



# Research Involving Children and Adolescents in Situations of Violence: Ethical Aspects to be Considered

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## Abstract

Around the world, an alarming number of children and adolescents experience violence daily. In childhood, traumatic stress experienced early in response to violence can impair brain architecture, immune status, metabolic systems, inflammatory responses, and even genetic structure. Damages resulting from violence are related to major causes of death in adulthood, including non-communicable diseases, HIV, mental and reproductive health problems, and even suicide. Researches that directly involve victims are considered essential tools for the correct dimensioning of the problem and for the planning of actions aimed at facing violence against children and adolescents. It is fundamental to consider the ethical aspects in the design and development of such research conducted in physically, socially and emotionally vulnerable populations.

**Keywords:** Ethics, Research, Child, Adolescent, Violence

"I hope all the efforts made to create parameters and guidelines, the result of so many simultaneous voices clamoring for quality of life and under the influx of so many preventable deaths, are accompanied by consistent and necessary sectorial and intersectorial actions. The health sector, in addition to the prevention tradition, sees care as an ethos, which differs from the praxis of public security, which aims to repress crimes and misdemeanors. This tradition of care and prevention can make all the necessary and appropriate difference."<sup>1</sup>

## Introduction

UNICEF data show that every "7 minutes a child or teenager, between 10 and 19 years of age, dies somewhere in the world, victim of homicide or of some form of armed conflict or collective violence."<sup>2</sup> In 2016, in the United States, around 676,000 children

were victims of abuse, ranging from abuse to neglect or both, with more than 1700 children dying as a result of this.<sup>3</sup>

In Brazil, between 2011 and 2017, 1,460,326 cases of interpersonal or self-inflicted violence were reported in the Notifiable Disease Information System (SINAN). These data are monitored by the Ministry of Health through the Violence and Accident Surveillance System (VIVA), and are related to the cases of interpersonal and/or self-inflicted violence against children and adolescents, the elderly, women, indigenous people, people with disabilities, people who identify as lesbians, gays, bisexuals, transvestites and transsexuals (LGBTB), as well as men victims of domestic/intra-family, sexual or self-inflicted violence, and cases of human trafficking, slave labor, child labor, torture and legal intervention. Characterizing an increase of 186% in the number of notifications of this type of violence in this period.<sup>4,5</sup> Of this

Quick Response Code:



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**Received:** 19 November, 2021

**Published:** 17 February, 2022

**Citation:** Platt VB, Guedert JM. Research Involving Children and Adolescents in Situations of Violence: Ethical Aspects to be Considered. *SOJ Pediatr Clin Neonatol.* 2022;2(1):1-5. DOI: [10.53902/SOJPCN.2022.02.000514](https://doi.org/10.53902/SOJPCN.2022.02.000514)

total, 40.5% referred to violence perpetrated against children and adolescents.<sup>6</sup>

In 2018, an editorial in the Brazilian Bioethical Magazine, already warned that the high levels of violence indicated the need to fight this serious problem in our society. "Violence against children is the first manifestation of a widespread phenomenon, which affects teenagers, young people, the elderly, the disabled, women, indigenous people, the black population, migrants, and people who identify themselves as lesbian, gay, bisexual, transvestites and transgender (LGBT), especially if they also belong to the poorest social segments".<sup>7</sup>

In this sense, research in the area is essential for the problem to be properly dimensioned and, therefore, it is necessary to establish ethical guidelines for conducting research on violence against children and adolescents. These guidelines are essential to minimize the risk of possible harm to the participants, resulting from the data collection process, to guide the proper conduct of researchers, to avoid or at least reduce the social stigmatization of victims, among other aspects; and ensure that the risks inherent in research are outweighed by its potential benefits. It is worth remembering that Ethics in research and methodologies applied to research are closely linked, and ethically sound research protocols and tools add value and give credibility to the research.<sup>8</sup>

In recent years, there have been growing efforts to collect data on violence against children and adolescents, aiming to reduce gaps in monitoring, evaluation and research involving childhood and the necessary protection of people at this stage of life. However, there is still a lack of internationally recommended or agreed ethical guidelines for research involving this topic and this population.<sup>8</sup> In a literature review covering the years 2000 to 2016 in the Pubmed and Google Scholar bibliographic databases, conducted by Radhika, Manjula & Jaisoorya (2018), the authors sought to list the studies that addressed the ethical aspects of research involving the impact of sexual violence childhood in surviving adults. As a result, it was unanimous among researchers the lack of structured training or supervision in sensitive research, which can negatively impact both the participant and the researcher. They also observed a lack of protocols in institutions and ethics councils (committees) to guide the approach of research on the subject (often the approach was carried out without the necessary distinction between child victims and adult victims).<sup>9</sup>

These authors emphasize that respect for the autonomy of the research participant is fundamental, regarding the decision to speak/disclose about the sexual abuse suffered, requiring a frank dialogue between the researched and the researcher, an environment of mutual trust and free from threats and constraints, where the participant feels free to talk about several other aspects

before making the decision to participate or not in the research.<sup>9</sup> They also emphasize the importance of clinical discretion and the researcher's moral integrity, with the latter's responsibility being great, even ambiguous (in the sense that it has to be discreet, but needs information), because there are conflicting issues of confidentiality *versus* denunciation. For them, if the researcher identifies risk situations, such as those where the aggressor represents a threat to the participant, to other people, or to other children, he is obliged to report them to the competent authorities.<sup>9</sup>

Another important aspect observed by the authors was that the anguish among those surveyed (adult survivors of child sexual violence), generated by participation in the research, is not general and, when it exists, is transitory, and may not be an impediment to conducting studies on the theme. They point out, however, that the existence of informed consent and psychological support to the respondent is essential, although many researches on the subject do not make clear in the methodology which resources were used to reduce the research participant's emotional suffering.<sup>9</sup> Violence is a socio-historical event that permeates the entire experience of humanity, being recognized as a public health issue because, in addition to being harmful not only to the individual, it also strongly impacts the entire community. It is understood as urgent the development of public policies and the structuring of services minimally organized in a network to meet the distinct and specific demands generated, to prevent and face this serious social problem<sup>1</sup>. Thus, it is urgent for academia to develop research to adequately scale the problem, list early signs that can identify suspicion or recognize the different forms of violence against children and adolescents, identify especially vulnerable groups, infer about its real prevalence and identify the sequelae resulting from it, aiming to prevent them and, if necessary, treat them properly.

### Objective

List and alert, based on the available literature on the subject, ethical aspects and care to be observed by researchers in the development of research with children and adolescents in situations of violence.

### Development

Despite the dimension of the problem and the importance of research on the subject, there is a huge gap in terms of ethical norms to be observed in investigative approaches involving children and adolescents in situations of violence. In addition to divergent views among authors, it is recognized that there is little data on the nature and duration of the "emotional distress" caused by the participation of children and adolescents in research; the need for greater focus on the production of knowledge in the area and the "inconsistent" and "inadequate" state of the literature to help researchers deal with ethical problems specific to this area of research.<sup>10</sup>

In line with the ethical need to protect children from harm resulting from research, there are the principles of beneficence and non-maleficence. This argument emphasizes the importance of researchers considering the desire to safeguard children and adolescents from the possible harms of research, and therefore not carrying out it, or assuming that they are necessary and promote benefits, even if indirect or social, in terms of your results.<sup>11</sup>

The protection of children and adolescents from the harm arising from the research is a genuine concern, but an attitude that is too protectionist may imply an impediment to the right of children and adolescents to express their views on issues that concern them.<sup>11</sup>

From this consideration emerges the fundamental importance of observing ethical aspects when planning the research, namely: how will children be protected against harm, such as actions to minimize their emotional suffering when reliving the traumatic episode; the adequate consent of a responsible adult who is committed to the well-being of the child and adolescent and the expression of their agreement through assent; respect for the manifest willingness of children and adolescents not to participate or refuse to share certain aspects of the violence suffered; strict observance of actions that ensure the confidentiality of the data collected and the participant's privacy; prior knowledge of the cultural context in which the participants are inserted and the way in which the research results will be returned.

As for protection from damage, the researcher must be prepared and know how to act in view of the possibility of coming across, during data collection, with the child/adolescent's disclosure of having been molested recently or being at risk. In this situation, the ethical conflict of the decision to intervene or not is imposed. The challenge is to obtain reliable information and ensure the safety of participants and responsible assistance. In the family setting, closely linked to aggression against children and adolescents, some of the factors that contribute to the occurrence and recurrence of violence are predominantly the silence and complicity of socially and family established networks, which are often attributed to these acts against children/adolescents meanings as natural and normal. Thus, the complaint to the competent services, the damage, consequences and sanctions are underreported.<sup>12</sup> It is recognized that the number of cases of violence against children/adolescents is probably higher than those reported in official reports due to underreporting and cover-up of cases. Global statistics estimate that sexual violence against children is 30 times higher than official notifications and that physical abuse is 75 times higher.<sup>13</sup>

As for the strategies to be developed to allow the appropriate approach of children and adolescents in situations of violence, without however exposing them to socially stigmatizing situations,

it is possible to suggest: referring children/adolescents at risk to protective services, providing the participant and your guardian a list of protective services that can be used and contact the child/adolescent again after the time of research. It is essential that researchers are able to properly handle conflicting situations. Regarding informed consent, it is alerted to the fact that caregivers are often the authors of violence and that legitimate protective behavior of relatives, professors and research ethics committees, for example, can limit researchers' access to children/teenagers for fear of additional harm arising from them.

Some authors suggest the possibility of using "passive consent", where, for example, the school sends a letter to parents to ask if they do not want the child to participate<sup>11</sup>. However, such consent is not supported by Brazilian ethical regulations. For situations where the consent of those responsible may compromise the safety of the participants or improperly influence the research procedures, there is, in Brazilian ethical regulations, the possibility of "undercover research".<sup>14</sup> According to Resolution 510/16<sup>14</sup> of the National Council of Health/Ministry of Health this would be the "research conducted without the participants being informed about the objectives and procedures of the study, and without their consent being obtained previously or during the performance of the research". The Resolution itself warns that this type of research "is only justified in circumstances in which information about objectives and procedures would change the target behavior of the study or when the use of this method is presented as the only way of conducting the study, and must be explained to the Committees of Ethics in Research (CEP) the procedure to be adopted by the researcher with the participant, with regard to risks, communication to the participant and use of collected data, in addition to the commitment or not to confidentiality. Whenever it proves feasible, the consent of the participants must be sought later".

Ethical issues related to privacy and confidentiality have a special meaning in studies with children and adolescents in situations of violence and are proposed to ensure them: explain clearly and comprehensively to the participant what will be done regarding the protection of information; the possibility of using computerized programs for anonymous surveys; ask if the child/adolescent is alone in telephone surveys; having a member of the research team linked to the institution other than the one that provides clinical and social care to the participant. According to the integrative review conducted in the main databases by Veenema, Thornton & Corley (2015), on sexual violence in low- and middle-income countries, in the studies in which the research participant was guaranteed anonymity and confidentiality of data, the prevalence of reporting child sexual abuse was higher.<sup>15</sup> As for the cultural context, although research ethics principles should be applicable in the most diverse

environments, the methodologies can be adapted to local contexts. Among the methodological considerations to be observed is the importance of adapting the data collection instrument to the understanding of the child/adolescent; and also the need to keep in mind that children may interpret the meaning of maltreatment differently than adults and that researchers may influence their responses.

Radhika, Manjula & Jaisoorya (2018), reinforce the importance of the role of CEPs and list items that are related to the guidelines already recommended by the norms of research involving human beings in Brazil. It states that such questions are based on research related to trauma victims and that they should be adapted to research with adult survivors of child sexual abuse (ASI), in view of the scarcity of research on this subject.<sup>9</sup> Which are:

1. Measures to reduce participant distress: before starting the study, there should be a brief "clarification" session about CSA and its effects, the need for disclosure; from the feedback to the participant, as soon as the interview ends; the availability of assistance with a psychiatrist/psychologist at the end of the session. Adults should be made aware of the availability of legal services and finally, help options should be discussed with participants!
2. Obligations of researchers: discussion and approval by an institutional board (CEP), with adaptation of the research protocol if necessary; provision of the informed consent, with an option to withdraw; responsible assistance; training on the topic before starting the research; knowledge of the legal implications of the project; supervision of researchers, mainly to beginners; possibilities for researchers to discuss their doubts about the conflicting ethical aspects in "bioethics committee"; institutional co-responsibility in relation to respecting the researcher's autonomy and maintaining an environment where ethically responsible research can be conducted.
3. Obligations of Institutional CEPs: aim to safeguard the interests of researchers and especially research participants. The protocols must have a detailed description of the principles and ethical implications and considerations, an informed consent clarifying the risks and benefits of the research, mention the measures to be taken to keep the participants safe, and to ensure the confidentiality of the data (information); the existence of a CEP member who is an expert on the subject and who can review the protocol, provide researchers with adequate training and supervision in order to avoid research that violates the integrity and autonomy of participants and that researchers respect current ethical guidelines involving human beings. All possible legal implications must be detailed.

4. Thus, it is observed that research with vulnerable populations, especially those involving minors in situations of violence, requires extra care in relation to the protection of participants. Issues related to obtaining informed consent, maintaining confidentiality and privacy, weighing the risks and benefits of the study and fairness should be carefully considered.<sup>16</sup>

### Final Considerations

Many ethical questions emerge from the proposition of researches where the participants are children and adolescents in situations of violence, among others: does the involvement of children/adolescents in situations of violence in researches conflict with the ethical principles of beneficence and non-maleficence? Is it justifiable to include children/adolescents in non-therapeutic research with indirect or limited benefits? What are the possible long-term consequences of this participation? How should responsible care be provided for the diseases identified by the research? What is the expected ethical and professional posture of the researcher in the face of future threats? The approach to violence against children and adolescents, whether physical, sexual, psychological or otherwise, as well as their study, requires special attention from professionals and researchers. The study of the theme involves specificities, delicate posture and compliance with ethical issues, in order to protect the participating population and contribute, based on the findings, to the effective discussion and resolution of the problem.

Ethical behavior in the development of such research is fundamental. In physically, socially and emotionally vulnerable populations, care for the protection of the participant must permeate the entire investigative process. The consideration of ethical aspects and reflection of the specificities mentioned in this article are fundamental from the conception of the research, in the elaboration of the project and in the development of research, as well as in the form of reporting and disseminating the results.

### Acknowledgments

None.

### Funding

None.

### Conflict of Interest

The author declared no conflicts of interest.

### References

1. Minayo MCS. The inclusion of violence in the health agenda: historical trajectory. *Ciência & Saúde Coletiva*. 2007;11(Sup):p1266.
2. Verdélio A. Unicef: violência mata uma criança ou um adolescente a cada 7 minutos. *Agência Brasil*. 1º nov 2017.

3. US Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth, and Families, Children's Bureau. *Child maltreatment 2016*. 2018.
4. Brasil. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Vigilância em Saúde no Brasil 2003|2019: da criação da Secretaria de Vigilância em Saúde aos dias atuais.[Health Surveillance in Brazil 2003|2019: from the creation of the Health Surveillance Secretariat to the present day] *Bol Epidemiol*. 2019; 50(n.esp.):1-154.
5. Brasil. Ministério da Saúde (Br). Secretaria de Vigilância em Saúde. Departamento de Vigilância de Doenças e agravos Não transmissíveis e Promoção da Saúde. Viva: instrutivo notificação de violência interpessoal e autoprovocada [Viva: instructive reporting of interpersonal and self-inflicted violence]. 2nd (edn) Brasília: Ministério da Saúde; 2016:P.92.
6. Brasil. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Boletim Epidemiológico 27. Análise epidemiológica da violência sexual contra crianças e adolescentes no Brasil, 2011 a 2017. [Epidemiological analysis of sexual violence against children and adolescents in Brazil, 2011 to 2017]. In: Saúde. SdVe, editor. Brasília. 2018.
7. Porto D, Ferreira S. Combating violence against children and adolescents: a challenge for Brazilian society. *Rev bioét (Impr)*. 2018;26(1):p.10.
8. CP MERG. Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature, Statistics and Monitoring Section/Division of Policy and Strategy, UNICEF, New York. [Internet]. 2018.
9. Radhika K, Manjula M, Jaisoorya TS. Ethical gaps in conducting research among adult survivors of child sexual abuse: A review. *Indian Journal of Medical Ethics*. 2018;3(3):186-192.
10. Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data - International Society for the Prevention of Child Abuse and Neglect (ISPCAN) March 2016.
11. Powell MA, Fitzgerald RM, Taylor N, et al. International Literature Review: Ethical Issues in Undertaking Research with Children and Young People (Literature review for the Childwatch International Research Network). Lismore: Southern Cross University, Centre for Children and Young People/Dunedin: University of Otago, Centre for Research on Children and Families. 2012.
12. Franco A, Ramírez L. Child sexual abuse: clinical perspectives and ethico-legal dilemmas. *Rev Colomb Psiquiat*. 2016;45(1):51-58.
13. Hillis S, Mercy J, Amobi A, et al. Global prevalence of past-year violence against children: A systematic review and minimum estimates. *Pediatrics*. 2016;37(3):e2015-4079.
14. Brasil. Resolução 510/16, de 7 de abr. de 2016 do Conselho Nacional de Saúde, do Ministério da Saúde. Normas aplicáveis a pesquisas em Ciências Humanas e Sociais.[Standards applicable to research in Human and Social Sciences]. 2019.
15. Veenema TG, Thorton CP, Corley A. The public health crisis of child sexual abuse in low and middle income countries: An integrative review of the literature. *International Journal of Nursing Studies*. 2015;52: 864-881.
16. Liamputtong P. Researching the vulnerable: A Guide to Sensitive Research Methods. *Sage Publications*. Londres - Thousand Oaks - Nova Deli: 2007:p.257.