PREPARE study which is presently being implemented. Secondly, our sample size was small and this limited the statistical power to detect associations. It is possible that there were associations between having a past history of abuse and finding the questionnaires distressing to complete, but we were not able to detect them. It is also possible that there were no associations between past abuse history and research experience. Thirdly, the most common feature of the questionnaire that participants did not like was that it included questions about sex. It is possible that they felt distressed, a bit bored, or annoyed with these questions; however, in our analyses, we did not regard this response as an indication of distress. Qualitative research might help elucidate this. Finally, this research has a moderate risk of selection bias for two reasons. (1) Only 76% of the learners who were sampled participated. It is possible that those who did not participate because their parents did not give their consent could be victims of violence (our target group) and their parents were aware of this and did not want this information to be known, or the learners themselves declined because they were victims of violence. (2) The item-specific response rates for the variables used in these analyses were substantial. It is possible that participants who found the questionnaire distressing did not respond to the questions included in these analyses, and therefore it is possible that we have underestimated the prevalence of distress.

7.3. Commentary on the findings and their relationship to the literature

The findings of our primary study and the systematic review seem to indicate that although answering questions about sensitive topics can be distressing, on balance participants tend to report more benefit. The qualitative responses of our primary study findings give us an idea of why this is, such as “it enabled them to be open and honest”, or they “learned something new”, or they had “gained self-insight”, or they had “felt a

sense of relief or clarity from reviewing past events”, or that “the topics covered were relevant to their life” and “made them think about life”, or that “the questionnaire had the potential to help others through participation” or that they “felt more prepared for the future”. These primary study findings are consistent with findings from studies among adolescents and adults reviewed earlier in the systematic literature review in this dissertation.

We found those who reported distress also reported benefit, which is similar to the study findings among adults by Kuyper, et al. (2010) and Decker, et al. (2011). Most of the studies in our literature review suggest that females report being more distressed by sensitive research than males (two studies among adolescents and three among adults). However, more females than males were found to report benefit in our study, which is consistent with only three of the studies among adults in our literature review (DePrince and Chu, 2008; DePrince and Freyd, 2004; Sikweyiya and Jewkes, 2012).

Slightly more than half of the studies in the systematic review which compared distress among victims and non-victims (three of five among adolescents and eight of fifteen among adults) found victims to be more likely to be distressed than non-victims. The findings of our study among Cape Town adolescents was, consistent with one study with adolescents (Chu, et al., 2008) and two studies with adults (Newman, et al., 2008; Ruzek and Zatzick, 2000), in which there was no significant difference in reports of distress and benefit amongst victims and non-victims of abuse. It is also consistent with one adolescent study (Ybarra, et al., 2009) and two adult studies (Rojas and Kinder, 2007; Savell, et al., 2006) in which there was no significant difference in reports of distress amongst victims and non-victims of abuse.

Factors that could account for why answering sensitive questionnaires elicits more relief/benefit than distress could be being reassured about confidentiality and having adults/teachers out of the room. Secondly, within our study, the most reported things that participants liked about the questionnaire was that it enabled them to be open and honest and that the questions were educational. Lastly, as mentioned in chapter 1 in our theoretical framework, the elements that might be associated with client-centred therapy could also account for why answering sensitive questions are more beneficial. These elements include disclosing abuse (during interviews or through completing anonymous questionnaires or surveys) within a safe environment, convey a non-judgmental approach, which could help participants feel relief from answering these sensitive questions.

7.4. Recommendations for future research

The findings from our primary study and systematic review shows that participants generally value being asked sensitive questions and do not necessarily find it distressing to answer questions about abuse. It is important to note that the factors mentioned above such as creating a safe environment in which participants can disclose by ensuring participants of confidentiality, asking adults to leave the room, convey a non-judgmental approach, could play a big role in whether participants find relief/benefit from answering sensitive questions in research. It is therefore important that these factors be taken into consideration when conducting this type of research.

When such research is conducted, researchers should assess the effect on participants. As our sample size in our primary study was small and research in this area is so rare, more research needs to be done on this topic to confirm this finding. Future studies might ask participants whether they felt the costs to them were worth the benefits. In this

way we will be able to tell more clearly whether those who reported dislikes also felt they benefited from the questionnaire. It may also be useful to develop some way of assessing and understanding what leads individuals to choose “not” to participate in a particular research study, or not to complete certain questionnaire items. Researchers could do this by asking participants in a follow-up interview or questionnaire the reasons as to why they chose not to participate.

As pointed out in the review of the literature, there is a need to have studies that follow participants and measure longer term effects of the research. Our primary study only looked at research participation changes over two weeks.

Finally, it is important for future research to be conducted into the extent to which “not” asking about abuse history may directly and indirectly be harmful to research participants as Becker-Blease and Freyd (2004) suggested.

7.5. Recommendations for policy and practice

As mentioned in the introduction of this thesis, research on sensitive issues is important because of the increased use of illicit drugs, the onset of the AIDS epidemic and teenage pregnancies (Tourangeau and Smith, 1996). Efforts to combat such problems need to be informed by accurate information about their prevalence, as well as risk and protective factors. Often the best way to gather this information is by asking research participants to respond to sensitive questions. IRB's and ethical committees are concerned as to whether recalling and answering questions about past abuse has negative or positive consequences for the participants of such research. Our study, as well as previous studies in our literature review, shows that although adolescents are seen as a vulnerable group, they do not necessarily experience as much distress when being asked sensitive

questions as originally thought, or if they do experience distress, the perceived benefit usually outweighs their distress. IRB members should therefore be aware that evidence to date suggests that participation in sensitive topic research seems less likely to cause distress than initially anticipated and more likely to cause benefit.

8. CONCLUSION

To our knowledge, this study was the first of its nature to be conducted with adolescents in South Africa. Our findings of our primary study were similar to previous studies reviewed: participants reported more positive experiences than negative ones and very few of them report distress while most participants reported benefit. And those that report a high proportion of participants reporting distress, a high proportion also reported benefit and there were few expressed regrets about participation. However, these findings are subject to selection bias: we know nothing about the experiences of the participants who did not answer the questions.

The findings when comparing victims to non-victims however, are not altogether consistent with the findings of the systematic review in which most of the studies (3 adolescent and 8 adult studies) found that victims of violence and abuse report experiencing more distress. A few studies (3 adult studies) did report however find victims more likely to find participation beneficial and a positive experience. This suggests that most often victims are more distressed than non-victims. However, whether adolescents or adults are victims of violence/abuse or not, they report low to moderate levels of distress, and those that do report high levels of distress and low levels of benefit also report no regrets. More research is needed in this area especially among adolescents in South Africa.

9. REFERENCES

- Ahern, K. (2012). *Informed consent: Are researchers accurately representing risks and benefits? LID - 10.1111/j.1471-6712.2012.00978.x [doi]*
- Becker-Blease, K., & Freyd, J. J. (2006). Research participants telling the truth about their lives: The ethics of asking and not asking about abuse. *American Psychologist, 61*(3), 218-226.
- Black, M. C., & Black, R. S. (2007). A public health perspective on "the ethics of asking and not asking about abuse.". *American Psychologist, 62*(4), 328-329.
- Black, M. C., Kresnow, M., Simon, T. R., Arias, I., & Shelley, G. (2006). Telephone survey respondents' reactions to questions regarding interpersonal violence. *Violence & Victims, 21*(4), 445-459.
- Campbell, R., Adams, A. E., Wasco, S. M., Ahrens, C. E. & Sefl, T. (2010). "What has it been like for you to talk with me today?": The impact of participating in interview research on rape survivors. *Violence against women, 16* (1), 60-83.
- 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 & Dissociation, 4*(2), 131-142.
- Carter-Visscher, R.M., Naugle, A.E., Bell, K.M. & Suvak, M. K. (2011). Ethics of asking trauma-related questions and exposing participants to arousal-inducing stimuli. *Journal of Trauma & Dissociation, 8* (3).
- Chouliara, Z., Karatzias, T., Scott-Brien, G., Macdonald, A., MacArthur, J., & Frazer, N. (2011). Talking therapy services for adult survivors of childhood sexual abuse

- (CSA) in scotland: Perspectives of service users and professionals. *Journal of Child Sexual Abuse*, 20(2), 128-156.
- Chu, A. T., DePrince, A. P. & Weinzierl, K. M. (2008). Children's perception of research participation: Examining trauma exposure and distress. *Journal of Empirical Research on Human Research Ethics: An International Journal*, 3 (1), 49-58.
- Cook, S. L., Darnell, D., Anthony, E. R., Tusher, C. P., Zimmerman, L., Enkhtor, D. & Hipp, T. N. (2011). Investigating the effects of trauma-related research on well-being. *Accountability in Research: Policies and Quality Assurance*, 18 (5), 297-322.
- Corey, G. (2005). *Theory and practice of counseling and psychotherapy*. U.S.A.: Thomson Learning Inc.
- 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(3), 55-64.
- 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*, 35-47.
- DePrince, A. P., & Freyd, J. J. (2004). Costs and benefits of being asked about trauma history. *Journal of Trauma Practice*, 3(4), 24-35.
- Draucker, C. B. (1999). The emotional impact of sexual violence research on participants. *Archives of Psychiatric Nursing*, 13(4), 161-169.

- Edwards, V. J., Dube, S. R., Felitti, V. J., & Anda, R. F. (2007). It's OK to ask about past abuse. *American Psychologist*, 62(4), 327-328.
- Ferrier-Auerbach, A.G., Erbes, C. & Polusny, M. A. (1222). Does trauma survey research cause more distress than other types of survey research? *Journal of Traumatic Distress*, 22(4), 320-323.
- Gekoski, A., Gray, J. M., & Adler, J. R. (2012). Interviewing women bereaved by homicide: Assessing the impact of trauma-focused research. *Psychology, Crime & Law*, 18(2), 177-189.
- Gleaves, D. H., Rucklidge, J. J., & Follette, V. M. (2007). What are we teaching our students by not asking about abuse? *American Psychologist*, 62(4), 326-327.
- 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(3), 221-227.
- Hays, S., Murphy, G., & Sinclair, N. (2003). Gaining ethical approval for research into sensitive topics: 'two strikes and you're out?'. *British Journal of Learning Disabilities*, 31(4), 181-189.
- Help To Heal* (2011) [ONLINE AVAILABLE]
<http://www.helptoheal.co.uk/abuse-counselling.html>
- Hern, M., Miller, M., Sommers, M., & Dyehouse, J. (1998). Sensitive topics and adolescents: Making research about risk behaviors happen. *Issues in Comprehensive Pediatric Nursing*, 21(3), 173-186.

- Hlavka, H. R., Kruttschnitt, C., & Carbone-López, K. C. (2007). Revictimizing the victims? *Journal of Interpersonal Violence*, 22(7), 894-920.
- Johnson, L. E., & Benight, C. C. (2003). Effects of trauma-focused research on recent domestic violence survivors. *Journal of Traumatic Stress*, 16(6), 567-571.
- Kashdan, T. B., Barrios, V., Forsyth, J. P., & Steger, M. F. (2005). Experiential avoidance as a generalized psychological vulnerability: Comparisons with coping and emotion regulation strategies. *Behavior Research and Therapy* 44(9), 1301-1320.
- Kuyper, L., de Wit, J. F., Adam, P. F., & Woertman, L. (2010). Doing more good than harm? The effects of participation in sex research on young people in the Netherlands. *Arch Sex Behav*.
- Langhinrichsen-Rohling, J. F., Arata, C. F., O'Brien, N. F., Bowers, D. F., & Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyway? *Violence and Victims*, 21(4).
- London, K., Bruck, M., Ceci, S. J., & Shuman, D. W. (2005). Disclosure of child sexual abuse: What does the research tell us about the ways that children tell? *Psychology, Public Policy, and Law*, 11(1), 194-226.
- Martsof, D. S., & Draucker, C. B. (2005). Psychotherapy approaches for adult survivors of childhood sexual abuse: An integrative review of outcomes research. *Issues in Mental Health Nursing*, 26(8), 801-825.
- McDonagh, A., Friedman, M., McHugo, G., Ford, J., Sengupta, A., Mueser, K., et al. (2005). Randomized trial of cognitive-behavioral therapy for chronic posttraumatic

stress disorder in adult female survivors of childhood sexual abuse. *Journal of Consulting and Clinical Psychology*, 73(3), 515-524.

National Health Resource Center on Domestic Violence. *National consensus guideline on identifying and responding to domestic violence victimization in health care setting*. San Francisco: The Family Violence Prevention Fund, 2002. Accessed on: 2 March 2012. [ONLINE AVAILABLE]

<http://endabuse.org/health17>

Newman, E. & Kaloupek, D. G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17(5), 383-394.

Newman, E. F., Willard, T. F., Sinclair, R. F., & Kaloupek, D. (2008). Empirically supported ethical research practice: The costs and benefits of research from the participants' view. *Accountability in Research: Policies and Quality Assurance*, 8(4), 309-329.

Newman, E., Walker, E. A., & Gefland, A. (1999). Assessing the ethical costs and benefits of trauma-focused research. *General Hospital Psychiatry*, 21(3), 187-196.

Priebe, G. F., Backstrom, M. F., & Ainsaar, M. (2010). Vulnerable adolescent participants' experience in surveys on sexuality and sexual abuse: Ethical aspects. *Child Abuse & Neglect* 34, 438-447.

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 and Marital Therapy*, 33(3), 193-201.

Rosenbaum, A. F., & Langhinrichsen-Rohling, J. (2015). Meta-research on violence and victims: The impact of data collection methods on findings and participants. *Violence and Victims, 21*(4).

Ruzek, J. I. & Zatzick, D. F. (2000). Ethical considerations in research participation among acutely injured trauma survivors: An empirical investigation. *General Hospital Psychiatry 22*, 27–36.

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 and Marital Therapy, 32*(2), 161-172.

Schwerdtfeger, K. L. & Goff, B. S. (2008). The effects of trauma-focused research on pregnant female participants. *Journal of Empirical Research on Human Research Ethics: An International Journal, 3*(1), 59-67.

Sikweyiya, Y. F., & Jewkes, R. (2012). *Perceptions and experiences of research participants on gender-based violence community based survey: Implications for ethical guidelines*. PLoS ONE 7(4): e35495. doi:10.1371/journal.pone.0035495

The Journal of Family Practice. (2005). [ONLINE AVAILABLE]

<http://www.jfponline.com/pages.asp?aid=2055>

Tourangeau, R., & Smith, T. W. (1996). Asking sensitive questions: The impact of data collection mode, question format, and question context. *Public Opinion Quarterly, 60*(2), 275-304.

- Ullman, S. E. (2007). Asking research participants about trauma and abuse. *American Psychologist*, 62(4), 329-330.
- Walker, E., Newman, E. F., Koss, M. F., & Bernstein, D. (1997). Does the study of victimization revictimize the victims? *General Hospital Psychiatry*, 19, 403-410.
- Walsh, D. & Downe, S. Appraising the quality of qualitative research. *Midwifery* 2006: 22:108-19.
- Ybarra, M. L., Langhinrichsen-Rohling, J. F., Friend, J. F., & Diener-West, M. (2009). Impact of asking sensitive questions about violence to children and adolescent. *Journal of Adolescent Health*, 45, 499-507.
- Zajac, K., Ruggiero, K. J., Smith D. W., Saunders, B. E., & Kilpatrick, D. G. (2011). Adolescent distress in traumatic stress research: Data from the national survey of adolescents-replication. *Journal of Traumatic Stress*, 24(2), 226-229.