



Ciência & Saúde Coletiva

ISSN: 1413-8123

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Associação Brasileira de Pós-Graduação em
Saúde Coletiva
Brasil

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Ciência & Saúde Coletiva, vol. 13, núm. 2, marzo-abril, 2008, pp. 399-406
Associação Brasileira de Pós-Graduação em Saúde Coletiva
Rio de Janeiro, Brasil

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Ethics in research with human beings: some issues about Psychology

Ética em pesquisa com seres humanos:
alguns tópicos sobre a psicologia

Sílvia Helena Koller¹

Abstract *This paper examines some ethical issues in research with human beings, especially addressing the area of Psychology, such as the use of ethical codes; minimum risk; informed consent; debriefing; confidentiality; and ethical committees. It suggests ways for researchers to increase understanding and the proper use of the ethical codes, to guarantee their own protection, and to avoid abuses of power. Special attention is given to methodological issues related to ethics.*

Key words *Ethics, Human beings, Psychology*

Resumo *Este artigo examina alguns aspectos éticos em pesquisa com seres humanos, especialmente endereçando a área da Psicologia, tais como o uso de resoluções éticas; risco mínimo; consentimento livre e esclarecido; decepção; confidencialidade e atuação de comitês de ética. Sugere caminhos aos pesquisadores para incrementar o entendimento e o uso apropriado de códigos de ética, para garantir sua própria proteção e evitar abuso de poder. Atenção especial é dada a assuntos metodológicos relacionados à ética.*

Palavras-chave *Ética, Seres humanos, Psicologia*

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Introduction

Ethical regulation for researches with human beings was being presented as an academic demand for Psychology, even before the 1990s when it was created the ethical regulation for research with human beings in Brazil. Some guidelines which were proposed by international associations were used to find solutions to national researches' inquietude of this area¹⁻³. The Professional Ethics Code for Psychologists, in vigor at that time, did not comprise important issues related to this practice, besides being contradictory in some aspects^{4,5}. With the Resolution n. 196/96⁶ applied by the National Ethics Research Council (CONEP), there was an initial attitude from Psychology scientific community of welcoming it. Since then, mechanisms of adaptation and implementation of the new researches, searching to deal with the protection of participants and researchers, were created. Collaboration with groups abroad and publications in international journals were also favored. National journals started to demand ethic approval of projects for the publication of produced articles. Nevertheless, as the researches started to become more structured, it was observed that the so hoped resolution did not embrace all the possibilities which were needed for the research. With the purpose of complementing the previous one, Resolution n. 16/07⁷ was proposed by Federal Counsel of Psychology (*Conselho Federal de Psicologia - CFP*). A draft of this resolution was initially elaborated by National Association of Research in Psychology (*Associação Nacional de Pesquisa e Pós-graduação em Psicologia - ANPEPP*), after it was presented and discussed at National Forum of Brazilian Psychology Entities (*Fórum Nacional de Entidades de Psicologia Brasileira*), then, in its final form, it was established by CFP. Since then, it consists in a more powerful regulation about ethics in research with human beings for this area.

Psychology's field keeps presenting issues that evoke answers which have not been found in both resolutions. For some critics, they do not fill in, in a complete way all the needs for research and even create obstacles for some investigations which could be developed⁸. However, there are still considerations and critics to be done in order to search perspectives for the continuity of production of knowledge and the guarantee of the accomplishment of researches.

The resolutions and Psychology

Several academic traditions and disciplinary fields of medical, social and human sciences are ruled by the Resolution 196/96 which establishes a set of demands for researches with people, who are their object of study. Research is defined as an activity whose objective aims at developing/contributing for general knowledge, based on theories, relations or principles. There is, however, the desire for the accumulation of information which may be corroborated by scientific methods of observation and inference. Such definition presupposes predetermination of people, contexts and procedures which are controlled to produce generalized facts. Nevertheless, not every research in Psychology is accomplished this way and they do not seek this purpose. There are qualitative researches whose the only possible generalization is that the results are not absolutely generalized⁹. Then, it could be taken as presupposed that these researches or the ones that do not generate generalized facts should not be submitted to the analysis of this resolution. But the definition of research in the Resolution n. 196/96 do not open another possibility to studies with human beings, when it keeps stating that every procedure "of any kind" which may involve them will be considered as research and, therefore, must obey such guidelines. There is a huge range of methods and themes for investigation and it is difficult to embrace every possibility and challenge. So many perspectives generate an improbable forecast of infinite and non-handable phenomena and methods which, finally, cannot be adequately summarized in just one ethic code.

For the Resolution 16/00 of CFP, research with human beings in Psychology aims the production of knowledge and propitiates theoretical development of its field and contributes for a professional practice able to cope with the demands coming from the society. The diversity of Psychology demands that theoretical and methodological suppositions of several fields of actuation and application are considered, taking into consideration the varied methodologies which research may have (laboratory, field and action).

Such resolutions, however, do not define research in the same way and neither are complemented as expected, causing even greater disparity in the direction which must be taken by researchers in Psychology. In order to favor discussions about ethics in research with human beings, it was created, in 2004, a forum at ANPEPP, which has joined researchers and has sug-

gested propositions about this topic to CFP, to scientific journals and to fomentation agencies. In 2005⁸, a consultation with the Psychology community about ethics in research was done, especially with professors from Post-graduate Programs. The main results revealed inquietude related to the interpretation of those resolutions, the need of adaptation to several methods, themes and perspectives of Psychology area and, mainly, the process of projects' analysis by Ethics Committees in Research (*Comitês de Ética em Pesquisa - CEP*) of generic composition, which not focus on the specific demands of the Psychology field. Some people complained the resolutions submit psychological research to the rules of medical science and, therefore, allow some committees to exceed in their attributions by trying to impose impossible adjustments and ignoring Psychology's specificities. Operational aspects have also been pointed regarding the time spent in the evaluation and fondness to formal issues, sometimes, irrelevant to a good proceeding and follow up of the study. On the other hand, the follow-up of procedures and the request for commitment with the feedback of results for the participants in the research and to the community involved, as well as the demand for publications which is textually and clearly presented in the resolutions have not been observed by CEPs. If to be ethical in research with human beings is a prerogative for the researchers and they do not need to be monitorated, then it would not be necessary the analysis of projects before the execution. But, as not every information are presented in a textual and clear format in the resolutions, besides, sometimes, being contradictory, the composition and functioning of CEPs lack of a greater and closer monitoring and qualification by CONEP. A good ethical monitoring of research transcends the control and propitiates learning for both, monitor and researcher, being favorable for the construction of knowledge and for the society as well. Though several CEPs work with adequation and guarantee of support to research, some have showed inefficiency, arrogance, abuse of power and incompetence to deal with the specificities of research¹⁰. It is clearly perceivable that some compositions are not always for interested people, but for those who are placed there to just fulfill a task.

Psychology community still expressed the need to revise the resolutions, aiming at embracing the diversity of approaches in researches with human beings, which characterize human and social sciences and are sensitive to its specificities⁸.

The matter is even broader than just separating biomedical and experimental research from that non-experimental, inductive and based in the field¹. Psychology is one of the disciplines of Human and Social Science, which uses quantitative and qualitative methods of research, about themes which surpass the topic of health, and also approaches education, work, social and community relations, human development, evaluation, personality, among others. Therefore, a resolution for research with human beings in Psychology would not need to be established by a health council. Experimental researches or those which use methods closer to medical areas, as the clinical ones, also face problems when seeking to contemplate all resolutions principles. They do not find support for the consecution of researches, i.e., with therapeutic propositions for special populations, for whom the request of informed consent is demanded and the concept of minimum risk could become relative.

Minimum risk

Resolution 196/96 presents as basic ethical aspects benefits and not malefactions. The first is described as the comparison of risks and benefits, both current and potential, individual or collective, associated to a commitment with the maximum of benefits and minimum damages and risks. The second involves the assurance that predictable damages will be avoided. One risk of the research is the possibility of damage to the physical, psychic, moral, intellectual, social, cultural or spiritual dimensions of the human being, in any phase of a research and after its completion. Moreover, an associated or consequent damage can be defined as the immediate or delayed aggravation, to the individual or the collectivity, with proven causal nexus, direct or indirect, in consequence of the scientific study.

To evaluate and guarantee minimum risk are difficult tasks to be predicted, as indicates the Social Science and Humanities Research Ethics Special Working Committee¹⁰. It also suggests that the "identifiable damages", that is, predictable damages that need extra attention during the study with human beings should be informed. Both the protection to minimum risk and the assurance of predictable damages can be surprising. A Psychology research can reveal information during its completion that could not be identified or predicted when it was first planned. The investigation can be ended if risks are identified

during the study, but sometimes they only are revealed in the final data analysis. To formulate informed and reflexive criticism is one of the universities' missions. So, the identification and revelation of damage after or during the research, in a responsible way, could heat up the legit and substantial debate about controversial social matters and provide more knowledge about them. Besides, what is hoped for in a responsible study with effective aims is to build knowledge. Such announcement of results can prevent other researches to begin with the same risks. The academic freedom and the announcement of results can, still, be cut by the demand of an anticipated preview of minimum risk, which is not possible to happen. Results of a research can damage some social group, in essence due to misinterpretation or misuse, regardless of diplomacy that these results express when they are released.

However, one of the main aspects that still does not have an answer is the demand of minimum risk for studies of some themes with special populations, such as domestic violence, where the risk of identification and denunciation of abuse is high and will certainly happen¹¹. Still, we cannot stop researching this topic, since it is a higher risk to ignore the dynamics of these families, the characteristics of abusers and his victims and to keep the complicity with the violation of these citizens' rights, usually gender minorities or children and teenagers. Therefore, considerations about risk should be balanced with the benefits that can come out from the study. Such study¹¹ points to many dilemmas that researchers face when talking to this family group and the ethical questions that they should consider, such as the attainment of informed consent *versus* legal guard and the confidentiality *versus* denunciation. Their responsibility with adequate interventions and returning the study to the scientific and social community is fundamental, and they cannot ignore the very victims of these violation processes. Even though the International Convention of Child Rights as well as the Child and Adolescent Statute (ECA¹²) do not mention or regulate the research, both call for the total protection of the child and the adolescent as a basic attitude. Therefore, this is also expected from the professionals/researchers. Children and teenagers are citizens able to benefit from all the essential rights inherent to human beings, opportunities that can promote their physical, mental, moral, spiritual and social development, with freedom and dignity. The demand of minimum risk keeps away the possibility for research-

ers to interview children that are victims. Among many situations two become more evident in these cases: the perpetrator does not sign the consent afraid to disclose the case, or signs it and afterwards is denounced by the researchers as an abuser. The validity of a consent signed by a denounced abuser is at least questionable, though was demanded as an ethical procedure *a priori*. It is well known that domestic violence always involves secret, and the unveiling can generate a reconfiguration of the family, taking the child away from the family, eliminating parents' power or even the expected imprisonment of the perpetrator. According to the Child and Adolescent Statute interpretation, no child or adolescent can be an object of negligence, discrimination, exploration, violence, cruelty and oppression, being all these acts punishable. Researchers that neglected the possibility of researching this issue, due to its ethical impediments, will be, in a certain way, neglecting the child victim and being abettors of the abuser¹³. ECA also ensures that in case of suspicion or confirmation of ill-treatment it must be communicated. Therefore, it becomes a demand for everybody, including scientists/researchers/psychologists, to zeal for the dignity of the child and the adolescent¹³.

The emphasis on risk may create barriers to the participation of groups that see researchers as their allies, for example, street children who see the researchers as the first adults that listen to them, as people that deserve dignity and respect and give voice to them. There is the need to empower these researchers and also the forecast that the usage of instruments must be stopped, ignoring the data collection, before a specific demand of the child that just wants somebody to talk to^{14,15}.

The understanding of Resolution 16/00 is that the extension of damages of a research in Psychology rarely exceeds those that the people are exposed to in their everyday life and that they also happen outside this context. Some warranty is given by professional's experience and knowledge. Psychologist researchers can work with vulnerable groups or in a risky situation (e.g., street children and teenagers, with no freedom, victims of violence), once they know their realities and have previous experience. Researches that can generate anxiety or deal with traumatic events must incorporate procedures that evaluate damage and offer immediate intervention.

Informed consent

The principle of respect to autonomy of will is the ethical and juridical foundation of informed consent. People are invited to participate in a research and by the informed consent they confirm acceptance, conscience and agreement with the objectives and procedures. There are five key elements for decision-making: information, comprehension, competency, will and ability to decide (reasoning). The information is regarded to the access to data which are relatively influent in the decision of taking part. Competence is the capacity to understand, ability to weigh results, and anticipation of consequences. Will consists in freedom to participate or refuse to do it. Ability to decide involves the capacity to choose and express this clearly¹⁶. The legal direction of informed consent foresees guarantees to the autonomy of the individual, mainly in controversial situations.

Parents or legal guardians are responsible for this consent because of the lack of a child's legal capacity to do it, but he/she must be informed, in the limit of his/her understanding. Such transference of decision power regarding the participation or not of children in the research should not be so dependent on the care and on the idea that they are ruled by the child's best interest principle. There are situations when the family does not fulfill effectively its protective function. These are the cases of those children living on the streets, being explored for work or sexual acts. The absence of protection is also observed in the domestic violence cases, like abandonment, negligence or sexual abuse within the family. In the researches with those who live on the streets, usually there is an impossibility of obtaining the consent. The impossibility of obtaining the term is due to the reduced contact of the children with the families and the difficulty to find them. Usually, they see themselves as negligent, making them afraid to take part in researches. The attainment of the consent demands the existence of an intact family, healthily united and interested in the benefits of the child. Definitely, this is not the case when the father, the mother or both are themselves the agents of violence. Sexual abuse, in general, is done by a person close to the victim, a familiar face in whom the child trusted^{17,18}. The child can be forced to lie about what happened, suffer some form of degradation, blackmailing, terrorism and aggression – what would define psychological abuse. In ignoring such possibilities, researchers would be omitted themselves of

intervening in areas needing better public policies and immediate solutions. Obtaining the signature and consent from abusing and negligent parents and, later on, denouncing them may seem paradoxical. The validity of these signatures, when considering the child's protection, would only reveal the hypocrisy of following an order to fulfill an ethical regulation in a bureaucratic and irresponsible way.

Resolution n. 16/00 affirms that the researchers do not need to accept the informed consent of parents that do not have contact with their children or legal keepers that effectively do not interact with them and do not know well the child or the teenager. It also adds that the consent of those who effectively abused or neglected the children/teenagers, or were connivent with such behavior will not be accepted. Psychology researchers must obtain permission from institutions that help or work to protect and care for these children's health, such as schools, shelters, health centers, protective councils and the Federal Prosecution Service. The understanding is that in the absence of a protective family, such institutions act continuously in order to protect and guarantee the well-being of children and teenagers. Such act does not exclude the necessity of receiving the consent of the child/adolescent to be part of the research. To insure the absence of any damage and tranquility to participate in the data collection, researchers should carefully establish the methods and know the cognitive development of the participants¹³.

Unexpected situations also occurred in the presentation of the consent terms. Even in simple language, sentences can be riddles for some people, as well as the very word "consent". Therefore, its quality can have a paradoxical effect. The demand for simple language usage, for example, can be a problem, especially when the replacement of technical expressions is not adequate to the formal language. One term, for the signature of mothers and girls, elaborated for a study¹⁹ with victims of sexual abuse was questioned by Ethics Committee in Research (CEP) due to the usage of the expression "sexual violence". In a pedagogical attitude towards the mothers and girls involved, the expression was kept, even though CEP's demanded to replace it. The argument that any other word or expression could be colloquial or even foul language was hard to be assimilated by CEP members. On the other hand, in a more common term that was shown as an experiment to one of the mothers, in the process of finding a language CEP would like best, the

mother refused to sign. She said that there should be something wrong with the research or with the team, because she could understand perfectly well all that was written and that if the informed consent was really from a university, she would not understand and much less find words so clear like the ones she found. Considering this answer of a participant it can be seen as an imposition the fulfillment of a regulatory demand.

Confidentiality

Anonymity, secrecy and confidence must be assured according to the resolutions. But in Psychology, some situations may occur and they may challenge this ethical principle. On the other hand, there are participants who want to be identified and express that, this way, they will be able to plead for the rights that the results of the research helped them to ensure. This is the case of a research done by demand, in slums with no sanitation, which aims at using the results to request a housing plan which better protects children²⁰. However, the distrust in relation to the guarantee of anonymity is, many times, produced by the signature of the Term of Informed Consent. Risky behaviors, conflict with the law, drugs abuse, aggressiveness and violence are variables which may become untouchable by the investigation because the requirement of signing a term. In a research done with 3500 youths who lived in the suburb and in institutions of shelter²¹, the number of answers in blanks was higher in questions which involved risky behavior. Some youths justified the lack of answers due to the fact of having signed a term, by which they feared to be identified and, consequently, punished even when they are aware about the possibility of interrupting or finishing the program with no explanations or sanctions. To try to solve this situation, it is essential the establishment of bonds and trust between them and the researchers, but it is not always possible. For those who have already been taken from their freedom or are in conflict with the law, a signed document may not only be a concrete register of participation in a research.

Debriefing

In social and human sciences, information got before the obtainment of consent is seen as a complex and indispensable process. In some research-

es, to anticipate the variables which are being studied (i.e., moral values) may induce the answers given in the instruments. In Brazilian resolutions for research with human beings, it is not foreseen the possibility of partial revelation before the collection of data or total revelation right after the collection.

In several regulations of international research there is the description of the use of words like deception, debriefing and disclosure – in a way of softening its meaning it is called partial “revelation”. Debriefing means to inform, after the collection of data, the objectives of the research as well as the hypotheses and theories which are being tested. Ideally, it means the possibility of obtaining some results for the participants. The way this information is provided may vary, depending on the nature of the project. It can be a verbal explanation of the project, as the rapport that is usually presented in the researches that expresses its goals in the beginning, or a text written with a summary or the whole text itself. Investigators can remove the data of its base if in the presentation of the goals the participants do not agree on continuing in the research. However, the possibility of data elimination cannot compromise the validity of the study delineation. If this is the case, exemption for getting the consent must be considered. The involvement and the consequences of the research, as well as its need have to be well evaluated. In an observational study with street children²², permission for the accomplishment of the study was requested before the beginning of each observation. This procedure, taken *a priori*, resulted in the observation and recording of countless stereotyped behaviors, since children knew that they were being observed. For the accomplishment of the study about daily activities the option made was to ask for a posterior consent after the observation, giving the child the right to be removed from the sample, once he/she did not want to be in it.

Still, in some studies the offering of information is not an only event, but something that must be reassured as long as the research is done, as well as in those which are done in phases, because it is known the subjects must agree to follow as participants. In a study which an evaluation is, *a priori*, accomplished as the procedure of sampling (participants' inclusion/exclusion), the consent must be signed in each phase. Therefore, the possibility of debriefing after the collection of data, with a later signature of consent, should be aggregated to the review of resolutions.

Ethics committees in research

National^{22, 8} as well as international²³ consultations about what researchers expect from ethics committees show impressive results. Shallow and rough appreciations of protocols, favoritism of colleagues, conflicts of interests, unjustified requests for changes, bureaucratic demands, non-realistic evaluation of risks, biased reports, inconsistent decisions, negation of the scientific merit and incompetence must be presented as past events.

An ideal ethics committee seems to be a group that applies fair procedures, respectfully deals with investigators, and give them the opportunity to raise their voices when divergent issues emerge. Materials and programs of training for researchers, students and members of committees must assure the knowledge of ethical principles which rule researches with human beings. The establishment of interpersonal relations must be based on appreciation and respect among people, whether they are from the academic context or from the research field.

Conclusion

It is essential for Psychology to organize itself in order to propose an adaptation and to update the regulation for research with human beings to the characteristics of human and social sciences, traditions and advances. The appropriation of diverse methods, techniques and theoretical

models and the possibility of creating new other ones must be visualized.

The practice of teaching research ethics is advisable to every researchers, professionals and students. It is also crucial to develop their critical knowledge about the available codes and demands for the execution of work. The organizational image of university will be, this way, protected by the guarantee that researchers follow ethical principles. Not without discussing the possibilities of updating and adaptation to new methods. Researchers do their investigations since the beginning of the project until their publication and feedback for social and scientific communities, not forgetting their own individual and institutional participants, for whom they have requested consent and agreement.

Another important aspect to be highlighted is the obligatoriness of publishing and giving back acquired knowledge for the general public being it communities of interest and/or the scientific ones. This would be an attitude which should not reach only those who receive public resources to perform their researches, but to every persons that participate in researches and share their time and energy in order to develop science. Giving back this knowledge must be a priority and much more emphasized and demanded than it is in the proposed resolutions. National Association of Research in Psychology has an Ethics Commission in Research, which is studying a proposal for the area. It is hoped that the whole scientific community may consider some of the points presented in this article.

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Artigo apresentado em 01/10/2007

Aprovado em 30/10/2007

Versão final apresentada em 01/11/2007