The ethics of child maltreatment surveys in relation to participant distress: Implications of social science evidence, ethical guidelines, and law

Abstract

Epidemiological surveys measuring the prevalence of child maltreatment generate essential knowledge that is required to enhance human rights, promote gender equality, and reduce child abuse and neglect and its effects. Yet, evidence suggests Institutional Review Boards (IRBs) may assess the risk of these studies using higher than normal thresholds, based on a perception they may cause high distress to participants. It is essential for IRBs and researchers to have an accurate understanding of the nature and extent of participant distress associated with these studies, and of the duties of researchers towards survey participants, so that meritorious research is endorsed and duties to participants discharged. Assessment by IRBs of the ethics of such research must be appropriately informed by scientific evidence, ethical principles, and legal requirements. This article adds to knowledge by considering participant distress in child maltreatment surveys and its appropriate ethical and operational treatment. We provide an updated overview of scientific evidence of the frequency and severity of distress in studies of child maltreatment, a review of ethical requirements including a focus on beneficence and participant welfare, and a new analysis of researchers' legal duties towards participants. Our analyses demonstrate that participant distress is infrequent and transitory, that researchers can satisfy ethical requirements towards participants, and that legal liability does not extend to emotional distress. Informed by these bodies of knowledge, we distil key principles of good epidemiological practice to provide solutions to operational requirements in these surveys, which both fulfil ethical requirements to participants, and demonstrate trauma-informed practice.

1. The need for surveys of child maltreatment

Nationwide surveys of the prevalence of child maltreatment – including physical abuse, sexual abuse, emotional or psychological abuse, neglect, and exposure to intimate partner violence – have been conducted in many countries (Mathews, Pacella, Dunne, Simunovic, & Marston, 2020; Meinck et al., 2016). These epidemiological studies continue to proliferate in diverse regions, both in individual countries, and in multi-country efforts such as the Balkans study (Nikolaidis et al., 2018), the Violence Against Children Surveys (Nguyen et al., 2019), and the Multiple Indicator Cluster Surveys (Cuartas, McCoy, Rey-Guerra, Britto, Beatriz, & Salhi, 2019). Research in this field has been spurred by a growing awareness of child maltreatment as a significant form of interpersonal violence that breaches children's human rights, constitutes a global public health challenge, and is associated with lifelong health problems, behavioural risks, and economic costs.

Increasingly, these surveys are conducted to pursue an international policy agenda expressed through the United Nations Sustainable Development Goals (SDGs), with Target 16.2 aiming to end abuse, exploitation, trafficking, and all forms of violence against children (United Nations, 2015). Nation states are required to report on their efforts to achieve the SDGs, and need reliable evidence of trends in maltreatment to determine if rates are declining.

Research into child maltreatment is essential to generate evidence about the magnitude and specific nature of the problem, and to identify avenues for better prevention, intervention, and responses. From a public health perspective, these research studies are exemplars of epidemiological studies directed towards fulfilling the duty of the State to enhance social justice for disadvantaged populations (Gostin & Wiley, 2016). They are an essential element of public health surveillance to measure and monitor the prevalence of a condition, and to identify contextual factors increasing or reducing the likelihood of this condition (Hammond, Whitaker, Lutzker, Mercy, & Chin, 2006). Without these studies, the capacity of policy-makers to enhance prevention is compromised; society sustains massive costs if we do not ask people about abuse (Becker-Blease & Freyd, 2006). These studies also provide individuals generally, and survivors of maltreatment in particular, with the opportunity to participate in research, have their lived experience validated, and influence policy. Studies with children and adolescents also promote their right to participate in and contribute to research and public policy that concerns them, as established in the United Nations Convention on the Rights of the Child article 12, and the SDGs.

Survey content and administration mode. Typically, surveys of child maltreatment prevalence ask participants to report retrospectively about their experiences of various kinds of abuse and neglect (Amaya-Jackson, Socolar, Hunter, Runyan, & Colindres, 2000; Mathews et al., 2020). Studies may be conducted with adult participants, but are also often conducted with children and youth (Mathews et al., 2020). Survey instruments have been designed for use with children as young as seven (Zolotor et al., 2009) and eight years of age (Hamby et al., 2005). Some studies ask only about the experience of maltreatment, while others also obtain information about other features of the experience (e.g., frequency, duration, and who inflicted the maltreatment) (Finkelhor, Turner, Shattuck, & Hamby, 2015; Meinck, Cluver, Boyes, & Loening-Voysey, 2016). Studies sometimes also ask about mental health symptoms (Nguyen et al., 2019; Radford, Corral, Bradley, & Fisher, 2013), and risk behaviours including self-harm and suicidal thoughts (Nguyen et al., 2019). Some studies use household or school-based surveys, through paper and pencil format or computer-assisted self-interviews (CASI); others use computer-assisted telephone interviews (CATI) where an interviewer records the participant’s responses (Mathews et al., 2020).

Institutional Review Board Concerns about Participant Distress. As with any empirical study, researchers conducting these surveys are required to comply with relevant ethical guidelines and to discharge duties towards research participants. This applies to studies focused on identifying the prevalence and contextual characteristics of maltreatment, and to those which also measure correlations with health and other outcomes. Researchers must carefully and thoroughly complete ethical approval requirements, demonstrate the project’s scientific and social benefit, and indicate how participant welfare is supported in relation to risks that may arise through participation. However, given the importance of these surveys and the need for their performance, it is essential that Institutional Review Boards (IRBs) and human research ethics committees (HRECs) (hereafter, IRBs) do not place unnecessary restraints on soundly-designed studies, or prevent them from proceeding, based on inaccurate assumptions about risks and harms to participants. IRBs have a duty to support research that has scientific and social value. The *International Ethical Guidelines for Health-related Research Involving Humans* (Council for International Organizations of Medical Sciences, 2016, p. xii), for example, states as a core principle that “Progress towards a world where all can enjoy optimal health and health care is crucially dependent on all kinds of research including research involving humans”. These guidelines also urge that children and adolescents be involved in health-related research unless a strong scientific reason supports their exclusion (Council for International Organizations of Medical Sciences, 2016). Canada’s ethical guidelines are similar. They state that a proportionate approach to IRB review requires an “appropriate balance between recognition of the potential benefits of research, and protection of participants from research-related harms”, and maintenance of participant protection while ensuring research is not unjustifiably impeded (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council, 2018, p. 9). In sum, although IRBs must ensure participants' interests are considered and protected, research that is soundly and ethically conceived and administered, and that is of benefit to society, should not be impeded.

A major problem in research involving adolescents and health is that there is high variability in IRB consideration and application of ethical guidelines (e.g., Mammel & Kaplan, 1995; Shah, Whittle, Wilfond, Gensler, & Wendler, 2004). Leading researchers have warned against IRBs' aversion to research involving children and adolescents based on misperceptions of heightened risk associated with the indiscriminate labelling of children as a vulnerable group (Fisher et al., 2013). This same warning has been expressed about IRBs' over-cautious position regarding trauma research in general (Newman, Risch, & Kassam-Adams, 2006). Evidence suggests IRBs may adopt overly cautious or misguided positions about the risks of research through overestimating the distress participants experience through being asked to think about maltreatment-related topics, and to answer questions about personal experiences of maltreatment. In preparing for their meta-analysis studying the effects of participation in research on trauma – which largely comprised research on child maltreatment, adult sexual and physical assault, and intimate partner violence – Jaffe, DiLillo, Hoffman, Haikalis, & Dykstra (2015) surveyed 114 U.S researchers and found that 61.4% reported encountering an IRB raising concerns about asking adult participants questions about traumatic experiences. They also found that 13.3% indicated an IRB had refused to approve a research study because of concerns about the effects on participants of asking such questions. IRB hesitancy is likely to be particularly acute for studies involving children and youth.

These findings are concerning, since inaccurate assessment of risk to participant welfare and constraints on research can deprive people of the opportunity to make an informed choice to participate in child maltreatment research which is both important to them, and essential to reduce violence against children. Any inclination amongst IRBs to the unwarranted obstruction of research should be rectified by an accurate understanding of three domains of evidence and obligation. In particular, IRBs and researchers themselves should proceed upon an accurate understanding of three domains of knowledge. These include: 1) scientific evidence of the frequency, duration and magnitude of distress to participants in these studies; 2) ethical guidelines and bioethical principles as they apply to participant distress; and 3) legal duties owed towards participants in relation to distress.

Informed by this need for further clarity, consensus, and solutions, this article addresses the issue of participant distress in child maltreatment surveys. We contribute new insights based on an overview of evidence about the extent and nature of distress reported in these kinds of studies, an analysis of ethical guidelines, and consideration of bioethical and legal duties towards participants in relation to distress. This overview and our ethical and legal analyses show that these studies should be supported, and contraindicate restraint of such research by IRBs. Nevertheless, informed by ethics and law, we adopt the perspective of good practice to consider sound principles and solutions to manage distress, spanning project design features to further minimise its likelihood, and protocols to respond to distress should it occur. In doing so, we draw on existing literature and optimal practices as demonstrated by large-scale studies. Our discussion therefore responds to the call for further “discussion to arrive at common standards for collecting data on violence against children … [and for] all bodies involved in research with children to be open and transparent about how they subscribe to these standards, as well as for continued reflection and learning about what these standards should be” (Devries, Naker, Monteath-van Dok, Milligan, & Shirley, 2016, p. 160).

2. Scientific evidence about distress in survey participants

It is important for researchers and IRBs alike to understand the frequency, magnitude and duration of distress caused by surveys of maltreatment, either due to their content, or their effect of triggering memories of traumatic experiences. Here, we draw on a solid body of evidence, which is consistent in showing that surveys of maltreatment rarely cause distress for participants, whether they are adults, youth or children.

Adult participants. A meta-analysis of studies of child abuse and other trauma (such as adult sexual assault) found that although this research can lead to some immediate psychological distress, its incidence and magnitude is low (Jaffe et al., 2015). Distress is greater for individuals with a history of abuse or trauma, or post-traumatic stress disorder (PTSD), but individuals generally report that participation in research is a positive experience and that they do not regret participation, including those with a history of trauma (Jaffe et al., 2015). In a systematic review of research into child maltreatment, McClinton Appollis, Lund, De Vries, & Mathews (2015) found similar results, including that almost all participants did not regret participation; they concluded the risk-benefit ratio in asking about abuse supports the conduct of research.

In a Canadian survey of 1000 adult respondents, Fortier et al. (2021) found 4.0% (n = 40) identified child maltreatment questions as upsetting. Of these respondents, 97.5% (n = 39) felt such questions were important to ask, and 95% (n = 38) thought they should remain in the survey. Only one participant thought they should be removed. Since 53.2% of the sample reported experiencing maltreatment, most respondents with a history of child maltreatment did not report feeling upset and thought the questions should be asked. Questions to adults about their own parenting strategies were reported as more upsetting than those about their own maltreatment. In an Irish study of sexual violence, 2.9% of 3,118 adult participants reported any degree of upset during the interview, and all felt better by the follow-up call 2-3 days later (McGee et al., 2002). Moreover, only two participants' reports of distress caused interviewers concern for their immediate safety, and in these cases the safety protocol was followed with no adverse events. In addition, 81% of participants indicated they would be willing to be re-contacted for further studies. Few if any occurrences of such severe distress have been reported in other studies of child maltreatment generally (Radford et al., 2011), or of childhood sexual victimisation in particular (Massey & Spatz Widom, 2013). A review of a range of trauma studies also concluded they have a positive ratio of benefit to risk, and reported substantial personal benefits from participation (Newman & Kaloupek, 2009). These benefits included satisfaction from helping others and contributing to socially useful research, positive self-reflection, and remembering the past, even where this was not the intention of the study. Less evidence exists about child maltreatment participation from non-Western samples, but similar findings have been reported in Japan (Allard, Straus, Ra, Thomas, Kawamura, & Tosaka, 2019).

Adolescent and child participants. Studies with adolescents and children show similarly low prevalence of distress in maltreatment surveys. As with adults, even distressed youth participants mostly report their involvement was worthwhile (Laurin, Wallace, Draca, Aterman, & Tonmyr, 2018; Finkelhor, Vanderminden, Turner, Hamby, & Shattuck, 2014). In a national study of 3,614 adolescents aged 12–17 years about sexual abuse, physical abuse and assault, witnessing parental violence, other stressful events, and mental health symptoms, 5.7% of participants (n = 204) reported finding any questions distressing (Zajac, Ruggiero, Smith, Saunders, & Kilpatrick, 2011). Only 0.2% of participants (n = 8) remained upset at the end of the interview, and less than 0.1% (n = 2) wished to speak to a counsellor.

Finkelhor, Vanderminden, Turner, Hamby, & Shattuck (2014) analysed distress among 2,312 participants aged 10–17 years in the second U.S. National Survey of Children's Exposure to Violence. This study employed the Juvenile Victimization Questionnaire (JVQ), a well-established instrument validated and used in multiple studies worldwide (Mathews et al., 2020). Participants were asked, "Overall, did answering the questions in the survey upset you?". Those answering yes were then asked: "How upsetting were the survey questions?" and provided responses using a 4-point scale (not very upsetting; a little upsetting; pretty upsetting; a lot upsetting). Of all participants, 4.6% (n = 104) reported being at all upset, with 26% of these saying the questions were "not very upsetting", and 49% saying they were "a little upsetting". Almost 90% of participants who reported exposure to rape or other extremely serious events did not report any upset. Only 0.8% of all participants (n = 19) reported being "pretty or a lot" upset by the questions, and even this did not unduly affect their reported willingness to participate. Almost all (95.3%) of the 104 youth reporting any level of upset said they still would have participated knowing now what was in the survey. Few participants 0.3% (n = 7) reported being both upset and that they would not participate again; one of these participants said they would not participate again because of the nature of the questions asked, while six said the reason was that the survey was too long.

In a study in the U.K. using the JVQ, Radford et al. (2011) found a slightly higher rate of distress (7.9%) in a sample of 2,275 adolescents aged 11–17 years. The prevalence of distress among youth was almost identical to that reported by parent proxy interviewees (7.4%).

Moreover, 95% of the distressed children said participation had still been worthwhile. A study in South Africa asked different questions about distress in a study of 3,264 children aged 12-15 years (McClinton Appollis, Eggers, De Vries, De Vries, Lund, & Mathews, 2020), and found that 12.3% reported feeling any distress (sad, angry or upset) without further details about its severity or intensity; in this study, a slightly higher proportion (14%) indicated they would not have participated again. Four participants required support, and this was reportedly about situations of risk rather than acute distress.

A Canadian study considered similar questions with 382 youth aged 14-17 years receiving child protection services (CPS), who were asked about maltreatment and trauma symptomatology (Waechter, Kumanayake, Angus-Yamada, Wekerle, Smith, & the MAP Research Team, 2019). The researchers employed a seven-point scale ranging from 0 (not at all) to 6 (a lot) to measure participants' research reactivity. The mean response to the statement: "Completing this questionnaire upset me more than I had expected" was 0.91. The mean response to the question: "How distressing did you find these study questions" was 2.18. Participants with more severe maltreatment histories and more severe symptomatology reported greater distress; however, they also reported greater benefit from participation, and were even more likely to still have agreed to participate had they known in advance how they might feel as a result of participating. The researchers concluded the risk-benefit ratio in such research was maintained even for this sub-population, and that study outcomes were consistent with previous findings that "extraordinary precautions are not generally needed for studies with CPS-involved adolescents as the risk-reward balance is favourable" (p. 7).

The Child Protection Monitoring and Evaluation Reference Group (2012) cited two studies in suggesting more problematic results, but even these found low prevalence of upset, and unknown reasons for reported upset. Of note, in a study of physical abuse, sexual abuse, drug use, and suicidality, 70.4% of participants reported being “not at all” upset, 15.4% “rarely” upset, and only 3.0% of high school student participants reported being “often” upset (Langhinrichsen-Rohling, Arata, O‘Brien, Bowers, & Klibert, 2006). Reasons for being upset were not considered, but the authors concluded the impact of the maltreatment questions appeared “relatively minor…[any] increased distress level might be more a function of the experiences these adolescents have endured than the survey … Overall, youth generally reported little distress”.

There are limitations in this evidence. Research into distress has rarely employed designs to consider causality or long-term effects (Jorm, Kelly, & Morgan, 2007), or social desirability factors that could inhibit revelations of distress. Studies have seldom considered a range of reasons for distress in order to distinguish emotional upset related to recall of trauma or the nature of the questions, from other remediable factors such as the length of the interview, concerns about confidentiality, or interviewer type. Moreover, the benefits of research participation are under-researched. As well, there is little comparative literature about how much distress is caused by participating in surveys about topics that are presumed to be less distressing, such as political attitudes, or, in the case of child and adolescent participants, other everyday experiences such as going to school, visiting a doctor, and watching videos and news. As a result, the standard for judging distress within the context of research studies should not be compared to an assumption of 0% distress for other daily experiences, but what may be moderate and acceptable levels of distress for such experiences.

Accepting these limitations and the desirability of further research, the best available evidence indicates a small minority of those who participate in surveys of child maltreatment experience distress. This has been shown in samples of adults and youth, including youth involved in the child protection system. Moreover, even where distress is experienced, it is unlikely to be intense or lasting, and studies have consistently found that participants provide positive responses when asked if they would participate in further studies or would have participated had they known the questions (Finkelhor et al., 2014; Waechter et al., 2019). Furthermore, to the extent that research has identified any levels of distress, it is not clear whether this exceeds the level of distress experienced in normal everyday activities. Accordingly, research teams and IRBs can reasonably proceed on the basis that in these studies, participant distress will be infrequent and of minimal gravity. This supports the conclusion by Newman & Kaloupek (2009, p. 600) in their review of the benefits and risks of trauma research that "extraordinary precautions are not warranted for trauma-related studies in general… [although this] does not preclude the need for careful attention to ethical issues in research planning and execution". Nevertheless, researchers can still ensure they comply with ethical and legal guidelines and evidence of good research practice in order to both minimise the likelihood of distress, and to respond appropriately and sensitively to different levels of participant distress when they do occur.

3. Ethical guidelines and bioethical principles: researchers' duties in relation to participant distress

Ethical guidelines. Principles in major ethical guidelines for research demonstrate that child maltreatment studies should be supported by IRBs, provided that standard requirements are met. Common principles can be seen in these guidelines, as set out for example in Canada (Canadian Institutes of Health Research et al., 2018), Australia (National Health and Medical Research Council, 2018), and the United States (United States Department of Health and

Human Services, 2018), and by international guidelines about health-related research (Council for International Organizations of Medical Sciences, 2016).

National ethics guidelines are consistent in their articulation of fundamental principles required of all research involving human participants. The core principle is that the likely benefit of the research must justify any risks of harm or discomfort to participants (e.g., National Health and Medical Research Council, p. 10; Canadian Institutes of Health Research et al., 2018, p. 23; U.S. Code of Federal Regulations §46.111(a)). The U.S. Code 46.111 requires that "risks to subjects be minimized by using procedures consistent with sound research design and that do not unnecessarily expose subjects to risk" and that "risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result." Risk assessment requires not only the identification of potential harm and discomfort. It also requires estimation of its probability, severity, and magnitude; identification of how such harm can be managed; and determination of whether any such risk is justified by the potential benefits of the research.

Ethical guidelines mirror bioethical principles. Acknowledging broader principles of bioethics may further inform analysis of the merits of research, as well as assisting in resolving ambiguities that may arise in the application of institutional ethical guidelines. The national research ethics guidelines outlined above seek to support research, while observing three fundamental ethical principles of respect for persons, justice, and beneficence. These mirror the core bioethical principles of autonomy, justice, and beneficence and non-maleficence (Beauchamp & Childress, 2018).

As applied to the topic of participant distress, the relevant bioethical principle is beneficence, sometimes referred to in the guidelines as welfare. Beneficence requires that the benefit of research as a whole justifies any risk of harm; it requires researchers to design research to minimise risk of harm, and it makes researchers responsible for participant welfare (National Health and Medical Research Council, p. 10-11; Canadian Institutes of Health Research et al., 2018, p. 7-8. As expressed by Canada's Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2018, p. 22), "The principle of Concern for Welfare imposes an ethical obligation to design, assess and conduct research in a way that protects participants from any unnecessary or avoidable risks." Australia's guidelines express this principle of responsibility or participant welfare similarly, again as part of the obligation of beneficence (National Health and Medical Research Council, p. 11). National ethics guidelines typically also state it is the responsibility of institutions and researchers to be aware of legal requirements applying to their research (e.g., National Health and Medical Research Council, p. 8) (Box 1).

Box 1: Common ethical guidelines and principles

1. Research serves fundamentally important purposes of benefitting society and advancing human interests.
2. Researchers require sufficient freedom to conduct research to fulfil this purpose.
3. Research must be conducted in an ethical manner.
4. To be ethical, the potential benefits of research should outweigh the risks.
5. Benefits of research include social benefit, advancement of knowledge, and any benefit to participants.
6. Risks of social survey research may exceed "minimal risks" such as inconvenience, by extending to diverse harms (e.g., social, psychological); these should be assessed from the perspective of participants, considering their magnitude, seriousness, and probability.
7. Core values underpinning ethical research include respect for human beings; justice; and beneficence.
8. Respect for human beings requires respect for autonomy (self-rule), privacy, and confidentiality, and requires research to be undertaken with informed consent.

9. Justice requires people to be treated fairly and equitably, with equal concern and respect, without exploitation, and to be appropriately included in research.
10. Beneficence requires the benefits of research to justify any risk of harm, requires the research design to minimise risk of harm, and entails researcher responsibility for participant welfare.
11. Researchers are also responsible for being aware of legal rules, and should seek to comply with these rules.

Interpretative challenges. Interpretative challenges arise in considering how these ethical guidelines – and particularly the principle of beneficence, as relevant to participant welfare – translate to researchers' duties towards participants in relation to distress. This is because guidelines set out general principles, leaving leeway for interpretation and application depending on the nature of the research study, the requirements of local ethics committees, legal obligations, and tensions that may arise between competing ethical principles. The guidelines acknowledge their application is not always clear. Canada's Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2018, p. 10) declares, for example, that: "Evaluating the ethics of research involving humans is not, and cannot be, an exact science. The interpretation and application of the articles and principles to particular circumstances will always be a part of the exercise". Similarly, the Australian Guidelines (National Health and Medical Research Council, p. 10) recognise that application of ethical guidelines requires "deliberation on the values and principles, exercise of judgement, and an appreciation of context". Even the core principle that research is ethically acceptable only if its benefits justify the risks requires best estimates of both benefits and risks, informed by knowledge of the context, measures that can be taken to minimise and manage risk, and overall value judgments (e.g., National Health and Medical Research Council, p. 11, 14).

The need for this operational leeway is consistent with the recognition in bioethics that these principles are not hierarchical, but are mutually important, require implementation according to the circumstances, and may involve a degree of reliance on value judgments which intrinsically involve subjectivity (Beauchamp & Childress, 2018). Just as ethical guidelines sometimes cannot provide a simple answer to the benefit-risk calculation, established theories of bioethics do not give paramountcy to any single principle. Instead, they acknowledge that as moral principles, they can be overridden by a competing principle. Situations where ethical principles and interests may conflict will require principle-based consideration. Resolution of such conflicts requires a process of constrained balancing of harms and benefits, and judgment about the respective weight to be ascribed to particular interests in the circumstances (Beauchamp & Childress, 2018). While value judgments are inevitably made when determining which interest prevails in situations of conflict, this deliberative process should be based on principles and rigorous reasoning to avoid arbitrariness and partiality. Resolution of such tensions can also be informed by consideration of legal requirements.

Surveys of child maltreatment are ethically merited, while satisfying participant welfare and beneficence. On an application of ethical guidelines and bioethical principles, it is relatively clear that the principle of beneficence and the derived interest of participant welfare means researchers in surveys of child maltreatment do owe participants an ethical duty to take reasonably practicable steps to minimise the likelihood of significant distress, and to appropriately manage distress that may occur. However, consideration of any conflict between ethical interests – such as the interest of protecting participant welfare while promoting sound research – must engage principle-based analysis and rigorous evidence-based reasoning, which in turn must be informed by scientific evidence. In sum, an IRB undertaking a principled and rigorous approach to assessing the salience of risk through potential participant distress in these surveys is obliged to consider the best available evidence about the frequency, magnitude and severity of distress experienced by survey participants, as well as the research design in the proposed study.

Our ethical analysis reaches three conclusions in relation to participant distress, based on the best available evidence. First, the principle of beneficence and its derived concern for participant welfare can clearly be satisfactorily upheld in surveys of maltreatment. Second, while it is prudent and ethical in the interest of participant welfare for researchers to consider measures that can further minimise and respond to such risks, and hence ensure the benefit-to-risk ratio of the research remains clearly acceptable, we find strong support for the conclusion expressed elsewhere that protection of participants in these studies does not require “extraordinary precautions” (Newman & Kaloupek, 2009; Waechter et al., 2019).

Third, experience has shown that researchers’ ethical duties towards participants are discharged in these surveys through several mechanisms, including informed consent, appropriate design of questions, sound administration methods, and trauma-informed responses and support. Leading researchers have aimed to maximise participation and the public benefit of the research, while promoting participant autonomy and agency. Yet, they also promote positive beneficence towards participants, including in studies involving minors, by further minimising the likelihood of significant distress and embedding sound management responses to rare incidents. Major studies adopting this approach include the Developmental Victimization Survey (Finkelhor et al., 2005) and the National Surveys of Children’s Experience of Violence in the U.S. (Finkelhor et al., 2015), the U.K. study by Radford et al. (2011), and the Longitudinal Studies of Child Abuse and Neglect in the U.S (Amaya-Jackson et al., 2000; Knight et al., 2006). In Part 5, we will distil these principles, but first we will add to the ethical analysis by including a novel analysis of researchers’ legal duties towards participants.

4. Legal rules about researchers' duties in relation to participant distress

As seen above, ethical guidelines require researchers to be aware of applicable legal rules, and to seek to comply with them. Both IRBs and researchers need to understand the nature and extent of legal duties towards participants in relation to distress. Identification of any such duties towards participants requires analysis of legislation and case law, using legal research methods. These analyses when applied in the context of national surveys in federated countries can be complex because laws may differ across multiple regions. The literature reveals few analyses of how legal duties apply to researchers (Mathews, 2021). There is no research providing comprehensive guidance across all jurisdictions about the nature of legal duties borne by researchers towards survey participants in relation to distress. However, a recent analysis in Australia identified the legal duties borne by researchers towards participants in child maltreatment surveys, including those in relation to distress (Mathews, 2021). This was conducted to inform sound approaches in a new national study (Mathews, Pacella, Dunne, Scott, Finkelhor, Meinck, et al., 2021), and involved extensive analysis of legislative principles and case law about the law of torts (civil wrongs) and its sub-branch, the law of negligence and the duty of care, across multiple states and territories.

The questions posed in Mathews (2021) about the legal duty of researchers in relation to participant distress were: (1) do those conducting a research study about child maltreatment and health owe a legal duty of care to survey participants? (2) If so, what is the scope of that duty? (3) If so, what must be done to discharge that duty? The full analysis is in Mathews (2021), but in relation to distress, four important conclusions can be distilled as follows. First: the law is uncertain in this field and so the existence of a duty of care in this setting is debatable, but on a conservative interpretation of legal principles, researchers do owe a legal duty of care to survey participants. Second: however, the scope of such a duty is not to prevent or insure against all possible harm, but to take reasonable care in response to reasonably foreseeable risks of significant harm, considering the nature, probability and likely seriousness of such harm. Third: to discharge this duty, it is sufficient for the researchers to adopt a strategy broadly consistent with standards of best practice in the field – which can be defined as standards widely accepted by peer opinion as competent professional practice (Mathews, 2021) – and to embed survey design and administration principles that sufficiently minimise the likelihood of harm to any participant.

The fourth conclusion is even more significant for practical purposes. The law is clear that the experience of distress, by itself, is not legally actionable; that is, simply experiencing emotional distress does not make the person who allegedly caused it legally liable. The key case law authority is *Tame v New South Wales* (2002) 211 CLR 317, where the High Court of Australia stated that apart from in exceptional circumstances, a person is not liable in negligence for being a cause of distress, alarm, fear, anxiety, annoyance, or despondency, without any resulting recognised psychiatric illness. A core policy reason for this legal principle is to avoid the potential for indeterminate and unpredictable liability for minor injuries. The law in Australia is therefore that mere distress is not legally actionable.

Similar legal principles in multiple countries prevent liability for mere distress. The Australian law on distress is mirrored in multiple other countries in the common law world, including the United Kingdom, Canada and the United States. These legal principles are significant because the common law system underpins around one third of all legal systems, and forms part of mixed common law and civil legal traditions in a further large majority of all global legal systems. While specific jurisdictions can have different approaches, core common law principles tend to characterise the nature of individual duties and entitlements across locations. In the United Kingdom, the law is settled that “mere distress, anxiety and heightened emotional reaction are insufficient to satisfy the test of material damage” (*Page v Smith* [1996] 1 AC 155, 189). In Canada, to be eligible for civil compensation for mental injury, a person must show a serious and prolonged mental disturbance beyond the ordinary anxieties and fears accompanying life in civil society: “The law does not recognize upset, disgust, anxiety, agitation or other mental states that fall short of injury… minor and transient upsets do not constitute personal injury” (*Mustapha v Culligan of Canada Ltd* [2008] 2 SCR 114, [9]). In the U.S., the situation varies by State (Kircher, 2007), but is broadly similar to Australia, the UK and Canada. The capacity to sue for negligent infliction of emotional distress has strong limits, again justified by the policy requirement to avoid indeterminate liability for trivial injury (*Consolidated Rail Corporation v Gottshall* [1994] USSC 30; 512 U.S. 532, 545. These limits would rule out legal liability for distress in survey situations.

5. Managing participant distress: good practice

The discussion above has shown there is no legitimate impediment to ethical approval of surveys of child maltreatment. However, it remains prudent and ethical to adopt good practice and a trauma-informed approach (Campbell, Goodman-Williams, & Javorka, 2019), to consider strategies to further minimise participant distress, and to manage any instances. This management strategy accommodates a tactical spectrum from minimisation of distress via sound project design, through stepped responses to different levels of participant distress.

5.1 Further minimisation of participant distress through study design features

Several studies have reported various study design features that further minimise the likelihood of distress (Amaya-Jackson et al., 2000; Finkelhor, Hamby, Ormrod, & Turner, 2005; McGee et al., 2002; Nikolaidis et al., 2018; Radford et al., 2011), and many of these have been reiterated elsewhere (Finkelhor et al., 2016; Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013; Meinck et al., 2016). Some strategies vary depending on the age of participants (e.g., children vs adults) and administration mode (e.g., hard copy vs CATI or CASI). However, we can synthesise these strategies here in the following principles.

1. **Use of a valid and reliable, non-aversive instrument**. A range of instruments to measure maltreatment and other frequently assessed characteristics such as health have been proven over time and through psychometric testing, with further empirical analysis showing they elicit no to low distress. These include the ICAST-C (Meinck, Murray, Dunne, Schmidt, & the BECAN Consortium, 2020; Neelakantan, 2020) and the Juvenile Victimization Questionnaire (Finkelhor et al., 2005; Hamby, Finkelhor, Ormrod, & Turner, 2005). Use of such proven measures is more likely to further minimise distress than use of a new and untested instrument.
2. **Sequencing of survey questions and framing of questions**. Survey sections can be sequenced so that questions about phenomena which may inherently be more difficult, such as those about sexual abuse, and suicidality, are neither first nor last, and instead are preceded and followed by sections about less intrusive phenomena. In addition, more difficult questions are likely to be less distressing if using behaviourally-specific questions with a Yes/No response, rather than asking for a narrative response.
3. **Employing professional interviewers**. Where possible, a study should employ interviewers who are skilled in administering surveys about personal topics, and who possess the required interpersonal skills to establish rapport and employ warmth and patience. However, interviewer characteristics may also be customised to the local setting; for example, young children may respond to younger interviewers, participants may prefer interviewers of the same sex, and participants from selected ethnic or

linguistic groups may respond more positively to interviewers of the same ethnicity or language. Conversely, participants may request interviewers of a different sex, or from a different ethnic group, so variation be required within study settings.

4. **Providing customised training to interviewers about the survey**. This should include content and resources about how to administer the questions sensitively, especially those about sexual activity and health risk behaviours such as self-harm and suicide. It should also include material about how to respond to lower-level distress to reduce the likelihood of its escalation, and how to respond to higher-level distress. Training should be accompanied by a manual and resources to which interviewers can refer throughout the study, and these should ideally be designed in collaboration with the interviewer agency and/or in consultation with the interviewers.
5. **Testing the instrument with a local sample**. As is good practice for most surveys, cognitive testing with a sample of the target population is important to establish face validity and cultural and linguistic appropriateness, to consider the acceptability of specific questions, and sensitive sequencing of survey sections. Similarly, testing with an advisory group of participants with lived experience of maltreatment can be beneficial.
6. **Inclusion of research team staff with required expertise**. As with all health-related research, as part of the process of providing informed consent to participate, participants should be informed about the following: 1) the nature of the study, 2) the names and affiliations of those responsible for the study; 3) the funding body, and 4) confirmation of study ethics approval with the name and affiliation of the IRB. The research team should ideally include staff with psychological and or medical qualifications, as well as researchers with sufficient expertise.
7. **Inform the participant their responses are confidential**. Participants should be reassured as part of the informed consent process that their identity and responses are

confidential and will not be released to anyone, save for exceptional circumstances where necessary to protect them from danger. The circumstances of such potential danger will vary, depending on the sample and the specific nature of the study. The interview should be conducted in a private place or under circumstances where the participant can provide responses without being heard or seen by others, and administration mode should align with cultural preference. In some modes (e.g., CATI), the participant may be asked to select a safe time to complete the survey. Participants should be assured they can stop the interview if it becomes unsafe to continue, and another time can be arranged if they wish.

8. **Reassuring participants they may withdraw their consent at any time**. As with all surveys, this should be done at the outset when providing participants with all relevant information before they provide informed consent. The mechanics of withdrawal may differ according to administration mode. Information should be included to explain at the outset that the survey deals with child maltreatment, although it can be advisable to introduce the study as being about childhood experiences and related topics such as health and family relationships.
9. **Reassuring participants they may choose not to answer questions**. Again as part of the informed consent process, participants should be reassured they can choose not to answer any question they do not wish to answer. As well, before sections of the survey containing questions about more difficult topics, participants should be reminded they can choose not to answer specific questions.
10. **Providing information about support agencies**. Information about support agencies can be provided so that any participant can seek external support or counselling. The type and number of such agencies will vary according to the sample, study type and context. The mechanism for providing this information may also vary. Depending on the mode of administration, the sample, and other practicalities, this could be done by providing the

information at the outset to all participants verbally or in written information, or by making the information clearly available on a website to which all invited participants are referred. In addition, at parts of the survey that may be more likely to be distressing – e.g., those about sexual abuse – interviewers could be instructed to be alert to signs of distress and to offer information to all participants about these agencies at that stage in the interview, before proceeding further. All participants could also be asked at the end of the survey if they would like these contact details to be provided directly.

11. **Designing the sample to avoid or minimise unnecessary inclusion of participants who may be extremely vulnerable**. In general, all individuals should have the opportunity to participate in research that affects them, including those in marginalised sub-populations. However, in exceptional circumstances a particular sub-sample may be at extreme risk of distress or traumatisation.

A note on children and consent. It is useful to make a brief observation about children's capacity to consent, given occasional confusion about this. We have already shown that children's participation is not associated with significant distress, and the developmental literature indicates this is consistent with their capacity. In their authoritative review of developmental evidence in cognitive, psychosocial, and neurobiological domains, Steinberg & Icenogle (2019, p. 34) emphasised that cognitive decision-making capacity in "cold" settings – those allowing "unhurried deliberation in the absence of emotional arousal" – is mature by age 16. They concluded adolescents aged 16 years should therefore be legally recognised as having capacity to make decisions about matters reliant on cognitive processing in these situations. Indeed, they expressly specified that settings in which this age threshold is appropriate include the decision to provide consent to participate in research, and decision-making in medical and legal contexts. This is consistent with the developmental literature about decision-making in general (Albert & Steinberg, 2011; Steinberg & Icenogle, 2019). It is also consistent with legal rules in common law nations about medical decision-making (Mathews & Smith, 2018), although other nations may have different legal approaches.

This conclusion does not rule out even younger children having sufficient cognitive capacity in such settings for diverse purposes. Elsewhere, Steinberg has concluded cognitive capacity is attained earlier than 16 (e.g., Albert & Steinberg, 2011). These findings are consistent with research over many years showing that children much younger than the age of majority are developmentally able to provide their own consent to health treatment and research (e.g., Susman, Dorn, & Fletcher, 1992; Wendler & Shah, 2003). They are also consistent with research finding that IRBs support adolescent consent to survey participation (Mammel & Kaplan, 1995), and guidelines from major advocacy bodies (Santelli et al., 2003). Numerous surveys of the prevalence of child maltreatment have obtained the child’s consent only and have not sought parental active or passive consent; many others, especially those conducted in schools, obtain the child’s active consent, and seek passive parental consent by informing the child’s parent about the study and giving them the option to actively refuse participation (Carroll-Lind, Chapman, Gregory, & Maxwell, 2006; Mathews et al., 2020).

5.2 Responding to distress through strategies for implementation and protocols

As shown above, distress is experienced by a small minority of survey participants, and a range of measures can be implemented to further minimise its likelihood. Additionally, protocols can be developed so that interviewers and the research team respond appropriately to any distress that does occur. Major studies have considered these challenges and developed similar strategies (Finkelhor et al., 2005; Knight et al., 2000; McGee et al., 2002; Meinck et al., 2016; Nikolaidis et al., 2018; Radford et al., 2011). While there is little research evaluating the benefits of these strategies and any potential negative effects, they are the product of multiple research teams' thoughtful efforts to create strategies for different levels and types of distress that may occur. This range of strategies can be summarised as follows:

1. **Design written protocols**. Protocols for dealing with distress should be detailed and recorded in writing. An example of this is seen in the LongSCAN report of their approach to situations of distress in a study of 12-year-olds (Dawes Knight et al., 2006, p. 769-70).
2. **Build interviewer capacity**. Where interviews are conducted by interviewers (rather than through self-administration), those conducting interviews should be trained in how to implement the protocols, and in how to recognise distress.
3. **Include a stepped approach in the protocol to enable appropriate responses to minor distress**. When responding to minor distress, shown for example by verbal or non-verbal cues, interviewers should acknowledge the response, support participants through empathic listening, and respond as appropriate to the level, duration and type of distress. For example, minor and temporary distress (such as momentary upset) may require simply a supportive and empathic comment, a pause and enquiry to make sure the participant is able and willing to continue, and a reminder they can skip any questions.
4. **A stepped approach also enables appropriate responses to significant distress**. If significant distress is present and ongoing (e.g., if the participant is crying), the interviewer should ask if the participant would like to stop the interview, and if so, whether they would like to reschedule, or withdraw participation. If consent is not withdrawn and the participant would like to reschedule, the interviewer and the participant should discuss suitable times for completion, provide contact details for support agencies, and offer a follow-up call or contact. If the participant withdraws consent and wants to end participation, information should be given about contact details

for support agencies, and a follow-up call or contact should be made. If a participant is in extreme distress and indicates a need for immediate further support, the interviewer should remain in contact with the participant while a dedicated member of the research team arranges provision of appropriate professional support.

5. **Follow-up calls or contact**. Most studies use a follow-up call or contact method in pre-designated situations as a means of supporting participant welfare, while taking care not to be over-intrusive and infringe privacy. Approaches differ regarding the circumstances in which follow-up calls are needed, influenced by the nature of the sample (e.g., adult vs child) and survey mode. At the far end of this spectrum, the study by McGee et al. (2002) provided follow-up calls to every participant whether or not they exhibited any distress. This is unusual, and may be explained by that study's detailed examination of sexual violence. The literature has not comprehensively recorded outcomes of follow-up call approaches (Finkelhor et al., 2016), but it seems few participants require follow-up calls for distress, or themselves contact support agencies. In the UK study by Radford et al. (2011), 0.6% of the young people (n = 35) asked for follow-up contact from support agencies. Studies in low- and middle-income countries may tend to employ social workers, community support workers, or therapists to respond to distress-related needs (Meinck et al., 2016). While its appropriate form may differ according to context, a suitable approach to such follow-up is an important part of participant welfare. For surveys of child maltreatment, we would suggest a follow-up call or contact should be provided to any participant who shows significant or ongoing distress, and to any participant who requests one; and should be offered to all participants at the end of the interview.

6. Conclusion

Surveys of the prevalence and nature of child maltreatment make vital contributions to knowledge, and are essential to inform health and social policy to enhance prevention. The need for these studies continues, both in countries where the evidence-base may be lacking, and elsewhere to chart trends over time and consider the impact of policy intervention on children's lived experience. Our analysis has demonstrated that surveys of child maltreatment, administered in various modes and with both adult and youth samples, do not present undue risk of participant distress, and can be designed to adequately safeguard participants' welfare, consistent with both ethical and legal frameworks in the local setting. Furthermore, common operational principles can guide all studies, even though each study's sample, administration mode and survey content have implications for specific measures that can be used to further minimise distress and support participants in managing any trauma-related distress. This analysis and synthesis of solution-based operational principles may assist in informing future studies, and their consideration by IRBs. The implications of our discussion apply to epidemiological and correlational studies, as well as the much-needed intervention studies they can best support (Berthelot, Lemieux, & Maziade, 2019). Our findings may also inform directions for further research about the effects of participation in studies of maltreatment and other trauma.

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