Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data

International Society for the Prevention of Child Abuse and Neglect (ISPCAN)

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Acknowledgements

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We are extremely grateful to all those involved in the preparation of this important document and hope that it will be useful for all those involved in undertaking research and the collection and publication of data regarding maltreated children.
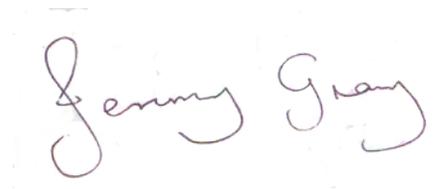
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Table of Contents

Introduction

Collecting information from children and their caregivers regarding child maltreatment is an important and challenging task. Although more attention has recently been paid to ethical considerations for this type of research and a growing number of documents can be found on this topic, internationally recommended or agreed upon ethical guidelines for collecting, analyzing and publishing child protection data are still missing (CP MERG, 2012). Through child maltreatment data studies, children and their caregivers are asked about children's experiences with maltreatment. Methodologies include face-to-face interviews, telephone surveys and Computer Assisted Self Interviewing.

The purpose of this paper is to provide practical suggestions to researchers who are conducting these types of studies. This project involved three activities: a review of the literature, interviews with key informants who have carried out child maltreatment data studies and the identification of case examples which illustrate ethical dilemmas and how these have been resolved.

We agree with experts in this field that there is a need for flexibility in designing research studies that collect child maltreatment data (Finke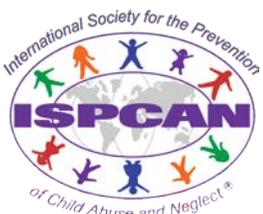lhor et al., 2016). There may not be one best way to conduct these types of studies, as the context in which studies are completed must be considered. It is our hope that through ongoing dialogue that includes sharing ideas, experiences and expertise in this area, we can learn from each other and continue to move towards guidelines that will assist researchers with conducting this important work.

Literature Review

Few studies or ethical guidelines have been designed specifically to address issues regarding collecting child maltreatment data. A recent report published by UNICEF included a review of ethical guidelines and research publications. The authors concluded that there are significant gaps in the available literature and conflicting views that create challenges for researchers in determining the best approach. The authors called for more research in this area (CP MERG, 2012). For example, there is a lack of understanding regarding the amount of information to provide to parents and children and how this might impact participation. The nature and duration of distress caused by research of this type is not known, although according to the literature and the key informants we talked to, the distress caused may be less than some suspect. A need for greater focus on the overall process of conducting this type of research has been identified. The state of the literature is described as 'inconsistent' and 'inadequate' for dealing with ethical dilemmas specific to children involved in research (Powell & Smith, 2009).

This literature review will provide an overview of some of the current issues.

Benefits

Experts agree that there is a pressing need for studies that collect child maltreatment data from children and their caregivers. The benefits of these studies include: providing information that otherwise would not be available, providing children with opportunities to tell their own stories and seek help and providing information to inform prevention and intervention efforts. It is clear that data reported to child protection authorities vastly underestimates the true incidence of maltreatment (Fallon et al., 2010; Radford et al., 2013). Without these data, we simply do not know the extent of the problem and as a result cannot plan adequate services.   According to Article 12 of the United Nations' Convention on the Rights of the Child, every child should be provided with the opportunity to express his or her views and that these views should be taken into account in matters that impact them (UNCRC, Article 12, 1989). By speaking to children directly we can honor their voices and ensure they are heard.

Ethical Considerations

The most common ethical considerations identified in the literature are: protection of children from harm, informed consent, privacy and confidentiality and payment of research participants (Powell et al., 2012). These considerations informed the development of the interview guide for this project. General methodological considerations and cultural considerations were also examined.

Protection of Children from Harm: Distress

Researchers go to great lengths to ensure children are not harmed through the research process. These efforts include informing children of the risks of the study, ensuring confidentiality, providing supports in case children are upset and in rare cases following up with children who present as in danger. Researchers recognize the importance of having resources in case children are distressed. Protocols are often in place that describe the support that will be provided if the participant experiences distress. These expectations for clinical support are universally part of an ethics plan. These protocols may include training of research staff, providing contact information for services (e.g. a psychologist, children's helpline) or funding services that otherwise would not be available. We are still trying to figure out: just how harmful are these studies? Researchers in this area are often confronted with challenges from

Institutional Review Boards regarding the perceived risks to child participants. Although safeguards must be in place, there is a growing body of literature that highlights the difference between perceived versus actual risk. Researchers are now arguing that the actual risk of the research is minimal (Finkelhor et al., 2014).

Most recently, researchers have taken to reporting the number of children who report feeling upset or distressed as a result of a research study. Radford et al. (2013) for example, found a small proportion of participants in a national study in the UK (7.9%) reported some distress, but 95% indicated their participation was worthwhile and the rate of distress for children was almost the same as that of the parents who participated (7.4%). Similarly, Finkelhor et al. (2014) who obtained national estimates of child and youth exposure to violence in the United States, found only 4.6% (n=104) of participants reported being upset, while 95.3% of those who reported being upset would participate again. The authors indicated that the concerns related to this type of research are often based on anecdotes and opinion rather than evidence. They concluded:

> The study supports the conclusion that survey related upset is not a serious problem for researchers asking about abuse and violence, but nonetheless there are a small minority of upset youth who should be of concern (p.222).

Protection of Children From Harm: Disclosures

While collecting data, should a child disclose they have recently been harmed or are at risk of being harmed, researchers are faced with a decision regarding whether or not to intervene. This intervention could include a range of activities, from offering to connect the child to services, to reporting the information to child protection authorities. The specifics of which may depend on local resources, cultural concerns and other concerns related to the particular child. The challenge in this area is the balance between obtaining accurate information about the extent of the problem and ensuring participants are safe. Depending on the context, there are reporting laws that require researchers to report suspected maltreatment. This presents unique challenges for studies that collect data from multiple countries (Nikolaidis, 2013). The debate regarding disclosures is not new. Runyan (2000) describes the results of a discussion with experts at a conference regarding collecting child maltreatment information directly from children. One group argued confidentiality should not be assured when there is

'clear, present and serious risk of harm', and researchers should not be blinded to avoid disclosures. Others argued ethical research can be conducted without reporting to authorities.

We do not have clear cut answers or guidelines that will assist researchers in all circumstances. Being aware of the range of methodologies that have been used to address this ethical dilemma is a step towards developing further understanding. The following is a list of some of the strategies used to address disclosures:

- developing a 'red flag' alert system that identifies children at risk of harm (children asking for assistance or appearing to be at immediate risk are connected to counsellors or reported to authorities) (Radford et al., 2013)

- referring children at risk to school officials (Carroll-Lind et al., 2006)

- obtaining certificates of confidentiality that exempt researchers from legislative attempts to obtain confidential information (Kotch, 2000)

- providing lists of services to participants in case they required help or actively linking participants (Pinheiro, 2006)

- re-contacting children who disclosed a concern during a telephone interview for further assessment (Finkelhor et al., 2009)

- training of researchers regarding managing disclosures (Nikolaidis, 2013).

The form of intervention possible depends on the methodology used to collect the data. In some cases, information is collected by interview or over the telephone. Information is confidential, but it is possible to follow up with a child who discloses a concern. In the case of anonymous surveys, researchers may not be able to follow up after a disclosure. Although, researchers in England who collect anonymous information through Computer Assisted Self Interviewing (CASI) put protocols in place to be able to identify the child who had completed the survey if they were concerned for their safety (Radford et al., 2013).

Informed Consent

There are major ethical concerns regarding obtaining consent for child maltreatment studies, including whether or not to obtain parental consent. Parental or guardian consent is a contested issue, as caregivers are the most likely perpetrators and could prevent researchers from accessing children who have been maltreated. Other gatekeepers who can limit the access of researchers to children include research ethics boards and other professionals working with children (for example, teachers). These gatekeepers may be reluctant to allow researchers to speak to children for fear of causing distress (Baker, 2005).

Researchers have found that very high response rates can be achieved through the use of passive consent, which is a relatively common practice when surveys are administered at schools (Finkelhor et al., in press). For example, researchers in New Zealand achieved a 93% participation rate when school officials approved the research and parents were sent a letter indicating that their children would participate unless the parents declined (Carroll-Lind et al., 2006). Participation rates differed from 62% for active consent and 93% for passive parental consent in a study conducted in the Unites States (Langhinrichsen-Rohling et al., 2006). Others argue that children should be provided with the opportunity to be supported by their parents (Muddaly & Goddard, 2009) and that informed consent is therefore necessary.

Privacy and Confidentiality

Ensuring privacy and confidentiality take on a special meaning with maltreated children, as they could be at further risk of harm if the perpetrator becomes aware of their involvement in a research study. Researchers use a number of methodologies to ensure privacy and assure children that their information will be protected. These methodologies include:

- clear explanations to children about the protection of their information

- computer Assisted Self Interviewing techniques that allow children to fill out surveys anonymously on a computer screen (Helweg-Larsen & Boving-Larsen, 2006; Radford et al., 2013)

- asking children during telephone surveys if they are alone and able to talk privately (Finkelhor, 1998; Zajac et al., 2011)

- conducting interviews with females and males in separate communities to limit the possibility a perpetrator would learn of the nature of the study (Pinheiro, 2006).

- providing a research staff member who is independent of the institution where the study is taking place who can help ensure the institution's staff do not violate confidentiality protocols (C. Wekerly & D. Wolfe, personal communication, April 21, 2015).

Cultural Context

Although key ethical principles in research may be universal (Clacherty & Donald, 2007), methodologies need to be adapted to local contexts and challenges arise when ethical practices are transferred from one culture to another. For example, the location of the interviews conducted in cultures with little privacy needs to be considered (Abebe, 2009). There is a gap in the literature regarding adapting methodologies to local contexts (Powell et al., 2012).

Further Reading

Fortunately, there is a growing body of literature that can assist researchers with these ethical considerations. For further reading on this topic we would like to suggest the following documents:

- CP MERG (2012). Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature, Statistics and Monitoring Section/Division of Policy and Strategy, UNICEF, New York.

- Finkelhor, D., Hamby, S., Turner, H., & Walsh, W. (2016). Ethical issues in surveys about children's exposure to violence and sexual abuse. In C. Cuevas & C. Rennison (Eds.), The Wiley-Blackwell Handbook on the Psychology of Violence. West Sussex, England: Wiley-Blackwell.

- Powell, M.A., Fitzgerald, R.M., Taylor, N. & Graham, A. (2012). International literature review: Ethical issues in undertaking research with children and young people. Childwatch International Research Network, Southern Cross University, Centre for Children and Young People, Lismore NSW and University of Otago, Centre for Research on Children and Families, Dunedin, NZ.

Key Informant Interviews

Key informants from a variety of professional backgrounds (i.e. social work, sociology, pediatrics and epidemiology) were identified and invited to share their expertise regarding collecting child maltreatment data. The purpose of the interviews was to gain insights and solutions for addressing ethical dilemmas from those who have experience in this area, as this has been recommended as a key activity that is needed to fill the current gaps in our knowledge (CPME, 2012). A total of 15 key informants were identified through the network of researchers known to representatives of the International Society for the Prevention of Child Abuse and Neglect (ISPCAN) as well as through the literature search. Eight interviews were completed by Skype in the fall of 2014. Key informants who participated have conducted research in the following countries: Belgium, Canada, Chile, Denmark, England, Greece, India, Saudi Arabia, South Korea and the United States.   Seven key informants from the following countries were contacted but did not participate: Australia, Denmark, England, Georgia, New Zealand, Sweden and the United States. The average time allotted for each interview was 35 minutes. The interviews were audio recorded for the purposes of analysis. The protocol for this project was considered by the Research Ethics Board Secretariat at the Public Health Agency of Canada/Health Canada and was judged to not require a full review as it does not constitute a human subjects concern.

Researchers were asked how they anticipated ethical concerns, addressed potential concerns through planning, and what occurred during as well as after data collection. Examples of ethical issues they have faced were provided as were recommendations for collecting, analyzing and publishing data. It is clear that every step of the research process, from design to obtaining consent to data collection and reporting results, needs to be carefully planned in order to address these concerns.

What are the most important ethical considerations related to research with children and their caregivers regarding their experiences of child maltreatment? How do you address them?

Responses regarding the most important ethical considerations related to this type of research were fairly consistent. Participants described their struggles to balance the potential harms and benefits of their studies. As the participants described the ethical considerations,
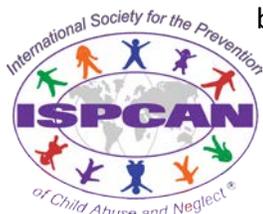
they were often discussing risk (i.e. risk of harm, risk of distress). However, participants expressed concern that the risks of conducting child maltreatment studies may be exaggerated.

> *There is this perception that there is a major risk associated with conducting this type of work. And people underestimate the potential benefits and don't look at – what's the risk of not having evidence based information about the extent of the problem of child maltreatment? Or, what's the risk of not having reliable and valid measures to be able to capture the effectiveness of an intervention? (Interviewee 6)*

The importance of collecting this information was highlighted. The need for more research to understand the actual risks was discussed, as our current knowledge regarding the impact of such research is limited.

> *People often put out theoretical risks, but that's not the same as what is based on empirical evidence (Interviewee 6).*

As we continue to develop this knowledge, researchers are facing the following ethical considerations: safety, distress, disclosures, methodological considerations (i.e. informed consent, data collection, reporting information) and the cultural context in which research is conducted.

Safety

Ensuring safety for child participants was consistently identified as one of the most important ethical considerations for this type of research. Researchers were concerned about possibly putting children at further risk of harm. For example, if the perpetrator of the abuse was aware of the study and retaliated against the child for making a disclosure.

> *For those children who are being abused, (this research) could lead to further harm. For example, being prevented from going to school or being punished afterwards (Interviewee 5).*

Strategies were suggested by the researchers in order to protect child participants, including ensuring the information the children provided remained confidential. These strategies varied according to the methods used to collect the data. For example, Computer Assisted Self Interviewing (CASI) has been used in England. The study was completed in school settings where children fill out surveys individually on computers. This is seen as a safe way to conduct the research and young people have been shown to say much more on screen than when they are interviewed face to face.

Distress

The potential for causing emotional distress or psychological harm to children and their parents through the research process was also identified as an ethical consideration. This could be caused by upsetting questions, bringing up memories the child had worked hard to forget or as a psychologist indicated, causing the child to feel ashamed or frightened.

Some people do what they can to forget those issues…[Asking children about maltreatment] can disturb the psychological balance they have found (Interviewee 2).

Researchers developed protocols to help reduce any potential distress in respondents. Information was provided to ensure clarity, transparency and provide options regarding what participants could expect from the research. For example, in computer assisted studies, researchers provided information about sensitive topics ahead of time and gave the participants the option of skipping questions. The key informants who spoke about this topic indicated children usually answered the questions. Throughout the process, participants were reminded they did not have to participate and that the information collected would remain private. In some cases, additional 'dummy' questions were added to surveys to ensure all children who participated completed at the same time. This was important when a child who had experienced maltreatment could be identified by the length of time it took them to complete the survey.

Services and Support

Careful attention was also paid to informing participants about the services available to them should they need help. These resources included contact information for help lines, psychologists and child protection agencies. Collaboration was necessary with these services in order to ensure everyone was prepared for possible disclosures. In some cases planned, universal debriefing was included as part of the process. Informed consent forms generally assured participants that they could still receive services if they dropped out and that their participation would not affect

services. Support was provided to those who were collecting the information, to determine if something should be reported and manage any distress the researchers themselves were experiencing. This was also seen as a way to reduce participants' anxiety, as discomfort experienced by the researchers could impact participants. Some researchers found

the fact that the research could only have limited direct benefits to individual participants as disconcerting.

Suspecting Maltreatment & Receiving Disclosures

Suspecting maltreatment or receiving a disclosure and determining how to respond is an important ethical consideration. However, consensus regarding what to do in such circumstances does not exist. Strategies depend on methodologies used and the context in which data are collected. Since studies are often designed to collect anonymous data, follow up is not always possible. Although researchers in England collect information anonymously, if deemed necessary, it is possible to track the responses back to the individual when there are serious maltreatment concerns. The researchers have had challenges with this design, as they have been concerned with the method by which children were subsequently approached by statutory local authorities (child protective services). For example, a child disclosed maltreatment and was approached at home in front of his or her parents. The child recanted and no other follow up occurred.

In Korea, data have been collected through face-to-face interviews. If an interviewer received a disclosure they were required to report it to the authorities; however, this protocol was never used as no disclosures were received. In Saudi Arabia, the researchers have taken the stance that no follow up regarding individual cases will occur. In Canada, researchers explain to child participants that the information they collect through the use of the survey will remain anonymous, but that a verbal disclosure by the child to the researchers would require them to report the concerns to a child welfare agency.

Preparation & Planning

In all cases, preparation and planning for disclosures were highlighted as important. An additional challenge for developing countries is the lack of available services for children following a disclosure of abuse or neglect. In such circumstances, researchers may take on the responsibility for providing services themselves or for arranging for other professionals (for example, medical professionals) to be available in case there is a disclosure. There is some need for creativity, flexibility and adaptation to the local context when services are scarce. The researchers expressed deep concern regarding balancing the safety of each child with the challenges of obtaining accurate information that can inform prevention efforts and ultimately reduce the incidences of maltreatment.

Informed Consent and Assent from Children and Youth

Informed consent was discussed at length by the key informants. As reported in the literature, there is no consensus regarding this issue. There are controversies and questions regarding obtaining consent or assent from children and youth as well as caregivers. With respect to children, it is clear that they should be active participants who need to be asked and not forced to participate. The term assent is sometimes used to describe the process for minors who are not legally capable of providing consent (Alderson & Morrow, 2011). Consent and assent procedures depend on the age of the child or youth. The age of consent varies by country and institutional review board, it is not something that can be predetermined. It is important to be aware of the local age of consent when planning a study. The challenge is: at what age should a legal minor be able to legally consent? The older the children being interviewed, the more likely researchers were to only require the consent of the child/adolescent and not the parent. Where parents were asked for consent, researchers in England also wanted to make sure children also had the option of saying no, a commonly required ethical practice. They were asked during the survey if they wanted to participate and they were reminded that they could skip questions. It was suggested that the developmental stage of the child be used to determine if they can consent.

Informed Consent from Caregivers

Obtaining permission from parents or guardians is a controversial topic. It may not be appropriate, especially since he or she could be the perpetrator of the abuse.

> *Traditionally we ask for parents' permission, but research has shown they are the most likely perpetrator (Interviewee 1).*

Some researchers have chosen to obtain the permission of the school board rather than parents. Others support the use of passive consent, which involves having parents contact the school only if they do not want their children to participate. For example, youth aged 16-18 in Belgium were approached after the school granted permission and informed parents of their right to refuse. Researchers suggest that using passive consent in this manner has improved response rates. One of the researchers we interviewed, who has collected data from children over the age of 11, used a passive consent procedure in part because the parent might be the most likely perpetrator. Researchers in Canada and England indicate in some cases you simply would not have access to children without the permission of their parents (for example, household telephone surveys). There is a call for more research in this area that would provide evidence regarding the impact of obtaining consent from parents.

Informed Consent: Language

Caution was suggested in considering the language that should be used in any consent form or script. In the experience of researchers from the United States, feedback from participants following participation in the study was that the language used to explain the study was frightening. Participants asked the researchers afterwards: "Where was the upsetting part you told me about?" The language required by the Research Ethics Board to explain the study to participants had in fact caused more distress than the survey itself. When the language was changed, the response rate improved. Another researcher echoed these concerns.

> *The whole area is fraught with ethical challenges. There are things about honesty too, you know, gaining access. How you balance between doing the research in the most rigorous way so that you are truthful to children's voices, but also how you can collect that data in a way so that you don't frighten people to death. Lots of divided opinion on how you do that (Interviewee 4).*

Researchers argue for the importance of communicating honestly with participants about the topic. They acknowledge, however, that this could lead to losing participants. Pilot testing of surveys in England with survivors of sexual abuse indicated participants would be angry if they were told a survey was about family life and then they were asked about sexual abuse. It is a dilemma for violence research that may lead to refusals and as a result an undercount of maltreatment. This was another area identified that needs further research.

Data Collection

The importance of asking questions in a way that children are most likely to understand and that is appropriate for their ages and stages of development was highlighted. For example, children may respond in ways that are meant to please the researcher or may understand questions in a literal way. Children with disabilities (whether or not they have been identified) may require appropriate adaptations in order to respond. In other cases, children may not interpret maltreatment in the same was as adults:

> *And I think in the area of violence against children, I know that there are huge issues developmentally in terms of how children understand experiences of violence – particularly when an adult has been perpetrating it and the way in which that power relationship distorts their ability to be able to interpret it and name it as abuse (Interviewee 4).*

In order to address these concerns, researchers pilot tested questions, used headphones for computer administered surveys so that children who struggled with reading could
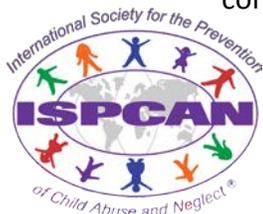
listen to the questions, or read the questions allowed. They also used screens between students when data were collected in schools to assist with concentration.

Researchers suggested asking very clear questions rather than using language that can be interpreted. For example, one recommendation was to avoid asking if someone has been sexually abused, but instead ask about specific activities that have occurred (For example, 'Have you had sexual relations with an adult?'). Ensuring questions are not misunderstood is also important. For example, children understanding self-harm as accidentally hurting themselves.

A number of other methodological concerns regarding collecting data were highlighted. Through the use of interviews, researchers may influence children's responses by reacting to their disclosures. The importance and the challenge of remaining neutral throughout this type of research was emphasized as was adequate training and qualifications of those who collect the data. In some contexts there are online tools that provide training regarding research ethics. For example, in Canada a course on Research ethics provides an introduction to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2).   It is available at: http://www.pre.ethics.gc.ca/eng/education/tutorial-didacticiel/. In the United States, the Collaborative IRB Training Initiative (CITI) at the University of Miami provides an online human subjects research ethics training module at: https://www.citiprogram.org. One researcher indicated there is a need for a human subjects online training program that is generalizable and less country specific.

Data Analysis

In the process of analyzing data we may misinterpret children's responses, and as a result report inaccurate results. For example, when asking about neglectful situations, it may be difficult to interpret and define what neglect is. As one participant described, a teenager may see not being able to use their phone after 10pm as neglect, whereas a child who misses meals and does not have warm clothes may have normalized these experiences. Designing and testing questions to ensure the most accurate information is being collected is an important step in the process. Making decisions when there are inconsistencies among responses from the same participant can be challenging. Do you remove such responses or report the information as provided by the participants?

Data Storage & Publication

Clearly, the need to ensure data are kept private was a priority for the key informants. Caution regarding identifying schools or regions when data were reported was taken. Researchers were concerned about the ethical implications of collecting data that subsequently was not used for various reasons. The politics regarding what happens to the results was mentioned as a potential ethical concern. This could be influenced by the source of funding and the current political climate, as well as the professional codes of conduct applicable to the researcher.

Cultural Context

The key informants who spoke to us during this project have conducted research in a variety of contexts including: Europe, the Middle East, Asia and North America. Research tools developed in the United States (for example, Longitudinal Studies on Child Abuse and Neglect –

LONGSCAN; ISPCAN Child Abuse Screening Tools - ICAST) have been adapted for use in several countries. The key informants emphasized the importance of modifying studies to local contexts. Clearly it is not possible to simply translate or transport surveys without paying attention to the culture and language of the participants.

When research is done in different languages, you have to be extra careful using tools in different cultural contexts and countries. Sometimes, straight translation won't work (Interviewee 3).

Methods used to mitigate this concern included testing questions with focus groups and key informants. If a researcher was entering the country for the purpose of conducting the study, local experts were relied upon to guide the research process. Issues with transferring methodologies across cultures need to be considered for developed as well as developing countries. For example, researchers in the United States successfully carry out telephone surveys. In England, as one key informant pointed out, researchers have opted for computer based surveys as a representative sample could not be guaranteed using telephone surveys due to fewer people having telephones.

Autonomy

Respect for the principle of autonomy and respect for persons was highlighted. For example, when researchers live in different contexts than where the research is being conducted, they may be tempted to intervene when they are concerned about a child rather than focus on collecting data. This can interfere with the research process. Researchers from the United States conducting studies in developing countries concluded using non-clinically trained students helped with the process, as they were less likely to intervene. Related to the topic of intervention, with a potential lack of resources to follow up regarding child maltreatment in such contexts, some key informants spoke of the responsibility of researchers to provide funding for such services. For example, hiring an independent counselor to follow up with those who experienced distress or needed assistance.

Low and Middle Income Countries

Participants emphasized the importance of conducting child maltreatment studies in low and middle income countries. There was a sense of urgency from some key informants as they indicated that such countries are changing rapidly. Since the current situation is very different than a few years ago, there is a need to evaluate the impact of such changes. A challenge associated with conducting studies in such contexts is obtaining sufficient funding to ensure the same level of quality and rigor as would be ensured in higher income countries. However, a key informant indicated 'we need to start somewhere' and simply acknowledge the limitations. A call for prioritizing such research and advocating for adequate resources was heard from the key informants.

The importance of setting local research agendas rather than copying what others are doing was highlighted. As one researcher indicated: local data will drive local change. Along with a local research agenda comes the importance of publishing research in regional as well as international journals. If research is only published in English, results won't always reach those who can use it.

What are the potential benefits for involving children and their caregivers in this type of research?

Clearly, collecting child maltreatment data from children and their caregivers provides information that is otherwise unavailable. By interviewing children soon after the abuse has occurred, recall bias may be reduced. Children's perspectives are different from adults, which could lead to new and important information about children's experiences that we are not aware of.

I think the obvious benefit is listening to what children say, because adults have defined what matters (Interviewee 4).

There are gaps in our knowledge. For example, peer to peer sexual violence has not been researched until recently because in the child protection field there's this dominant view that child abuse is in the family…(Interviewee 4).

Without this information, we are left with data from official reports to child welfare authorities and we know these data are only the 'tip of the iceberg' (Trocmé et al., 2010);

We've shown with our LONGSCAN study that you get a very different picture. Official statistics got less than half of what the kids told us about. Using parents got us a little bit more than social services told us about, but we would have missed more than half…Any study that is taking a look at the impact of maltreatment that doesn't ask the kids, is going to miss a large part of the problem (Interviewee 7).

You get more from self-reports than you get from official records because there's a lot of violence in children's lives that we just don't know about (Interviewee 4).

There is no other way we have of getting that type of information, of understanding the extent of the distribution and determinants of maltreatment. Because, official reports are the tip of the iceberg. There's a stigma attached on the part of caregivers on what they do and under-reporting. I don't think we can rely on caregivers to tell us what they do to children (Interviewee 6).

Some studies did in fact involve the collection of data from caregivers and teachers, especially to collect information about young children. One participant spoke about the importance of their voices:

Involving teachers and caregivers is important because they're the ones spending time with these children. So, it gives from their point of view an idea of what these children deal with or what is important to these children (Interviewee 8).

Not only do these studies provide information that would not otherwise be available, the information collected provides children a chance to be heard:

Involving children in this kind of research gives them the floor to talk about their experiences and their opinions about either child maltreatment or parental support.

I think it is essential to involve children's voices and opinions in this kind of research, otherwise we are only talking about their experiences instead of listening to their experiences (Interviewee 8).

In some cases, this has allowed children to seek assistance regarding the maltreatment that has occurred. It is common practice to provide opportunities for children to connect with professionals (for example, psychologists and social workers) following the study if they are upset or would like support. This was also seen as a risk of the research, as some children have worked hard to forget what happened to them.

Impact

One of the key ethical principles of research is beneficence. Given the important role of beneficence in ethically based research, it is essential that there is some connection between the research and the development and sustainability of prevention and or treatment programs. Child maltreatment research has lead to changing attitudes regarding children's rights and the implementation of programs.

This can provide us information that can help us develop interventions that can prevent maltreatment, recurrence and maltreatment (Interviewee 6).

For example, in Greece, community awareness was raised by the research. Clinical as well as health promotion services were implemented. Unfortunately, these programs did not last due to funding cutbacks. But, they were able to use the data collected to promote child safety through the identification of a high number of sexual abuse occurrences in a particular community. This lead to the identification and arrest of a pedophile. Data were used in Saudi Arabia to assist with establishing prevention programs, including hospital based child protection teams and a child help line.

What are the potential risks? How often have these risks actually emerged?

As mentioned above, researchers are concerned that the risks of this type of research may be exaggerated. Key informants have experienced challenges with Institutional Review Boards that have initially said no to child maltreatment studies or insisted on language on consent forms that seemed to frighten or upset participants.

I think some of the risks that we are worried about are exaggerated. I think we have a tendency to be a bit on the paternalistic side. There were huge concerns from the psychiatrist that we couldn't ask children about their experiences of violence because it would be too upsetting. In actual fact, my experience from doing this research has been and other researchers have said the same thing – children want to say [what's happened] because they want to

help other children and they want to be heard (Interviewee 4).

One of the key informants described ongoing challenges with a Research Ethics Board that was critical of self-report data and tried to deter her from collecting self-report data. Through the development of partnerships, relationships and multidisciplinary teams, she was able to convince the members of the board of the merits of overall beneficence of this type of research.

Distress and Disclosures

We wanted to know how often risks actually occur. The main risks that were described included: distress and disclosures. Overall, a very small proportion of participants in any of the studies the researchers described actually reported one of these risks. For example, in Korea there was a protocol in place for maltreatment disclosures. From a sample of approximately 5,000, no disclosures were received. Similarly, when over 6,000 children participated in a study in England, six cases were identified through a red flag system. This system identified children who may be in immediate danger. Children were subsequently asked if they would like to talk to someone. Only two children's names were passed on to local authority social services (child protective services).

In Denmark, when approximately 6,000 child participants were given the name of a psychologist in case they were upset or would like to talk following the study, only three children called and when given the opportunity to skip sensitive questions, most young people chose to respond. Similarly, only three or four students requested emotional support following a study in Belgium. There were fewer than 10 disclosures in a study conducted in the Balkans and approximately 1% of a sample of 16,000 children in Saudi Arabia asked for help. A researcher who led a study in the United States involving over 6,000 interviews, found only 5-6 actually appeared distressed. There were more children who reported suicidal ideation (17) than abuse (14). In twenty years of conducting LONGSCAN studies about twenty children were reported to authorities when there was serious abuse currently occurring (i.e. physical abuse that might be life threatening or sexual abuse).

Researchers in the United States and England explicitly asked participants if they were upset as a result of the research. A small proportion of children indicated they were upset, although

those who were upset felt the study was worthwhile. This speaks to the importance of ensuring children have a voice regarding how studies are conducted.

> *I think you have to start from what children tell you, what they find upsetting – that's why it matters greatly to me. Being able to give children the right to say what they think and also be involved in how that research is designed and used (Interviewee 4).*

Summary

The key informants involved in this project provided important insights into collecting child maltreatment data. They reaffirmed the importance of these studies and the benefits of the information collected. Researchers are concerned that the perceived risks of harm of these studies may be exaggerated. Nonetheless, they have developed strong practices that create safety, reduce distress and manage disclosures should they occur.

Case Examples

Case examples from the literature which illustrate ethical considerations and how these were resolved were identified through this project. Please see Appendix A for summaries of eighteen studies. Ethical considerations described included: consent, safety, disclosures, distress, confidentiality and cultural considerations. A further source of case examples is the Ethical Research Involving Children (ERIC) website: http://childethics.com. ERIC is an international project that works towards helping researchers conduct ethical research regarding children.

Conclusions & Recommendations

The objective of this project was to describe key ethical issues as well as recommendations for use by researchers, policy makers, analysts and statisticians when collecting, analyzing and publishing data/statistics on child maltreatment. This project involved three activities: a review of the literature, interviews with key informants who have carried out child maltreatment studies and the identification of case examples which illustrate ethical dilemmas and how these have been resolved. Based on the information collected, the following recommendations and areas for future research are provided:

- ensure supports are available to participants during and after the study

- use clear language that is pilot tested when designing questions

- provide thorough training for those collecting data

- prioritize studies in low and middle-income countries

- develop an online research training tool regarding research ethics that can be applied internationally

- develop and maintain a resource of ethics reports and ethical protocol descriptions

- continue to conduct empirical studies regarding the impact of child maltreatment studies (for example, informed vs. passive consent) and the most appropriate methodologies

- explore and compare levels of comfort of children and youth in completing surveys regarding other sensitive issues (e.g. suicide, grades, peer relationships, substance use, sexual orientation)

- prioritize studies for younger children

- prioritize longitudinal studies

- develop ongoing forums for discussion.

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Runyan, D. (2000). The ethical, legal, and methodological implications of directly asking children about abuse. Journal of Interpersonal Violence, 15, 675-681.

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Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
Radford, L., Corral, S., Bradley, C., & Fisher, H. L. (2013). The prevalence and impact of child maltreatment and other types of victimization in the UK: Findings from a population survey of caregivers, children and young people and young adults. Child Abuse & Neglect, 37, 801-813. - This case example was also published by Ethical Research Involving Children	- The National Society for the Prevention of Cruelty to Children (NSPCC) conducted a national study in the UK in 2009. The purpose of the study was to determine the prevalence and impact of violence towards children and young people at home, in school and in the community. - Participants included: 2160 caregivers of children under 11 years; 2275 children and young people aged 11 - 17 and 1761 were young	- Safety	- Computer Assisted Self Interviewing (CASI) methods were used to ask children privately about their experiences of violence.
		- Privacy, Anonymity, Confidentiality	- Limits of confidentiality were explained. This may have impacted the willingness of caregivers to participate and of participants to report maltreatment. The findings may therefore underestimate the actual prevalence.
		- Consent	- Written consent was obtained from parents for children under 18. Participants aged 11-17 were also asked for consent.
		- Disclosures	- A red flag alert system was used to ensure researchers were informed if children asked for assistance or if there appeared to be an immediate risk to the child. A protocol was developed that included the following steps: two research team members reviewed surveys that were flagged; cases requiring further action were passed on the same day to ChildLine counsellors or the NSPCC child

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
(ERIC): http://childethics.com/resources/case-studies/	adults aged 18 - 24.		protection services. - 85 cases (0.6%) were referred on for assistance with all but 4 passed on with the agreement of the participant.
		- Distress	- 7.9% reported some distress, but 95% indicated their participation was worthwhile and the rate of distress was almost the same as that of the parents who participated (7.4%).
Carroll-Lind, J., Chapman, J., Gregory, J., & Maxwell, G. (2006). The key to the gatekeepers: Passive consent and other ethical issues	- Conducted a study with 2,077 children ages 9 -13 in New Zealand that asked about experiences of violence (physical, emotional, sexual, witnessing violence,	- Consent	- Used passive consent in order to gain direct access to children's perceptions of violence. All children were included unless parents indicated they could not participate. Researchers saw the right to participate as more important than parental rights to privacy about abuse in the home. Only 7% of parents declined participation. - Consent forms were kept separately from questionnaires. Students completed the questionnaires at school the way

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
surrounding the rights of children to speak on issues that concern them. Child Abuse & Neglect, 30, 979-989.	media violence) and traumatic events. - The study took place at randomly selected schools.		they complete tests.
		- Privacy, Anonymity, Confidentiality	- Administered questionnaires in classrooms in order to provide anonymity. Researchers read the questions allowed to ensure clarity. School personnel were not present.
		- Disclosures	- Reporting of a concern regarding a child is not mandated in New Zealand. But, if the child identified themselves to the researcher as being at risk by writing their name on the questionnaire, the researcher would interview the child to get more information and if a disclosure occurred the researcher would tell the principal or the teacher.
		- Safety	- Supports were identified and phone numbers for services were provided to participants.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
		- Distress	- Questionnaires ended with questions about the 'good' things that had happened to participants.
Mudaly, N., & Goddard, C. (2009). The ethics of involving children who have been abused in child abuse research. International Journal of Children's Rights, 17, 261-281.	- Qualitative interviews of 9 children in Australia about their experiences of abuse. - Recruited from an agency that provides therapeutic intervention to children who have been abused. - All participants had received abuse-focused therapy.	- Distress	- Some participants were distressed during the interview and were provided with a planned debriefing. No child required follow up therapy. Children weren't asked directly about the details of the abuse. - Took the position that having the non-offending parent's support of the research was essential. Offered to have the parent in the room. Only included participants whose parents were assessed as protective and supportive of their children. - Used child-centered counseling techniques during the interviews. - Participants with known protection concerns were excluded from the study. - Interviews conducted outside the home to keep living

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Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
			situation free from abuse related issues.
		- Consent	- Children asked to sign consent form. Both parent and child had to consent for participation to occur. - Provided clear information about the study to participants and provided them with multiple opportunities to withdraw
		- Confidentiality	- Children and interviewer discussed what information about the interview would be shared with their parents and/or therapists.
Kotch, J. (2000). Ethical issues in longitudinal child maltreatment research. Journal of Interpersonal Violence, 7, 696-	- Described ethical considerations applied by the North Carolina site of Longitudinal Studies Consortium on Child Abuse and Neglect (LONGSCAN). The	- Privacy, Anonymity, Confidentiality	- Maintained confidentiality of participants.
		- Consent	- Allowed parents to grant consent for their children. Provided assent forms to 8-year-olds. - Avoided the terms child abuse, child maltreatment and child neglect in the consent in order to avoid having refusals

Appendix: Case Examples

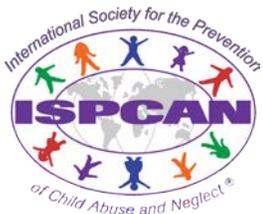| Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
709.	study began in 1985 and was then called Stress, Social Support and Abuse and Neglect in High Risk Infants. Mother-infant pairs were recruited at birth. Follow-up interviews were later completed and at the time the article was written, the children being interviewed were 12. - Asked parents about abuse their children had experienced and asked 12 year olds directly about abuse.		to participation.
		- Disclosures	- Concluded confidentiality of the research should be maintained and is ethically superior to reporting suspected maltreatment, with certain exceptions. In North Carolina there is duty to report legislation. Researchers were blinded to responses that may lead to suspicion of child maltreatment. Obtained a certificate of confidentiality that exempted the researchers from legislative attempts to obtain information. Indicated reporting could place a child at risk of harm and that this harm is greater than the harm of non-participation. - Would report if a child disclosed directly to an interviewer about a concern. Reported concerns regarding 5 participants. - Future plan to use audio-assisted computer-administered subject interviewing for children aged 12 and over. The child may be provided with the option of revealing a disclosure to the interviewer for follow up.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
		- Distress	- Following almost 2000 interviews, no reports of any serious consequences of the research. - Provided access to child psychology consultants in case children were distressed by the study.
Runyan, D. (2000). The ethical, legal, and methodological implications of directly asking children about abuse. Journal of Interpersonal Violence, 15, 675-681.	- Described the following study: Longitudinal Studies Consortium on Child Abuse and Neglect (LONGSCAN). - This paper described the results of a discussion that occurred at a conference regarding collecting child	- Disclosures	- Parents informed that if maltreatment was suspected due to disclosures by the child or parent, a report to the appropriate authorities would be made. - Disagreement among researchers regarding the need to provide services for children who revealed maltreatment. One group at the conference argued confidentiality should not be assured when there is 'clear, present and serious risk of harm'. And researchers should not be purposively blinded to avoid disclosures. Others argued ethical research can be conducted without reporting to authorities.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
	maltreatment information directly from children. - LONGSCAN Included 5 cohort studies of child maltreatment at five sites in five different states in the US.		
	- Data collection included administrative data, measures from caregivers and children.	- Consent	- Participants informed they could withdraw and no refusals of participation due to the inclusion of maltreatment questions occurred. - Consent should not involve deception of children or parents.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
		- Future Research	- Within the 5 sites there was disagreement regarding resolution of the ethical concerns. - Research is needed regarding the impact of research, including benefits as well as harms. - Asking children aged 12 and over about maltreatment may be reasonable, but research about the appropriate lower age limit should be undertaken.
		- Confidentiality	- Interviews conducted in private to protect confidentiality.
		- Distress	- Protocol established that linked service agencies with participants who were upset or asked for help.

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Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
		- Cultural Considerations	- Ethnographic research conducted to ensure instrument was culturally appropriate. - Testing of the instruments to ensure comprehension.
Finkelhor, D. (1998). A comparison of the responses of preadolescents and adolescents in a National Victimization Survey. Journal of Interpersonal Violence, 13, 362-382.	- National telephone survey: National Youth Victimization Study - Sample of 2000 youth - First interviewed parents by phone and asked for consent to speak to child. - This article compared responses of 10 -11 year olds with 12 -16 year olds	- Consent	- Obtained consent from parents. Parents were slightly more likely to refuse to allow younger (18% vs. 13%, x2= 10.87, p < .001) children to participate. Non-white parents and those who expressed concern about violence in their communities were less likely to bar their children from participation. Parents who saw the study as relevant may have been more likely to allow participation.
		- Privacy, Anonymity, Confidentiality	- Interviewers tried to ensure child was alone and able to speak freely.
		- Distress	- Offered phone number of national child-protection hot line at end of interview. - Two thirds of the youth indicated the interview had been a

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
	- Suggested findings support including 10-11 year olds in victimization surveys.		good experience. 5 reported it had been bad. 39 out of the 2000 participants indicated something was upsetting. Younger children were no more likely to report being upset than older youth. - Children who found something in the interview upsetting were more likely to have disclosed sexual and/or family assaults. - Telephone interviews provide a high degree of control as children can hang up if they are upset or if the situation becomes dangerous.
Finkelhor, D, Vanderminden, J, Turner H, Hamby S, & Shattuck, A. (2014). Upset among youth in response to questions about exposure to	- Obtained national estimates of child and youth exposure to violence (for example, crime, child maltreatment, sexual victimization, witnessing victimization) in the	- Distress	- The researchers asked each of the participants to indicate if they felt discomfort as a result of participating in the survey. 4.6% (n=104) reported being upset. 19 of these children indicated it was pretty or a lot upsetting (0.8%). 95.3% of those who reported being upset would participate again. - The survey included the Trauma Symptom Checklist for Children (TSCC). Being upset by the survey was strongly associated with high scores on the TSCC. Upset was not

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
violence, sexual assault and family maltreatment. Child Abuse and Neglect, 38, 217-223.	US. - Cross-sectional national telephone survey - Survey: National Survey of Children's Exposure to Violence II - Sample included the 2312 respondents aged 10-17 (total sample included 4503 children and youth ages one month to 17 years).		associated with age. - Concluded: 'survey related upset is not a serious problem for researchers asking about abuse and violence, but nonetheless there are a small minority of upset youth who should be of concern' (p.222).
		- Safety	- The researchers had a protocol in place for identifying children and youth who reported high risk experiences and researchers were also able to identify children for whom they were concerned. Participants were provided with a toll-free phone number if they wanted to get more help and a clinician trained in telephone crisis counseling was available. Those who were flagged were reviewed and called back. 17.3% of youth were flagged. 2% of these were evaluated as serious enough for clinician follow-up.
Nikolaidis, G. (2013). Balkan Epidemiological	- BECAN is an epidemiological study that collected data	- Privacy, Anonymity, Confidentiality	- Surveys were administered in classrooms, anonymously by trained researchers. - For students who had dropped out of school, two

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
Study on Child Abuse and Neglect (BECAN) Final Summary Report. Retrieved from: http://cordis.europa.eu/publication/rcn/16654_en.html - Further details regarding ethical issues retrieved from: http://www.becan.eu/node/19	regarding child abuse and neglect in nine Balkan countries: Greece, Bulgaria, Romania, Albania, Former Yugoslav Republic of Macedonia, Turkey, Croatia, Serbia, Bosnia & Herzegovina. - Instrument: ISPCAN Child Abuse Screening Tool - Data were collected from matched pairs of children and their parents. 42,272 children aged 11, 13 and 16 completed a survey. 26,287 parents completed		researchers collected data from children/youth in their home after consent from a caregiver was obtained.
		- Consent	- Three forms of consent were obtained: parental consent for child participation, parental consent for their own participation and child consent.
		- Distress	- Contact information for resources provided to children. - Trained researchers were available to provide assistance if child upset by survey.
		- Disclosures	- Participants reported sexual abuse and coach was subsequently arrested.
		- Cultural Considerations	- A specific ethics advisory board was established for the project along with nine national advisory boards. - Due to differences in legislation, codes of ethics and child protection systems among the 9 countries, ethical issues were handled differently (for example, type of parental consent required, reactions to disclosures)

Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
	surveys.		
Ybarra, M. L., Langhinrichsen-Rohling, J., Friend, J., & Diener-West, M. (2009). Impact of asking sensitive questions about violence to children & adolescents. Journal of Adolescent Health, 45, 5 499–507.	- Secondary data analysis of Growing up with Media survey - Examined the impact of a survey that asked questions about victimization, perpetration and exposure to violence. Asked participants if the questions were upsetting. - National online survey of 1588 youth aged 10-15 in the United States.	- Distress	- 23% (n=394) were upset by the questions about violence. Reasons included upset by type of questions (sex, drugs), distressed by idea young people were engaged in such behaviours and tone of survey as accusatory. Upset youth three times likely to be younger. Researchers hypothesized younger children could be more upset due to more monitoring by caregivers during participation. - Suggested asking about distress should be a routine question given the percentage that reported being upset by this survey. - Suggested more research to understand the impact of questions and ensure resources are available to support participants. - Suggested being 'upset' does not necessarily mean the participant was harmed. - Suggested measuring the magnitude of distress and

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
			following up with participants after the survey is completed.
		- Consent	- Obtained informed consent from caregivers. - Suggested careful methodologies to ensure participants are informed and understand risks especially with methodologies that don't involve direct contact with a researcher.
		- Privacy, Anonymity and Confidentiality	- Conducted online to increase self-disclosure. Hypothesized that participants who don't interact with an interviewer, who may be perceived as judgmental, may be more likely to disclose. - Encouraged youth to complete online survey in separate space from others to ensure privacy.
Langhinrichsen-Rohling, J., Arata, C. M., O'Brien, N., Bowers, D., &	- Examined distress of adolescents who were surveyed about drug use, suicidal behavior	- Participant distress/upset	- Upset caused by the research ranged from 2.5 -7.6%. - Those adolescents who had a history of suicidal ideation or attempt, illicit drug use or experiences of physical or sexual

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyways? Violence & Victims, 21, 425–444.	and physical and sexual abuse from multiple convenience samples in the United States. - 1,540 participants over a 3 year period from four sites. - Samples recruited from high school, middle school and adolescents involved in the juvenile justice system. - Administered in classroom and juvenile justice settings.		victimization were more likely to report being upset. - Participation rates differed from 62% for active consent and 93% for passive parental consent.
		- Consent	- The researchers concluded that methodological choices (including active vs. passive consent) are likely to impact participation rates, sample characteristics, and adolescent participants' willingness to disclose concerns (for example, suicidality, child physical or sexual abuse, and drug use).

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
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.	- Survey regarding traumatic stress: National Survey of Adolescents-Replication in the United States - Nationally representative sample of 3,614 youth aged 12 -17 - Telephone survey	- Distress	- 5.7% (n=204) of sample found some questions upsetting - 8 (0.2%) remained upset at the end of the interview - 2 (<0.1%) wished to speak to a counselor - More girls reported distress than boys. - Adolescents who had experienced traumatic experiences or mental health problems more likely to report distress. - Authors concluded survey questions about trauma appear to pose minimal risk to adolescents.
		- Privacy, Anonymity, Confidentiality	- Adolescents were asked during the interview if they were in a private setting in order to ensure they could answer the questions freely.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
		- Consent	- Parental consent was obtained prior to the interview.
		- Consent	- Ethics approval was obtained by school authorities. Consent was obtained from classroom teachers and students.
		- Distress	- Children who had experienced violence found it more stressful to complete a survey, as well as too difficult, embarrassing and excessively long. Victims were asked to fill out follow-up questions for each reported type of victimization, which led to their questionnaires being longer. - The majority of those exposed to violence saw the importance of violence research.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
Smith, A., Stewart, D., Peled, M., Poon, C., & Saewyc, E., & The McCreary Centre Society. (2009). A Picture of health: Highlights from the 2008 BC Adolescent Health Survey. Vancouver, British Columbia, Canada: McCreary Centre Society.	- Provincial survey regarding physical and emotional health of youth in British Columbia, Canada. - Included questions about violence and abuse. - Fourth survey of its kind in British Columbia. - Approximately 29,000 students in grades 7 -12 from 1760 classrooms completed the survey. - The survey was administered by nurses, nursing	- Consent	- Parental consent procedures were determined by each school district. In districts that required parental consent, students were less likely to report ever having had sex.

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
	students and other trained personnel.		
		- Privacy, Anonymity, Confidentiality	- The authors used Computer-Assisted Self-Administered Interviews (CASI) as they found support in the literature for this type of methodology for studies regarding sensitive issues. It was reported this methodology enhances confidentiality, reduces bias by reducing respondents' fear of retaliation and assists weak readers with participation.
		- Distress	- 0.3% expressed difficulty in filling out the questionnaire, no students criticized the sensitive nature of the survey, 2 students sought counseling after the survey was completed.

Appendix: Case Examples

Reference	Brief Summary	Ethical Issue(s) Identified by the Researchers	Resolution
Fisher, C. B., Higgins-D'Alessandro, A., Rau, J. M. B., Kuther, T. L., & Belanger, S. (1996). Referring and reporting research participants at risk: Views from urban adolescents. Child Development, 67, 2086-2100.	- Surveyed seventh, ninth and eleventh graders regarding what to do when an adolescent discloses a concern during a survey. - 147 participants from a low-income urban environment in the United States.	- Disclosures	- Responses differed regarding the course of action researchers should take when faced with a disclosure: take no action, disclose to an adult or assist the adolescent with making a self-report. These differences depended on the severity of the risk. Confidentiality was viewed more favorably for lower risk behaviours for which adult knowledge was seen to perhaps introduce greater risk. Participants supported reporting to adults regarding child maltreatment and threats of suicide. - One child approached the research team with personal problems. After obtaining the agreement of the child an appointment with the school's counselor was made.
		- Consent	- Obtained active parental consent and child assent. Resulted in a response rate of about 30% for each grade.