**The known and unknown of conducting ethical research in adult survivors of child sexual abuse: A narrative review**

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**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. It is in this background that the article aims to review the existing literature between January 2000 and December 2016 on reporting of ethical guidelines followed in research on adult survivors of CSA. A PubMed (MEDLINE) and Google Scholar search was conducted in order to find published research, using the following keywords: “child sexual abuse”, “adult survivors”, “research”, “guidelines” and “ethics”. The review suggests that participation in trauma research has more benefits than the distress experienced. There is no one assessment method which is superior to others and there is ambiguity on legal reporting for adult survivors. There are serious lacunae in structured training and supervision of researchers possibly resulting in hesitation of the researchers. Similarly, institute review boards feel unequipped to take up/facilitate work in this area because of lack of clarity on ethical issues. The authors suggest the need for clear guidelines and support of Institute review boards to further research in this sensitive area.

**Key words:** child sexual abuse, adult survivors, ethical issues, perceived distress, procedural safeguards

**INTRODUCTION**

Research in adult survivors of sexual abuse is considered as 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 categorized by Lee & Renzetti (1993) falls into three broad areas a) Intrusive threat - which deals with areas that are ‘private, stressful or sacred’ b) Threat of sanction - relates to studies on deviance which may reveal information which is stigmatizing and incriminating in some way c) Political threat - refers to vested interests of the powerful in society. Medical research which is sensitive mostly relate to aspects which address sexual behaviours, deviance, abuse, violence, death, and suicide which are often labelled as taboo subjects (2). Child sexual abuse is highly prevalent in India as across the world (3,4). Consequences of child sexual abuse are reported to be pervasive and as adults these survivors are more likely to have poor academic achievement(5,6), substance use (7,8), depression and suicidality (6,9) and a range of other negative outcomes. While there is accumulated research on consequences (short term and long term), these studies rarely report on specific ethical procedures followed in addressing the sensitivities involved. Though there have been recent studies reporting the ethical dilemmas encountered during assessment of children exposed to sexual abuse, there is less research on the ethical procedures followed in research in adult survivors of child sexual abuse. Lack of clear ethical guidelines may discourage research owing to the current heightened legal and social sensitivities. This will eventually hamper development of more effective treatment protocols for this vulnerable population.

It is in this background, that the paper aims to provide a narrative review of the ethical aspects of adult survivors of child sexual abuse focusing on the following: i. Distress experienced by research participants and methods of addressing distress ii. Obligation of the researchers and research institutes iii. Impact on researcher and iv. Recommendations on ethical and procedural safeguards.

**Methodology**

**Search strategy and selection criteria**

Articles published from January 2000 to December 2016 were searched on PubMed (MEDLINE) and Google Scholar using the keywords “child sexual abuse”, “adult survivors”, “research”, “guidelines” and “ethics”. Further all published guidelines on research involving survivors of child sexual abuse were examined/hand searched to review material focusing on adult survivors. Articles focusing on research on adult survivors of child sexual abuse, and elaborating the nature of ethical dilemmas, guidelines used in dealing with research on sensitive issues; those highlighting procedural safeguards for researchers, participants and institutes were determined to be relevant. The choice of articles was by consensus between the authors. The articles reviewed included original research, review articles, metanalytical reviews, reports and book chapters. There were no ethical issues in processing this article.

**i. Distress experienced by research participants**

The major concern that has consistently been raised is the distress experienced by participants taking part in research.It has been suggested that distress among participants could be rekindled in multiple ways. When survivors participate in research they are said to relive the trauma they had experienced thereby causing 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 are arguments that exploratory research involving survivors in sexual abuse may contribute to researchers knowledge but may not actually benefit the subject and in some cases may actually produce harm (12,13).

There is accumulated research on distress involved in participating in research related to trauma/abuse. In a study on distress experienced by woman survivors of trauma found that 5% reported regret in completing the questionnaires, while 77% reported no regret and 86% reported benefit from participation(14). A recent systematic review which included thirty studies showed that 4-50% of adult participants reported harm, 23-100% reported benefits and 1-6% reported regrets on participating in research on their experiences of violence and abuse(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, assault severity, perpetrator aggression, self- blame and perceived benefits of research participation prior to participation (16). While the experience of penetrative sexual abuse was not significantly related to discomfort in answering questions, sexual inexperience and rape myth acceptance was associated with increased discomfort. However, researchers opine that it is important to ask individuals about abuse, since the cost of not asking them about it may have greater negative consequences (17). By avoiding to ask about such sensitive issues, an important mediator of current and future problems may be missed(18–21).

There is also emerging evidence that research participation may also be positive. A recent metanalysis 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 research participation to be a positive experience and do not regret participation, regardless of trauma histories or PTSD (22–25). Another study also reported that the reactions of participants did not differ on the basis of whether or not one had undergone child sexual abuse (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, scientific evidence of the often held view that participation in trauma related research leads to distress among participants might not be supported by evidence with majority of subjects reporting benefit (26,29–31). While pre-existing PTSD symptoms and other negative emotional states can produce discomfort in subjects participating in research, the experience could be mediated by myths and misconceptions which could be addressed with education and awareness programs (32). Thus the findings seem to indicate that it may be more pertinent to address the factors causing distress and 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 attempted to address possible distress experienced by participants through various ways. Telephonic methods, paper-pencil questionnaires and in-person interviews are the most common methods of data collection. A study looking at disclosure rates and methods of disclosure of information on sensitive topics including sexual abuse found no difference in disclosure rates due to method of interview, but telephonic methods produced significantly higher participation rates than other methods (in-person interview, paper-and-pencil questionnaires) (33) and participants in the former group found it more comfortable in answering the 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 paper-and-pencil questionnaire or face-to-face interview. However, the computer based administration was also rated as the most preferred format by the participants (35). One of the possible reason for this could be owing to the fact that computer based assessment may offer the anonymity while a face to face assessment may be inherently superior to handle the possible post-assessment distress. However, these studies have not recorded the ways in which participants’ distress impacted them during or after the completion of the study.

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

**ii. Obligation of the researchers and research institutes:** Legal mandatory reporting of the abuse is a grey area wherein each country, and in some cases, each state, have different criteria for reporting abuse (37). Where a child survivor of sexual abuse is concerned, in most parts of the world, mandatory reporting is followed (14). In India specifically, POSCO Act (Protection of Children from Sexual Offences - India) (2012, 2015) (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 in the case of the survivors being children. Currently the legal obligation of the researcher as per the POSCO Act would supersede the ethical obligation of ensuring confidentiality of information given by the participant when the victim is not an adult. When it is done, the participant needs to be informed about the legal requirements which entails that the information received to be disclosed. The POCSO Act mentions various measures to be taken to ensure that recounting the victim’s experiences is least traumatic.

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

Legal responsibility is even more unclear in research involving adult survivors of sexual abuse as compared to children. Such reporting in adult survivors often needs to be balanced with aspects of confidentiality of research participants and the information shared by them(40). Laws are unclear about the steps to be taken and regarding reporting of the abuse disclosed at retrospect, be it in a research context or otherwise. Regarding adult survivors, each state/ country follows different laws- some following mandatory reporting and others leaving the choice up to the adult survivor himself or herself. Neither do the POSCO Act/ other laws specifically mention considerations to be taken 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, in adult survivors, most researchers work on the principles of autonomy. While researchers often ensure to do everything within their power to avoid usurping an adult’s right to make autonomous decisions about her life, they also ensure that the survivor become 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 straight forward and much depends on the researchers’ clinical discretion and integrity. There is a need of a collaborative discussion, in a non-threatening atmosphere, where 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 psychological intervention for those adult survivors in which case there are conflicting issues of confidentiality versus reporting. There is ambivalent and inconsistent information available, and making these judgments could be trying. But even so, there could be an exception in cases where the researcher deems that the abuser poses a current threat to the participant/others/children, it may be obligatory to report. Though the Indian laws have not addressed this scenario, the Tarasoff’s ruling of the United States may be a guidance which mandates reporting (41)

The above review clearly indicates lack of ethical guidelines/studies on carrying out research in the area of adult survivors of child sexual abuse.

iii. **Impact on the researcher** - Researchers involved in trauma- focused work might have to undergo an emotional toll of listening to trauma stories, which may induce emotional distress in themselves especially if they have had similar experiences, thus making support, training and ongoing supervision a requirement, which may not be ensured in many cases (19). Another issue concerning researchers working in the area of adult survivors of child sexual abuse is vicarious traumatization, i.e. disruptions in the researcher’s own schemas related to esteem, trust, control, intimacy and safety, as a result of being exposed to individuals who have undergone traumatic experiences. Risk factors to 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 traumatization in 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, self-doubts 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 child sexual abuse 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 having history of abuse/trauma. In addition, especially early in their career, they may also require guidance to ensure adherence to ethical principles and also ensure their well-being. However, there seems to be lack of adequate training of professionals. According to a study, when asked to rate their satisfaction in training to address the issue, most mental health professionals rated themselves as being only moderately competent (44). Thus, from the literature reviewed, it is evident that this might lead to a wide range of problems –they might have their own attitudes, myths and misconceptions about the issue, leading to problems in proper identification, addressing disclosure and treatment of survivors with child sexual abuse, as well as addressing their own reactions when exposed to survivors and their experiences. Bias also occurs in the judgements made by investigators themselves causing investigators to reach different conclusions about child sexual abuse allegations (15,45). Characteristics of the survivor of abuse, e.g. age and behavior of the victim during investigation, are shown to influence the perceived credibility of the information by professionals (46,47). Also, despite having WHO guidelines for procedures for taking history of trauma lack of sufficient training often results in adopting insensitive procedures (48,49).

**iv. Ethical and procedural safeguards used in sexual abuse research:** In recent years, ethical guidelines have been published to ensure ethical practices in sexual abuse research. These standard safeguards have been mostly based on expert consensus. According to Neglect(50), before conducting any research on human subjects, it is required that the research protocol be reviewed by an appropriately constituted institutional review board. The researcher must design an informed consent procedure that explains costs, risks and possible benefits of research participation. Issues on how to deal with state reporting requirements, how to reduce the trauma of the interview itself need to be considered by the researcher. In case information is being withheld to maintain validity of the study, it should be ideally disclosed at the end of the individual’s participation.

With respect to aspects of privacy and confidentiality, a statement as follows should be used and explained: “What is discussed during our session will be kept confidential with two exceptions: I am compelled by 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 regarding the aims of the study, the methodologies used, the expected results, and potential risks and discomforts that participation in the study may entail. Additionally, each participant should be informed that the individual is free to abstain from participation in any part of the study at any time. The integrity of the participant should be respected, and 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 suggested that it is best that women researchers work with girls and women, and men researchers work with boys and men. Researchers should be prepared as to how they would react if told of shocking experiences. Any kind of psychological support to the respondents, as and when required, should be operationalized and provided. Debriefing and ending the interview with discussion of pleasant topics are essential so that they are not left focused on abusive experiences with no time to adjust.

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

In a major study on child abuse done in India, researchers followed the UNICEF guidelines on rapport building, 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 participant was made to participate without having first given informed consent. Pre-defined guidelines mentioned that it was important to explain both how the research process will be conducted, and what use the research will be put to when it is completed. The identities of the respondents were protected. Care was taken to never write respondents’ names on the data sheet and personal information was kept in a separate and secure place. Women researchers worked with girls and women, and men researchers worked with boys and men (3).

Other studies conducted in the Indian context also have taken measures to address the ethical issues. For instance, a study done by Ravindran, in 2013(52), studied resilience among CSA survivors (n=600 college students) conducted a screening phase followed by in-depth interviews (n=10). The screening phase was preceded by a sensitization 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 need felt. Similar considerations were followed in another study as well (53).

Though these guidelines have been put forth, it addresses children and failed to account adults survivors specifically, and in current practice many of these guiding principles are extended to adult survivors.

**Discussion**

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

However, the findings have its limitations, as the inferences are drawn from a handful of studies. Most research studies in the area of adult survivors of child sexual abuse do not detail methods employed to prevent or minimize participants’ distress, thus hinting that much thought has not been given to the process of ensuring ethical issues in the area, and a lack of consistency in the procedures followed in such research.

It is evident that much of the research on trauma/ child sexual abuse has selectively focused on children exposed to sexual abuse and has failed to consider the significant number of adults who present in practice/research, some maybe with long term consequences of child sexual abuse. The current practice of extending ethical guidelines used for children to adult survivors in totality may not be meaningful. There seems to be missing links between safeguards offered by individual researchers, IRBs and administrators of research institutions. Such disconnection leaves the clinician/researcher/IRB in confusion and reluctant to embark/encourage research in this area. Addressing and refining the ethical aspects involved in research for 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 impact of lack of proper training of professionals in this area and lack of consistent procedures to be followed by mental health professionals during research and practice in this field not only gives rise to possible inhumane approach towards survivors of child sexual abuse, but also results in maintenance of myths and misconceptions about abusive experiences among practitioners, and stigma around seeking help among participants.

This lack of guidelines might result in-1) Researchers carrying out studies without following any or adequate ethical guidelines, 2) Institute ethics boards lacking the framework to consider protocols and facilitate research. 3) Institutions bereft of instructions to ensure the welfare of the researcher and participants. 4) Lastly, the uncertainty of legal procedures in the background of increasing social sensitivities and media outrages may give rise to hesitation and in exceptional cases rejection of proposals from both within Institute Review Boards (IRBs) and Institutions. All these issues have resulted in lesser number of studies on abuse and fewer studies on ethics of trauma research (55,56). Given this, based on what is known both from research in child sexual abuse and other trauma research, the authors suggest that the following measures may be incorporated into practice:

Measures to reduce distress of participants: The following steps may be useful in distress reduction: 1. A brief psychoeducation on child sexual abuse and its effects, need for disclosure, and statistics to build awareness and rapport with the participant before the initiation of the study. 2. Feedback to be taken from each participant which may be addressed as much as possible at the end of the interview which can lead to participants feeling better understood. 3. Handouts regarding available psychiatric/ psychological services provided to participants at the end of the session. 4. Adult participants who are survivors of child sexual abuse should be given information about availability of legal services. 5. The choice of availing help should be left to the participants after discussing options.

Researchers Obligations/Safeguards: Researchers need to ensure the following: 1. All research protocols should be first discussed in details in IRBs and suggested changes incorporated and approved before initiation of research project. The research protocol shall incorporate detailed description of the ethical concerns and considerations taken, and the difficulties likely to be encountered while putting it into practice. 2. A detailed informed consent/psychoeducative leaflet incorporating risks/benefits of taking part in research 3. In the event of participant experiencing distress, the researcher must ensure that participant is kept safe and referred to appropriate help. The contact details of researcher/nearest centre for psychological support in the event of distress should be made available to all participants. 3. Adequate training in assessments and competence in handling concerns of trauma survivors before commencement of the project. 4. Awareness of legal implications of all aspects of the project including identification of individuals with child sexual abuse for e.g. reporting, providing information to the client, assessment etc. 5. Ensuring adequate supervision especially in initial years of career. 6. Researchers to ensure that difficult subjects be discussed among non-judgmental peer group forums like balint groups to ensure both researchers and participants experience minimal harm. 7. Lastly, a duty and responsibility in, in respecting the autonomy of the researcher and creating a conducive environment for ethically responsible research.

IRBs/Institutional Obligations/Safeguards: IRBs need to facilitate research as well as safeguard the interests of the researcher as well as participants. Some of the aspects that need attention are: 1. Research protocols need to have: detailed description of the ethical concerns and considerations; informed consent incorporating risks/benefits; measures researchers have taken to keep participants safe; measures to maintain patients’/information confidentiality. 2. Ensure adequate training and supervision of researchers to ensure that they refrain from taking up any research that violates their integrity/ autonomy/ethical guidelines. 4. Ensure all legal implications are detailed. 5. Ensuring adequate independent supervision of researcher. 6. IRBs should have at least one member who is an expert on the subject or should have the protocol reviewed by a subject expert.

Given the paucity of research, most aspects recommended here are ethical practices identified in ‘other trauma research’ which 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 to ensure a broad framework from which a consensus guideline may be framed.

**Conclusion**

Ethical aspects of research on Adult Survivors of Child Sexual Abuse remain ill defined. Most researchers incorporate practices employed for children exposed to sexual abuse. This may be less than perfect in this age of heightened awareness and sensibilities. Ethical guidelines need to be drawn as a priority which are made sensitive enough throughout the ‘entire process of research- from the moment of conceptual designing to data analysis, and from writing up to dissemination’. Moreover, mechanisms to facilitate healing and catharsis should be added onto the design, thus merging concepts of caring and ethics in research(57). The institute review boards have a larger role to play in making sure the welfare of both researcher and participants and at the same time facilitate research. Doing so will help foster research and develop effective interventions for a large group of people who remain orphaned with inadequate support.

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