

Ethical gaps in conducting research among adult survivors of child sexual abuse: A review

RADHIKA K, MANJULA M, JAISOORYA TS

Abstract

Although there have been numerous studies, especially in the last few decades, on the impact of child sexual abuse (CSA) on adult survivors, there is a dearth of studies focusing on the ethical aspects of research in this area. Against this background, we reviewed the literature published between January 2000 and December 2016 on the reporting of ethical guidelines followed in research on adult survivors of CSA. We conducted a PubMed (MEDLINE) and Google Scholar search to find published research, using the keywords: "child sexual abuse", "adult survivors", "research", "guidelines" and "ethics". Our findings suggest that no particular assessment method is superior in terms of disclosure of information or reduction of distress. The use of developmentally appropriate educative materials, sensitisation, and debriefing sessions have shown some benefit in reducing distress. There is a lack of legal or social consensus on mandatory legal reporting of information provided by adult survivors of sexual abuse, with most researchers working on the premise that adults have the freedom of choice. Often, a constraint among researchers is the lack of structured training or supervision in sensitive research, which may negatively impact both the participant and the researcher. Institute ethics boards and institutions currently lack the framework to consider protocols and facilitate research, and this poses serious obstacles to fostering research. In this situation, ongoing research needs to focus on ethical aspects. Together with this, we recommend certain ethical practices drawn from various studies that may be employed for participants, researchers, and institutional ethics boards.

Introduction

Research among adult survivors of sexual abuse is considered sensitive as it falls under the category of research that intrudes into the private sphere or delves into some deeply personal experiences of the individual (1). Sensitive research,

as categorised by Lee and Renzetti in their 1993 book, falls into three broad areas: (i) intrusive threat, which deals with areas that are "private, stressful or sacred"; (ii) threat of sanction, which relates to studies on deviance and may reveal information that is stigmatising and incriminating in some way; and (iii) political threat, which refers to vested interests of the powerful in society. Medical research that is sensitive relates mostly to aspects which address sexual behaviours, deviance, abuse, violence, death, and suicide – often labelled as taboo subjects (2). Child sexual abuse (CSA) is highly prevalent in India, and across the world (3,4). Its consequences are reported to be pervasive and as adults, the survivors are relatively more likely to fare poorly in terms of academic achievement (5,6), substance use (7,8), suffer from depression and suicidality (6,9), and have a range of other negative outcomes. While there is accumulated research on the consequences (short-term and long-term), these studies rarely report on the specific ethical procedures followed when addressing the sensitivities involved. Though recent studies have reported the ethical dilemmas encountered during the assessment of children exposed to sexual abuse, there is less research on the ethical procedures followed in research among adult survivors of CSA. The lack of clear ethical guidelines may discourage research owing to the current heightened legal and social sensitivities. This will eventually hamper the development of more effective treatment protocols for this vulnerable population.

Against this background, we aim to provide a narrative review of the ethical aspects of research among adult survivors of CSA, focusing on: (i) the distress experienced by research participants and methods of addressing this distress; (ii) the obligations of researchers and research institutes; (iii) the impact on the researcher; and (iv) recommendations on ethical and procedural safeguards.

Methodology

Search strategy and selection criteria

We searched for articles published between January 2000 and December 2016 on PubMed (MEDLINE) and Google Scholar, using the keywords "child sexual abuse", "adult survivors", "research", "guidelines" and "ethics". The articles reviewed included original research, review articles, meta-analytic reviews, reports and chapters of books. Further, all published guidelines on research involving survivors of CSA were examined/hand-searched for matter pertaining to adult survivors of CSA. We could not find any articles which focused exclusively on "ethical aspects of research among adult survivors of CSA". However, a total of 48 articles dealt with aspects pertaining to adult survivors of CSA, specifically, the nature of ethical dilemmas; guidelines used in dealing with

Authors: **Radhika K** (radhika3688@gmail.com) PhD Scholar, Department of Clinical Psychology, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, INDIA; **Manjula M** (corresponding author – drmanjula71@gmail.com,) Additional Professor, Department of Clinical Psychology, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, INDIA; **TS Jaisooriya** (tsjaisooriya@googlemail.com), Associate Professor, Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, INDIA

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research on sensitive issues; and an emphasis on procedural safeguards for researchers, participants and institutions. We identified these specific aspects and included them in the narrative review. The choice of the material included was by consensus among the authors.

Distress experienced by research participants

The major concern raised consistently has been the distress experienced by the participants in research. It has been suggested that this distress could be rekindled in multiple ways. When survivors participate in research, they are said to relive the trauma they had experienced, which causes significant distress (10). The questionnaires and in-depth interviews may unleash painful emotions and memories, which, if not addressed adequately, may lead to psychological harm (11). Further, there is the argument that while exploratory research involving survivors of sexual abuse may contribute to researchers' knowledge, it may not benefit the subjects and in some cases, may actually cause harm (12,13).

There is accumulated literature on the distress involved in participating in research related to trauma/abuse. A study of the distress experienced by women survivors of trauma found that 5% regretted completing the questionnaires, while 77% did not; and 86% reported having benefited from participation in the study (14). A recent systematic review of 30 studies found that 4%–50% of adult participants reported being harmed by participation in research on their experiences of violence and abuse; 23%–100% reported having benefited and 1%–6% reported regretting participation (15).

Certain factors increase the chances of women with a history of sexual assault reporting negative emotional reactions, particularly in studies involving interviews. The factors include mood, severity of the assault, aggression by the perpetrator, self-blame and expectations of benefits of participation (16). While the experience of penetrative sexual abuse was not significantly related to discomfort in answering questions, sexual inexperience and rape myth acceptance were associated with increased discomfort. However, researchers opine that it is important to ask individuals about abuse, since the cost of not asking may have greater negative consequences (17). By avoiding probing such sensitive issues, an important mediator of current and future problems may be missed (18–21).

In addition, there is emerging evidence that participation in research may even be positive. A recent meta-analysis of 70 studies involving 73,959 participants showed that though trauma-related research can lead to some immediate psychological distress, it is not extreme. Also, individuals generally find that participating in research is a positive experience and do not regret participation, regardless of their trauma history or post-traumatic stress disorder (PTSD) (22–25). Another study reported that the reactions of participants did not differ on the basis of whether or not they had suffered CSA (26). Similarly, other studies which examined the cost-benefit ratios among adult participants in trauma-related research

in the community showed that participants rated personal benefits significantly higher than negative/unexpected emotional reactions and drawbacks of participation (27,28). Thus, the often-held view that participation in trauma-related research leads to distress among the participants might not be supported by the evidence of the majority of subjects reporting benefit (26,29–31). While pre-existing PTSD symptoms and other negative emotional states can produce discomfort among participants in research, the experience could be mediated by myths and misconceptions, which could be addressed with education and awareness programmes (32). Thus, the findings seem to indicate that it may be more pertinent to address the factors causing distress and that assessment of trauma of any kind, including sexual abuse, and such research may carry more benefits than harm.

Methods for reducing participants' distress

Studies have used various means of attempting to address the possible distress experienced by participants. Telephonic methods, paper-and-pencil questionnaires and in-person interviews are the most common methods of data collection. A study examining disclosure rates and methods of disclosure of information on sensitive topics, including sexual abuse, found no difference in disclosure rates due to the method of interview. However, participation rates were significantly higher with telephonic methods than others (in-person interview, paper-and-pencil questionnaires) (33) and participants in the "telephonic methods" group found it more comfortable to answer questions (34).

In another study, which reported paradoxical findings, participants with a history of abuse reported more distress when the survey was administered on a computer, as compared to paper-and-pencil questionnaires or face-to-face interviews. However, computer-based administration was also rated as the most preferred format by the participants (35). One of the reasons for this could be that computer-based assessment offers anonymity, while a face-to-face assessment may be inherently superior in handling the possible post-assessment distress. However, these studies have not recorded the ways in which the participants' distress impacted them during or after the completion of the study.

The use of developmentally appropriate, brief video interventions that instruct the viewers about the research and coping strategies to be used during the time of the comprehensive medical examination of children/adults exposed to sexual abuse has been shown to be helpful in reducing the distress of victims and their caregivers (36).

Obligations of the researchers and research institutes

Legal mandatory reporting of abuse is a grey area, with each country, and in some cases, each state, having different criteria for reporting abuse (37). In most parts of the world, mandatory reporting is followed in the case of survivors of CSA (14). In India specifically, the Protection of Children from Sexual Offences Act (POCSO Act), 2012 (38), aims to secure a child's

right to safety, security and protection from sexual abuse, and makes it mandatory for researchers/clinicians to report abuse if the survivors are children. When the victim is not an adult, the legal obligation of the researcher as per the POCSO Act would supersede the ethical obligation of ensuring the confidentiality of the information given by the participant. The participant needs to be informed about the legal requirements, which entail the disclosure of the information received. The POCSO Act mentions various measures to be taken to ensure that the trauma faced by the victim in the recounting of experiences is minimised.

One of the consequences of such a lack of clarity in procedures is that institutions/institutional review boards (IRBs) might discourage research on sexual abuse owing to issues of vicarious responsibility (27,39).

There is even less clarity regarding legal responsibility as far as research among adult survivors of sexual abuse is concerned, as compared to children. Reporting in a case of adult survivors often needs to be balanced with aspects of their privacy and the confidentiality of the information shared by them (40). The laws are unclear about the steps to be taken and regarding reporting of abuse disclosed in retrospect, be it in a research context or otherwise. As for adult survivors, each state/country follows different laws – some follow mandatory reporting and others leave the choice to the adult survivors themselves. Neither the POCSO Act nor other laws specifically mention the guidelines to be followed with respect to sexual abuse research among adult survivors in India.

Legally it is accepted that adults have the option of making choices. Extending it to research among adult survivors, most researchers work on the principles of autonomy. While researchers often make sure that they do everything within their power to avoid usurping an adult's right to make autonomous decisions about their life, they also see to it that the survivor becomes aware of the pertinent legal framework and avenues through which help can be sought. Though adult survivors make their own informed decision (19), this process may not be straightforward and much depends on the researchers' clinical discretion and integrity. There is a need for a collaborative discussion, in a non-threatening atmosphere, in which the participant feels free to discuss various aspects before coming to a decision. Thus, a lot of responsibility rests on the researcher's shoulders, and the extent of the role and duties of the professional in the event is left ambiguous. This is especially so when he/she is also the one providing a psychological intervention for those adult survivors in whose case there are conflicting issues of confidentiality versus reporting. The information available is ambivalent and inconsistent; thus making such decisions challenging. However, even so, there could be an exception in cases where the researcher deems that the abuser currently poses a threat to the participant/others/children, and it may be obligatory to report. Though the Indian laws have not addressed this scenario, the Tarasoff ruling of the United States of America may be considered as guidance that mandates reporting (41).

The above review clearly indicates that there is a lack of ethical guidelines/studies on carrying out research in the context of adult survivors of CSA.

Impact on the researcher

Researchers involved in trauma-focused work might have to pay an emotional toll listening to stories about trauma. This may induce emotional distress in them, especially if they have had similar experiences, thus making support, training, and ongoing supervision a requirement. This, however, may not be found in many cases (19). Another issue concerning researchers working in the area of adult survivors of CSA is vicarious traumatisation, ie, disruptions in the researcher's own schemas related to esteem, trust, control, intimacy, and safety, as a result of exposure to individuals who have undergone traumatic experiences. The risk factors for developing vicarious traumatisation are the amount of exposure to information regarding the trauma, and one's own personal history of trauma (20).

The impact of counter-transference and vicarious traumatisation among therapists who engage in research can give rise to serious consequences, such as lack of therapeutic boundaries, intense feelings of anger/other emotions towards the client, and self-doubt regarding one's own therapeutic skills which, if not identified and addressed, may lead to unethical practices (21). Often, the competency of the researcher in interviewing and providing any service/information to survivors of CSA may not be adequate, which may lead to more damage than benefit (42,43).

In the absence of training in ethical aspects and research competencies, researchers can themselves suffer during the course of research/therapy.

Methods used to address impact on researcher

There is an obvious need for training of researchers working with people with a history of abuse/trauma. In addition, especially early in their careers, they may require guidance to ensure adherence to ethical principles and also ensure their own well-being. However, it seems that professionals are not trained adequately. According to a study, when asked to rate their satisfaction with training in this area, most mental health professionals rated themselves as being only moderately competent (44). From the literature reviewed, it is evident that this might lead to a wide range of problems – mental health professionals might have their own attitudes, myths, and misconceptions about the issue, leading to problems in the proper identification of individuals who have suffered CSA, addressing disclosure and treatment of survivors of CSA, as well as addressing their own reactions when exposed to survivors and their experiences. In addition, the judgements made by investigators may become biased, as a result of which they may reach erroneous conclusions about allegations of CSA (15,45). The characteristics of the survivor of abuse, eg, the age and behaviour of the victim during investigation,

have been seen to influence the perceived credibility of the information among professionals (46,47). Also, insensitive procedures are often adopted due to insufficient training, despite having WHO guidelines for procedures for taking history of trauma (48,49).

Ethical and procedural safeguards used in sexual abuse research

In recent years, ethical guidelines have been published to ensure the use of ethical practices in research on sexual abuse. These standard safeguards are based mostly on expert consensus. According to the US National Research Council (50), before conducting any research on human subjects, the research protocol must be reviewed by an appropriately constituted IRB. The researcher must design an informed consent procedure that explains the costs, risks and possible benefits of participation in the research. The researcher should consider the issues of how to deal with state reporting requirements and how to reduce the trauma of the interview itself. In case information is being withheld to maintain the validity of the study, it should ideally be disclosed at the end of the individual's participation.

With respect to privacy and confidentiality, a statement such as the following should be used and explained: "What is discussed during our session will be kept confidential with two exceptions: I am compelled by the law to inform an appropriate other person if I hear and believe that you are in danger of hurting yourself or someone else; or if there is reasonable suspicion that a child, elder or dependent adult has been abused" (33).

Most of the ethical issues that arise when implementing a study protocol among children may remain relevant for corresponding studies among adults, except issues regarding consent from persons with parental responsibility. These include providing sufficient information on the aims of the study, the methodologies used, the expected results, and the potential risks and discomforts that participation in the study may entail. Additionally, the participants should be informed that they are free to abstain from participation in any part of the study at any time. All measures should be taken to respect the individual's privacy, as well as to ensure that the study has a minimal impact on the individual's physical, mental, and emotional integrity (51).

According to the guidelines laid down by UNICEF and Save the Children in the context of research with child participants (3), it is best that women researchers work with girls and women, while men researchers work with boys and men. Researchers should be prepared to handle their possible reactions if told about shocking experiences. Any kind of psychological support to the respondents should be operationalised and provided as and when required. Debriefing and ending the interview with a discussion about pleasant topics are essential so that participants do not remain focused on abusive experiences, with no time to adjust.

Ethical and procedural safeguards used in sexual abuse research in Indian studies

In a major study on child abuse carried out in India, researchers followed the UNICEF guidelines on rapport-building and the nature of questions to be asked and ensured that the participants had access to further skilled support after participating in the study, if required. No one was made to participate without first having given informed consent. Pre-defined guidelines mentioned that it was important to explain both how the research process would be conducted and what use the research would be put to when it was completed. The identities of the respondents were protected. Care was taken never to write the respondents' names on the data sheet and personal information was kept in a separate, secure place. Women researchers worked with girls and women, and men researchers with boys and men (3).

Other studies conducted in the Indian context have also taken measures to address ethical issues. For instance, a study conducted by Ravindran in 2013 (52) explored resilience among survivors of CSA (n=600 college students). A screening phase was followed by in-depth interviews (n=10). The former was preceded by a sensitisation programme in a group format. As part of the ethical considerations, the participants were offered individual/group therapeutic services or referred to the appropriate agency, if needed. Another study, too, followed a similar format (53).

Though these guidelines have been put forth, they address children and fail to account for adult survivors specifically. In current practice, many of these guiding principles are extended to adult survivors.

Discussion

The reviewed literature suggests the following. Among adult survivors of childhood sexual abuse, the experience of distress on participation in research is not universal, and even in cases in which there is distress, it is transient. Participants may actually report benefits (27,47). Sensitisation and debriefing sessions may help prepare the participant and reduce distress (54). The methods of assessment may not have an impact on distress. All methods, including paper-and-pencil, face-to-face, telephonic and computer-based, are noted to have advantages and disadvantages, and no method can be stated to be superior. There is preliminary evidence that video-based coping interventions are useful in reducing distress (43–46). There is ambiguity on legal reporting in the case of adult survivors and most researchers work on the premise that adults have the freedom of choice. In most instances, structured training and supervision of researchers are lacking, and most researchers face challenges in the process of research. This can have a negative impact both on the participant and the researcher. The guidelines for research on children exposed to abuse are the only frameworks for IRBs and administrative authorities to fall back on.

However, these findings have their limitations, as the inferences are drawn from a handful of studies. Most research studies in

the area of adult survivors of CSA do not detail the methods employed to prevent or minimise the participants' distress. This points to the conclusion that not much thought has been given to adherence to the ethical aspects in this field of study, and that there is a lack of consistency in the procedures followed in such research.

It is evident that much of the research on trauma/CSA has selectively focused on children exposed to sexual abuse and has failed to consider the significant number of adults who present with consequences of CSA in practice/research, some maybe with long-term consequences. The current practice of extending the ethical guidelines used for children to adult survivors in totality may not be meaningful. There seems to be no standardisation in the safeguards offered by individual researchers, IRBs and administrators of research institutions. Such discordance leaves clinicians/researchers/IRBs in confusion and they are reluctant to embark on or encourage research in this area. Addressing and refining the ethical aspects involved in research among this sub-group will help foster research in a climate which is minimally intrusive to the individual, and socially, culturally, and legally acceptable. Further, the lack of proper training of professionals and the lack of consistent procedures to be followed by mental health professionals during research and practice may give rise to an insensitive approach towards the survivors of CSA. These factors also result in the perpetuation of myths and misconceptions in practitioners about experiences of survivors, thus adding to the stigma experienced by individuals seeking help.

This lack of guidelines might result in (i) researchers carrying out studies without following any or adequate ethical standards; (ii) institutional ethics boards lacking the framework to consider protocols and facilitate research; (iii) institutions lacking instructions to ensure the welfare of the researcher and participants. (iv) The uncertainty of legal procedures in the background of increasing social sensitivities and media outrage may give rise to hesitation and in exceptional cases, rejection of proposals from within both IRBs and institutions. All these issues have resulted in a relatively meagre number of studies on abuse and on the ethics of trauma research (55,56). Based on what is known both from research in CSA and other trauma research, the authors suggest that the following measures be incorporated into practice.

Measures to reduce distress of participants

The following steps may be useful for reducing distress.

- Before initiating the study, there should be a brief session of psychoeducation on CSA and its effects, the need for disclosure, and the statistics to build awareness and a rapport with the participants.
- Feedback must be taken from each participant. This should be addressed as far as possible at the end of the interview as it can help the participants feel better understood.
- Handouts on the psychiatric/psychological services available should be provided to participants at the end of the session.

- Adult participants who are survivors of CSA should be given information about the availability of legal services.
- The options regarding help should be discussed and the participants should be given a choice as to whether they will take help.

Researchers' obligations/safeguards

Researchers need to ensure the following. To begin with, all research protocols should first be discussed in detail in the IRBs, and the changes suggested should be incorporated and approved before the initiation of the research project. The research protocol should include a detailed description of the ethical concerns and considerations taken into account, and the difficulties likely to be encountered while putting it into practice. Second, a detailed informed consent/psychoeducative leaflet, incorporating the risks/benefits of taking part in the research, should be prepared. Third, if a participant experiences distress, the researcher must ensure his/her safety and refer him/her to an appropriate source of help. The contact details of the researcher/nearest centre for psychological support should be made available to all participants to help deal with distress. Fourth, before the commencement of the project, researchers should be given adequate training in assessment and to increase their competence in handling the concerns of trauma survivors. Fifth, researchers should have an awareness of the legal implications of all aspects of the project, including the identification of individuals who have suffered CSA, for reporting, providing information to the client, assessment, etc. Sixth, adequate supervision of researchers should be ensured, especially in the initial years of their career. Seventh, researchers must see to it that difficult subjects are discussed among non-judgmental peer group forums, like Balint groups*, to ensure that both researchers and participants experience minimal harm. Last, it is the responsibility of the concerned institutes to respect the autonomy of the researcher and create an environment conducive to carry out ethically responsible research.

IRBs/institutional obligations/safeguards

IRBs need to facilitate research as well as safeguard the interests of the researcher and participants. The following are some of the aspects that need attention. Research protocols should have: a detailed description of the ethical concerns and considerations; informed consent incorporating the risks/benefits; a mention of the measures that the researchers have taken to keep the participants safe; and a mention of the measures intended to maintain the confidentiality of the patients' information. IRBs should have at least one member who is an expert in the subject or should have the protocol reviewed by a subject expert. Further, IRBs should ensure adequate training and supervision of researchers so that they refrain from taking up any research that violates their integrity/autonomy and ethical guidelines. In addition, all legal implications must be detailed. Finally, there should be adequate independent supervision of researchers by experts/supervisors.

Given the paucity of research, most aspects recommended here are ethical practices identified in "other trauma research" that may be extended to adult survivors for now. It is also important that in the future, the ethical aspects of research in this area be studied so that consensus guidelines may be framed on the basis of a broad framework.

Conclusion

The ethical aspects of research among adult survivors of CSA remain ill-defined. Most researchers rely on practices employed for children exposed to sexual abuse. This may be less than perfect in this age of heightened awareness and sensitivities. It is a matter of priority to draw up ethical guidelines that are sensitive throughout the entire process of research – from its conceptualisation to dissemination of findings. Moreover, mechanisms to facilitate healing and catharsis should be added to the design, thus merging concepts of caring and ethics with research (57). IRBs have a larger role to play in ensuring the welfare both of the researcher and the participant, as well as in facilitating research. Doing so will help to foster research and develop effective interventions for a large group of people who remain orphaned owing to inadequate support.

Note* A Balint group is a group of clinicians who meet regularly to present clinical cases in order to improve and to better understand the clinician-patient relationship. It focuses on enhancing the clinician's ability to connect with and care for the patient sustainably. Available from: <http://americanbalintsociety.org>. (Accessed on 2018 May 31).

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Medical case reports published in PubMed-indexed Indian journals in 2015: Adherence to 2013 CARE guidelines

RENJU RAVI, ALHAD MULKALWAR, URMILA M THATTE, NITHYA J GOGTAY

Abstract

In 2013, an independent group of researchers developed the

Authors: **Renju Ravi** (renjusravi1@gmail.com), Senior Resident, Department of Clinical Pharmacology, Seth GS Medical College and KEM Hospital, Mumbai 400 012, INDIA; **Alhad Mulkalwar** (alhad.mulkalwar@gmail.com), Undergraduate Medical Student, Seth GS Medical College and KEM Hospital, Mumbai 400 012, INDIA; **Urmila M Thatte** (urmilathatte@gmail.com), Professor Head, Department of Clinical pharmacology, Seth GS Medical College and KEM Hospital, Mumbai 400 012, INDIA; **Nithya J Gogtay** (njgogtay@hotmail.com), Additional Professor, Department of Clinical Pharmacology, Seth GS Medical College and KEM Hospital, Mumbai 400 012, INDIA.

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CARE guidelines, a checklist to standardise reporting of case reports. This study assesses adherence to CARE guidelines among PubMed-indexed Indian medical journals in 2015 and the extent of endorsement of these guidelines by the journals. Case reports published in 2015 in journals indexed by PubMed, belonging to the medical stream, currently active, and that had an impact factor were included for analysis. Case series and journals that were published from India but for another country were excluded. Total adherence score and classification of adherence as "excellent", "very good", "good", and "poor" as also adherence to individual components of the checklist were the outcome measures. A total of 162 journals were identified by the search strategy, of which 36 satisfied the selection criteria. In these 36 journals, 1178 case reports were published. We tested the association between the type of journal and impact factor with adherence by using the chi-squared test and generated crude odds ratios. All analyses were done at 5% significance. Based on the total percent score, no case report had excellent adherence,