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A review of the ethics in research on child abuse

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Abstract

Research on violence and abuse, particularly involving vulnerable groups such as women and children, has many ethical ramifications. There are few published reports in India on ethical guidelines and standards in this area. This paper reviews Child Abuse: India 2007, a study conducted by the ministry of women and child development, government of India.

The review highlights the need for conducting an ethical inquiry in this area. Certain concerns about the conduct of the study are raised. Core ethical issues pertaining to consent and refusal, risk and benefit, effects of the study process on the researcher and the researched and the reporting of adverse events are discussed. The ethical implications of the study and ethical responsibilities of the researcher are emphasised.

Research on sensitive aspects of human experience is invariably fraught with ethical dilemmas and questions that the researchers must grapple with. This is more so when the research is carried out with vulnerable populations such as children and when it concerns intimate aspects of the respondent's life. Research in areas such as sexual or emotional abuse involves two unique components. First, it includes the possibility that some revelations are occurring for the first time and are likely to be emotionally charged. Second, research of this nature by its very act of disclosure may involve risks for the respondent.

Research on child abuse thus becomes several things at once: data gathering, building a two-way relationship between the researcher and the respondent with some unspoken expectations, and bringing several distressing and difficult issues into the conscious awareness of the respondent. It also entails the subsequent responsibility of the researcher to publish findings in such a manner that confidentiality is preserved and the rights of the child and others are protected. The child is often too young to understand her/ his rights and the relevance of the research, is innocent about the violation of rights and interests, is suggestible and vulnerable, and therefore rendered helpless. Although ethics are integral to any research, they are more imperative in studying sensitive issues in such a vulnerable sample.

Based on this premise, we have reviewed and commented on the *Study on Child Abuse: India 2007* done by the ministry of women and child development, government of India (1), which is a bold and commendable initiative. The study aimed to

develop a comprehensive understanding of child abuse with a view to facilitating the formulation of appropriate policies and programmes and thereby curbing child abuse in India. The research was done across 13 states and it involved 2,447 children, 2,324 young adults, and 2,449 stakeholders. Children in the family environment, in school, at work, on the streets, and in institutions were interviewed. Different forms of child abuse -- physical, sexual, emotional, and neglect of the girl child -- were studied.

The major results were as follows: children in the 5-12 age group are most at risk of different kinds of abuse and exploitation; two out of three children were physically abused; 53.2 per cent of children reported having faced one of more forms of sexual abuse, with 21.9 per cent facing severe forms of sexual abuse; and 5.7 per cent of the respondents reported being sexually assaulted. Street children, children at work, and children in institutional care were found to be particularly vulnerable to sexual assault. Every second child reported facing emotional abuse, and 48.4 percent of respondents who were girls wished that they were boys. For a large number of children reporting abuse of any form, parents and those in a position of trust and responsibility were the abusers. Most children did not disclose the matter to anyone. The states of Andhra Pradesh, Assam, Bihar, and Delhi reported higher rates of abuse of all forms as compared to other states.

Concerns and recommendations

The investigators undoubtedly used a sensitive and sound methodology to survey the prevalence of child abuse in India. Every study is bound to have limitations and the study under review is no exception. We will now discuss some of the ethical concerns related to the report, the ethical implications of the study, and the responsibilities of researchers.

The report compiled ethical guidelines from various sources, which inform the reader about what should be done in conducting ethical research of this nature. It is unclear what was actually done during the investigation. Guidelines enumerate what ideally should be done, though in reality one may or may not accomplish everything and may encounter several difficulties in the process.

Issues of consent: The investigators took consent from parents, teachers, and children, as is essential in research involving minors. They assured these sources about confidentiality, anonymity, and the liberty to withdraw consent. The

investigators seem to have given the participants detailed information about the study and the information sheet referred to in the consent forms appears to have been crucial in determining consent. However, this sheet is not presented in the report's appendix, so we do not know what the participants were told about the study. It is important to know how the rationale was presented to the participants so as to ensure their consent and participation.

In addition, consent in most research involving vulnerable samples and sensitive issues is a process and not a one-shot prerequisite to collecting data from the respondents. This is because the respondent is often unclear about the questions until actually asked. Although in the beginning the option is given to withdraw from the study at any point, the researcher should check the respondent's level of comfort and desire to continue or terminate the interview. We recommend taking informed consent at every level of gathering sensitive information in such a study -- while moving from questions related to emotional abuse to the section on physical abuse and so on.

It is important to note that in Appendix 8 of the report (schedule for children), the instructions state, "Children who are smart and have rich experience will be interviewed." This deeply judgemental statement could have been avoided.

Refusal rates: Refusal rates in sensitive research are important not just for methodological reasons and interpretation, but also to indicate reticence on the part of the respondent or guardian to participate in such research. Issues related to autonomy thus form an important part of the ethics of refusal. This report does not discuss refusals to participate by the child, parent, or teacher. Is it possible that the consenting parent is likely to be the non-offending parent? Are such parents likely to be women who were giving this opportunity to their child to disclose and get help, while preserving the family's respect because they were assured that the information would be kept confidential? In such a case, by allowing disclosure the woman may be putting herself and the child at risk.

Communication of risks and benefits: It is necessary to anticipate and inform the respondents about the possible risks and benefits of participating in a study of this nature (2-5) and the 'Informed Consent Form' should reflect this. On the contrary, the report mentions that the participants were informed that the research does not pose any risk/ cost to the child. How does one guarantee this? Each participant must be given a realistic appraisal of the possible risks and benefits, though the risks involved may be less tangible and immediate in this case.

It is often felt that risks are an inherent part of drug-related or biological research and are absent or minimal in behavioural research. This unfortunately is not always true. Children are likely to risk experiencing the emotional consequences of disclosure. Their family and authority figures may be aware of the possible disclosure, which is a threat. The benefit that respondents might directly or indirectly accrue from participation also needs to be specified for them to be able to

make a truly informed choice.

Research team: In sensitive research, particularly research related to violence of any kind, training and supervision of the research staff is an important ethical issue (2-4). While the report does mention that training was offered, ongoing supervision of the research staff has not been detailed. Not only does the researcher affect the process of research of abuse and violence, she/ he may also be affected by it. The interviewers may sometimes relate to certain narratives, they too may have been abused in the past, or they may be victims of abuse at present. Repressed feelings may come to the fore, jeopardising their capacity to retain objectivity.

The interviewers may have several dilemmas about handling potentially difficult situations that need to be addressed. These situations may bring about intense emotional reactions of helplessness, guilt, anger, frustration, and sadness, which require a sounding board. Discussion with peers and supervisors often serves this purpose, and debriefing can become therapeutic/ cathartic for the staff and help them move on. Not addressing these issues may prove detrimental to the mental health of the staff and may adversely affect the quality of the data that is collected.

The meaning of abuse: Emotional abuse is a poorly defined and understood construct in India. A high rate of such abuse may be prevalent though it may not be recognised as emotional abuse. For example, many parents think that they can motivate their children to do better by comparing them with others, and children may not consider this to be abusive. Therefore, along with its presence or absence, the intensity and subjective feelings or the emotional/psychological reactions of the child to emotional abuse are important. The research staff must be sensitised to these issues to control for false positives.

Another important issue is that the child may be unaware that a particular event or experience is abuse. Often there is a thin line between acceptable and unacceptable forms of behaviour. So when the research staff conceived of some event/ experience as abuse and the child was unaware of its seriousness, what was done? This delicate issue is a double-edged sword. In disclosing reality or concealing it, both might be harmful.

Adverse events: Adverse events are as important in behavioural research as in clinical drug trials. The report does not give information about adverse events concerning the researched or the researcher. One would expect that the children who disclosed abuse were likely to have emotional consequences prior to, during, or following disclosure. Children are vulnerable and their protection in India is considered to be the responsibility of the child's family. But as the results of the study show, what if the perpetrator belongs to the same family?

The report mentions that research of this nature should have systems in place to report ongoing abuse and adverse events, but it does not mention follow up interviews with children

who disclosed abuse. These would be important to monitor the child's emotional state, possible risks, and adverse implications. The report mentions that the social worker of the school would be informed in such a case (with the child's consent?), which is advisable provided the social worker can offer protection and services. How many schools in India have visiting social workers? How often did this happen during the study?

Implications: Is it better not to open a Pandora's box when we do not yet have the resources to put things back in order? Is this more damaging than not speaking about abuse at all? Or is it important to sound an alarm to set up services to address this intense social issue? What minimal help can the research team provide to fulfil its ethical responsibilities?

The ethics of research is not just about the conduct and methodology of research; it must also ask whether the research has value for the population being researched. A dilemma that is often faced by research on violence is the extent to which the investigators should go beyond their aims and objectives. Is it the responsibility of the researcher to undertake research only if there are local provisions for monitoring and handling adverse consequences? We believe that it is. Any research on violence or abuse should provide for such services or have pre-existing liaisons with such services before embarking on a study. Studies of this nature cannot be done without intervention and follow up (4), which in fact is mandatory and ethically required.

What is reported and achieved by the investigators of this report is stage one. We recommend a stage two that addresses the ethical responsibilities towards the participants. The report will hopefully bring about changes in policy, but this may take time and effort. While trying to influence policies, one should not overlook what can be done to the affected the child participants in the study. We recommend that such research should include generating awareness about helplines, giving pamphlets about local services, and group and individual interventions with children, teachers, and families. Identifying children who may benefit from more intensive help and appropriate referrals to social workers and mental health professionals should also be considered. This might have been done, but the report does not elaborate and thus loses out on a

chance to inform best practices in this area of research.

Child protection in families: In many parts of the developed world, child abuse can be reported irrespective of the context in which it is unearthed or disclosed (4). The State subsequently takes the responsibility to safeguard the interests of the child and offer protection. As rightly reported by the authors, the study puts the issue of child protection on the national agenda. The study has furnished ample evidence and rationale for enforcing a child protection system in India. But do we have the resources of countries like the UK or Australia, where children are the State's responsibility and child protection agencies are active and ready for such eventualities? Or should we let the community and family handle these issues? When sex education in the country is facing so much opposition, what can be the role of parents and schools in at least discussing some of these issues? Patriarchy and power imbalances in relation to children, particularly female children, are so high in some parts of India that we wonder how far rules and laws will penetrate families where emotional and physical abuse is the norm.

Conclusions

Conducting a study of this nature and magnitude is a laudable task. The investigators obviously feel strongly about the issue and their research methodology is strong. The investigators have also safeguarded privacy, confidentiality, and have been sensitive to culture and gender. We have discussed several ethical issues, but the most important ethical implication will be to ensure that the envisioned child protection laws, policies, and systems soon become a reality in our country.

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