APPLIED RESEARCH

Social Work and Ethical Challenges in Research: a bibliographic study

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Abstract: Ethics in research has been an issue of growing importance in the disciplinary field of Social Work due to the increased number of studies involving human beings and the need to protect the rights of participants. The purpose of this article is to present a profile of the people studied and the ethical care adopted in studies involving humans published in the *Revista Katálysis* from 1997 to 2011. This study is based on bibliographic research. The survey found 53 articles based on studies involving humans with the following profile of the research participants according to age range: 73% involved adults; 21% children and adolescents; and 6% senior citizens. Since 2007, 53% of the articles published describe the ethical care adopted in the research, such as the preservation of anonymity and the return of the results to the participants.

Keywords: Research ethics. Social Work. Vulnerability. Resolution 196/96. Revista Katálysis.

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Introduction

The current Brazilian system concerning the ethical review of research projects was created in 1996 to protect the rights of people participating in scientific studies. In Europe and the United States, the discussions about ethical review systems arose earlier, in the second half of the 20th century, because of the discovery of abuses committed with people involved in research (GOLISZEK, 2004; BARROCO, 2005; GUILHEM; DINIZ, 2008; SARMENTO, 2011). Regardless of their age and format, the ethical review systems from each country share the goal of protecting the rights of the participants in studies. In Brazil, Resolution 196/96 is the document that defines the ethical guidelines to be observed in studies involving human beings. The text of the resolution establishes a system for ethical review for studies in all of Brazil and the requirements that must be complied with in projects involving people (GUILHEM; GRECO, 2008). Although it encompasses all fields of knowledge whose studies involve human beings, such as Social Work and the human and social sciences, Resolution 196/96 is commonly associated to biomedical research and in particular to clinical studies (GUERRIERO; DALLARI, 2008).

Among the main challenges of Resolution 196/96 is that of contemplating the specificity of qualitative studies, in which, as in other types of research, the participants can be exposed to risks. The text of the resolution focuses more on clinical studies that present risks of physical harm, and for this reason the researchers need to present their complete research protocol and a declaration of free and informed consent from the subjects (TCLE), and describes possible harms and repercussions of the study (GUERRIERO; DALLARI, 2008). The same requirements are applied to studies with qualitative techniques. Nevertheless, a complete research protocol of the type required in the resolution cannot always be presented at the beginning of a qualitative study and a declaration of free and informed consent cannot always be used at the beginning and provide information about the possible results and effects of the study. As a consequence, the requirements foreseen in the resolution have been the target of criticism in disciplinary fields that, although they recognize the importance of protecting research participants, disagree about the forms and the theoretical-methodological references suitable to the ethical evaluation of their projects (OLIVEIRA, 2004; MACRAE; VIDAL, 2006; DINIZ, 2008; MINAYO, 2008; SCHRAMM; PALACIOS; REGO, 2008; SCHMIDT, 2008; GUERRIERO; DALLARI, 2008; BARROCO, 2009; FLEISCHER; SCHUCH, 2010).

Social Work is a field of knowledge that maintains an ethical and political commitment to protecting the rights of the participants in research. Prior to the creation of the resolution, the Social Workers' Professional Code of Ethics already indicated the need for professionals to respect the rights of participants to have prior information about the study procedure, freedom of choice and access to the results of the studies (CFESS, 1993; BARROCO, 2009). In research projects conducted by social workers, it is common for the object of the study to be users of Social Work who belong to socially stigmatized social classes or groups due to factors such as income, level of education, profession or even physical and mental deficiencies. Some of the people who participate in Social Work studies can be described, according to Barroco (2009, p. 132), as "a population considered vulnerable to certain requirements presented by scientific research." In this sense, the adoption of ethical care in the realization of scientific studies is an attribute of considerable importance in the education and professional exercise of social workers.

The ethical review of research projects can be considered one of the attributes of social workers, because it is a means to prevent abuses and protect the rights of participants. The text of Resolution 196/96 has limitations, given that it gives little attention to the types of studies conducted most often in Social Work – those that use qualitative techniques. The demands made by Committees of Ethics in Research (CEPs) have caused delays in the schedules of research in Social Work, creating particular difficulties for graduate students. These issues have sparked debate and articulations among researchers in the field and an attempt to develop alternatives.

The issue of ethics in research was debated at events such as the National Seminar of Graduate Studies of the Brazilian Association of Social Work Education and Research (Abepss), in 2009, and the National Congress of Social Work in Healthcare, in 2010 and 2012. The final plenary of the Sixth National Congress of Social Work in Healthcare approved the following motion, which was sent to the National Council of Ethics in Research and to the Ministry of Health:

> Through this document, the social workers and other participants in the Sixth National Congress of Social Work, held on April 11-13 2012 in São José dos Campos (SP), express their recognition of the importance of Resolution 196/96 as a tool to protect the rights of participants in studies in the biomedical fields and communicate to the National Council of Health (CNS), the National Council of Ethics in Research (Conep)

> and the Ministry of Health the need: to improve the text of Resolution 196/96 and the CEP/Conep system to contemplate the specificities of qualitative studies.

Another important initiative in this field was the establishment of the Committee of Ethics in Research of the Institution of Human Sciences of the University of Brasilia (CEP-IH), "the first committee specialized in social research created in Brazil" (CEP-IH, 2011). The original proposal for the establishment of the committee arose in the Department of Social Work of the University of Brasilia. This was an important step in the ethical review of qualitative research projects because it represented an attempt to adapt the criteria contained in Resolution 196/96 to the methodological specificities of the human and social sciences.

Considering the current situation in Brazil, characterized by an ethical review system that is not very sensitive to the particularities of research in Social Work, the purpose of this article is to present the profile of the people studied and recognize the ethical care adopted in studies involving human beings published in *Revista Katálysis* from 1997 to 2011.

Methodology

This was a bibliographic study[1] conducted in three phases. In the first phase, the titles and abstracts of all the articles published in the *Revista Katálysis* from 1997 to 2011 were analyzed to identify which studies involved human beings. The articles published in the sections: thematic space, open themes, applied research, theoretical, research, essays, and reports on experiences, studies and articles were considered. The editorials, presentations, interviews, book reviews, lectures and communications were not considered.

As a result of the first phase of the survey, 53 articles were identified that were the result of empiric research involving human beings. According to Resolution 196/96, which establishes the basis for the ethical requirements for the publication of articles in the *Revista Katálysis*, articles involving human beings are those that directly or indirectly study people in an individual or collective manner.

The second phase of the study consisted in an in-depth analysis of the 53 articles selected, with the assistance of guidelines developed to serve as a data collection tool. These guidelines were prepared to orient and systematize the reading of the articles, and to standardize the data collected to facilitate the analysis. To prepare the guidelines, data collection tools used in other studies that adopted the same technique were used as a reference, such as the work of Diniz and Foltran (2004) and Pereira (2006).

After the data collection, began the third phase that involved a thematic categorization of the information obtained. This consisted in classifying the data extracted from the articles studied according to the themes addressed (GIBBS, 2009). The categories used emerged from the key words of the articles themselves. The relative frequency was calculated using as a reference the universe of the 53 articles identified as resulting from research involving humans. The research team decided to use whole numbers in the presentation of relative data, based on the rule of rounding. There was no need to submit the project to a committee on ethical research or to maintain the anonymity of sources because this was a study of secondary sources available to public access.

Results and discussion

The *Revista Katálysis* was chosen due to its editorial characteristics and its importance in the Brazilian disciplinary field of Social Work. It is a journal linked to the graduate and undergraduate programs in the School of Social Work at the Federal University at Santa Catarina. It is indexed and has allowed free access to all issues since its first publication. The journal was launched in 1997, the year after publication of Resolution 196/96 and a period in which the issue of ethics in research began to advance in Brazil. In the second issue of 2006, the journal presented the following instructions in the section of Norms for Publication of Articles:

> All articles resulting from research, or reports on experiences, which involve human beings must indicate that the procedures respect the Helsinki Declaration of 1975 (revised in 1983). Papers by Brazilian authors must also indicate that they respect Resolutions of the National Health Council n. 196, of Oct. 10, 1996, and n. 251, of Aug. 7, 1997 and present a report from the Ethics Committee of the author's institution of origin (EDITOR REVISTA KATÁLYSIS, 2006, p. 268).

In the next publication, the first issue of 2007, the magazine reaffirmed the need for authors to comply with the ethical guidelines for data collection "that involves human subjects" and warned that publication of articles would be "conditioned" on the description of the ethical care used in the methods section:

> All articles resulting from research, or reports on experiences, which involve human subjects will have their publication conditioned on compliance with ethical principles, which must be clearly described in the final paragraph of the Methodology section of the article. They should indicate if the procedures respect the Helsinki Declaration of 1975 (revised in 1983). Papers by Brazilian authors must also indicate that they respect Resolutions of the National Health Council n. 196, of Oct. 10, 1996, and n. 251, of Aug. 7, 1997, and present a report from the Ethics Committee of the author's institution of origin (EDITOR REVISTA KATÁLYSIS, 2007, p. 127).

Considering the journal's requirement that the papers it publishes comply with ethical principles and the objective of this study, first a survey was conducted to identify the articles that resulted from studies involving the participation of human subjects. From the universe of 285 articles published in *Revista Katálysis* from 1997 to 2011, the 53 that resulted from studies involving human subjects correspond to approximately one-fifth (19%) of the total. The data show how the participation of human subjects, although in reduced quantity, considering the total number of articles published, is a reality found among empiric studies conducted by researchers in the field of Social Work (LARA, 2007). The preference for conducting research with the participation of people can be considered a theoretical methodological strategy adopted with the main objective of expanding and strengthening citizenship, according to the Professional Code of Ethics for Social Workers (CFESS, 1993). In this way, social workers or researchers with degrees in the field of Social Work conduct studies that explore, in partnership with the users of social services, a means to develop critical knowledge of reality to guide their professional intervention (LARA, 2007).

Who is studied

For a better understanding of the profile of participants of the studies published, it is necessary to understand the meaning of vulnerability in the realm of scientific research. The subjects of studies in Social Work may be experiencing some type of vulnerability. The ways that the studies are conducted, and their published results, can contribute to intensifying the situation of vulnerability and exclusion found in the reality of the subjects who participate in the studies (ROGERS; BALLANTYNE, 2008). People cannot be described as being vulnerable at any time, but find themselves in situations of vulnerability determined by specific situations, as in the case of studies in which researchers ignore the ethical principles related to the rights of the participating subjects (ROGERS; BALLANTYNE, 2008).

There are different understandings and uses of the term "vulnerability" (ARREGUI; WANDERLEY, 2009; MUÑOZ SÁNCHEZ; BERTOLOZZI, 2007). This article understands that an individual is not ontologically vulnerable, but can become vulnerable in specific conditions (DINIZ; CORRÊA, 2001; ROGERS; BALLANTYNE, 2008). According to Gomes and Pereira (2005), vulnerability can be triggered both as a consequence of a context of structural inequalities or because of a loss of family ties. Arregui and Wanderley (2009, p. 49) discuss the consequences of the various uses of the terms "vulnerability" and suggest that it arose to "substitute that of poverty", to provide a broader scope and include the possibility of confronting a situation inherent to the individuals who experience it. In addition to not being able to separate vulnerability from poverty, the term vulnerability came to be related to debility, disadvantage and risk.

Resolution 196/96 (BRASIL, 1993, II.15) presents a definition of vulnerability in the realm of research: "the state of people or groups of people who, for whatever reasons or motives, have their capacity for self-determination reduced, above all concerning free and informed consent." The definition of vulnerability contained in the resolution can be considered fragile and insufficient, given that it does not explain what are situations of "reduced self-determination" and suggests that the consent agreement be an instrument capable of identifying it or even for measuring the capacity of expression of the subjects involved in the study.

We use the concept of vulnerability proposed by Rogers and Ballantyne (2008), who classify it according to two types: extrinsic and intrinsic. Both forms of vulnerability can coexist in a single person. The extrinsic form stems from the denial of "social and political rights" (ROGERS; BALLANTYNE, 2008, p. 126). Hierarchical societies, such as ours, classify individuals, subjugating some people to others. In this system, the subaltern individuals tend to believe that they are inferior to the others, which compromises their autonomy. Examples of extrinsic vulnerability include: the "lack of power" attributed to groups that are considered incapable of making decisions such as indigenous peoples, and to a certain degree, women; and also those who lack access to the benefits and services provided by social policies.

Meanwhile, intrinsic vulnerability concerns the personal characteristics that compromise the ability of an individual to make his or her own decisions (ROGERS; BALLANTYNE, 2008). The factors of intrinsic vulnerability are, for example, age (children, adolescents and the elderly), mental incapacity (due to a mental disability or disease) or dependence on medical care (such as unconscious people or those in an intensive care unit). Intrinsically vulnerable participants, according to Resolution 196/96, require the consent of the people who are legally responsible for them to participate in research, due to the supposed limitation of their ability to make their own decisions.

The survey of the *Revista Katálysis* revealed, as indicated in **Table 1**, that 27% of the subjects involved in the studies can be considered intrinsically vulnerable due to their age, because they are children, adolescents or elderly. Eleven articles were identified that involve children and adolescents (research subjects younger than 18). Among the adults in the studies published in the *Revista Katálysis* there are people who can be classified as extrinsically vulnerable due to characteristics such as: a precarious work situation; residence in non-urban and indigenous areas; being victims of social, sexual or domestic violence; or belonging to the gay and transsexual community.

Table 1 – Age range of the participants in studies published in *Revista Katálysis* from 1997 to 2011

Age range of the participants	Absolute frequency	Relative frequency
Adults	39	73%
Children and adolescents	11	21%
Elderly	3	6%

Upon defining vulnerability, Resolution 196/96 leaves a margin to consider various factors. The age of the participants, for example, is one important factor for defining vulnerability, although not an exclusive one. The research participant must be seen within the complexity and reality in which he or she is inserted and in this context age range is only one of a number of factors to be considered (BOURGUIGNON, 2007). In this study, the level of instruction and situations of conflict with the law are examples of factors that can expand the context of extrinsic vulnerability of the research subjects.

The data obtained show that many participants had low levels of education and suffered from a lack of access to the benefits and services of public policies. One of the articles analyzed was an exploratory study with children and adolescents in Rio de Janeiro, and the researchers came to the following finding about the profile of the participants:

> The difficult access to school for children in a situation of vulnerability and social risk is visibly greater than that of children of wealthier families of the Rio de Janeiro population, that is, 60% of the children have access to school, while for the low income families, this percentage is only 32% (RIZZINI; PEREIRA; THAPLIYAL, 2007, p. 169).

The following statement in another article reveals a situation of extrinsic vulnerability, considering the practice of actions that violated the human rights of an adolescent infractor whose liberties had been restricted and who is a participant in the study:

> [...] He realized that it would be different, because the agents who received him terrorized him by saying that the best place for him is not there, but in a ditch. Then the boy was submitted to a torture session [...] (OLIVEIRA, 2003, p. 88).

The survey found that in the studies published the participants include: people who are living in the street, individuals whose liberties have been restricted, migrant indigenous women, members of communities along remote rivers and swamps, gays, transvestites, users of the federal Family Healthcare program, unemployed people, people who have lived or are living in situations of domestic and social violence, municipal administrators and counselors, social workers and others.

To know the profile of the subjects involved in the Social Work studies is essential for protecting the rights of these participants by providing ethical care when collecting data and publishing the results. For example, in the case of participants without any degree of instruction, written consent, as called for in Resolution 196/96, is an instrument that is not suitable for informing the participant about the purpose and possible repercussions of the study. Depending on the profile of the participants, it is necessary to employ other consultation strategies such as oral consent, by means of which people can state if they agree to participate in the study.

The ethical care adopted

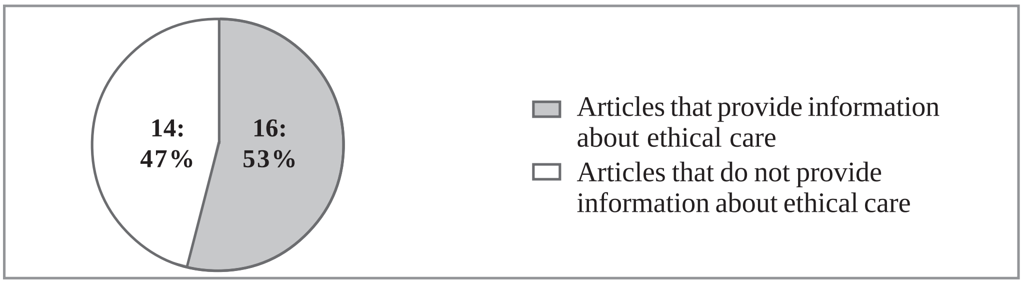
The ethical care required by Resolution 196/96 includes, in the case of qualitative research, mainly: the concession of a free and informed consent form, maintaining the voluntary nature of participation and respect for the dignity and the decision of the participant in the research; an equilibrium between the risks and benefits that the research can bring, the realization of the study only when there is some social relevance for the participants; the maintenance of confidentiality and privacy, guaranteeing that the information is not used to harm the participants; the respect for cultural and social values and for the customs of those studied; the commitment that the study will provide benefits to the people and populations studied; and the assurance of a social return from the study (BRASIL, 1996).

As mentioned, ten years after the enactment of Resolution 196/96, *Revista Katálysis* published for the first time instructions about how the ethical criteria should be addressed in studies involving human beings, affirming that the resolution must be complied with.

One of the ways to meet the requirements of Resolution 196/96 is to submit the research project to evaluation by a Committee for Ethical Research (CEP). *Revista Katálysis* did not specify how the authors should prove compliance with the ethical guidelines established in the documents mentioned. The survey conducted showed that only 27% of the articles published since 2006, the year in which the observance of ethical care came to be an editorial requirement for the publication, mentioned that the projects were originally submitted for evaluation to a CEP. This low frequency may reveal either an absence of information – so that the authors deem that it was not necessary to mention it in the article, although it is an editorial requirement – or the lack of submission of the research projects for evaluation by a CEP. Among the articles where there is a declaration of submission to review by a CEP, none involved children, adolescents or the elderly. Of the total of 11 articles involving children and adolescents, ten maintained the anonymity of the research subjects and one, because it involved a case study of a crime that had received considerable attention in the media, did not maintain anonymity. In relation to obtaining free and informed consent, only one article expressly declared it had requested this informally. Of the 11 articles that involved children and adolescents, one article mentioned their voluntary participation and one mentioned that the research results were returned to the people studied as the form of ethical care adopted.

The survey showed that, before 2006, no article published declared that it knew of or had intentionally followed the care called for in documents such as the Helsinki Declaration or Resolution 196/96[2]. Nevertheless, after the requirement made by the journal, 47% of the articles based on studies involving humans reported the observance of ethical care expressed in these documents, see **Graph 1**. The editorial decision of the magazine was a deciding factor in making the authors aware of the need to declare compliance with ethical principles in studies involving human subjects. The impact generated by *Revista Katálysis*' editorial requirement shows that the ethical principles for research contained in Resolution 196/96 and in the Professional Code of Ethics for Social Workers can be reinforced and better defined with the support of the scientific community, by means of its journals.

Graph 1 – Articles whose authors reported observance of ethical care expressed in documents such as the Helsinki Declaration and Resolution 196/96, *Revista Katálysis*, 2007 to 2011



Explanatory Note: This graph refers only to the period after 2006, when the description of ethical care used became an editorial requirement of the *Revista Katálysis*.

The study showed that the fact that the articles do not explicitly mention the observance of ethical guidelines found in the Helsinki Declaration and in Resolution 1996/96 does not indicate an absence of ethical care in the data collection process. An important observation is that 14 articles that were published after 2006 that did not declare compliance with the Helsinki Declaration and for Resolution 196/96 obeyed at least one of the criteria mentioned in Resolution 196/96: 12 of these articles maintained the anonymity of the subjects and in 2 articles the authors said they had asked for authorization from the participants to publish their names. In one of the articles, the Code of Ethics for Social Workers is mentioned as an instrument used to support the ethical criteria adopted by the author:

> The study and the presentation of the case comply with the ethical and ontological norms of the Code of Ethics for Social Work professionals [the author is referring to the code of ethics adopted by the general assembly of the IFSW in Colombo, Sri Lanka, in July 1994] (CARVALHO, 2011, p. 245).

This suggests that, at times, the norms and resolutions established to insure ethical research involving human beings do not contemplate the specificities of research in Social Work, and it is necessary to adapt them or use other norms that encompass these particularities. There are fields of knowledge, such as anthropology, in which some of the professionals believe that the observance of its codes of ethics is sufficient for disciplining the practice of researchers and the ethical care to be adopted (VÍCTORA *et al*., 2004).

After 2006, 16 articles indicated that written or oral consent was requested and no article reported informal consent. The absence of information about the term of consent does not necessarily mean that the researchers did not request voluntary participation and that they did not explain the reasons for the research to the participants. Considering that all the authors knew of the editorial requirements and the need to observe the ethical guidelines of Resolution 196/96, the silence about the use of the documents can be explained as an option of the researchers to adopt alternative forms of consent beyond those specified in the text of the resolution, which is aimed at the reality of biomedical studies.

Another challenge raised by the debate about research ethics in Social Work is that of analyzing the limits of Resolution 196/96 and the best way to overcome them. The text of the resolution offers ethical guidelines that are still not very sensitive to the specificities of qualitative research.

Social Work professionals recognize that the subjects of research have the right to prior consent and the voluntary nature of participation in studies, and this is part of professional education and action. For example, the use of statements in studies that may be published later, without previous authorization of the person interviewed compromises voluntary participation. This can discredit both the professional and the institution to which he or she belongs. More broadly, it can re(victimize) the research participants, and deepen the vulnerability experienced, resulting in discrimination and stigmitization. The use of instruments such as free and informed consent forms serve, therefore, as a parameter for the researcher to observe ethical principles, to methodologically perfect their studies and maintain the rights involved in the studies (BARROCO, 2009).

Ethical care for preserving the anonymity of participants was observed in 48 articles (91%). Anonymity was guaranteed in a number of ways, for example, with the use of pseudonyms, the omission of names or the use of numbers to identify statements. In 2 articles (4%), the names of the participants were mentioned, either because they were involved in widely publicized crimes, or because the sources of information were available on the Internet, and thus were already in the public domain. One article (2%), mentioned names, but there is no indication if these names are fictitious. Finally, two articles (4%), indicated that participants gave authorization to reveal their identity. In one of the articles analyzed, the author declared:

> I chose to mention the name of those interviewed with their respective authorization by e-mail and personally in the context of the respective interviews. I also decided to maintain the statements in their original form, because they express particular world views related to certain cultural traditions (GONÇALVES, 2008, p. 141).

As observed, in some cases the anonymity of the subjects studied was not maintained, and this was a decision previously agreed to and authorized by the participants. This procedure indicates the need to revise the requirement in Resolution 196/96 for anonymity of the subjects studied, as if this was an ethical principle in and of itself. In qualitative research, there are times when anonymity is not necessary or cannot be maintained considering the specificities of the object of study.

Another criteria established by Resolution 196/96 is the presentation of the research results to the participants. The survey found that only 2 articles from before 2006 included information about the return of the results to the population studied and only 3 articles after 2006. The very publication of the article may be considered as a form of returning the data and would, therefore, do away with the need for this type of information in the text. However, it can be questioned if all the participants in the study would have access to this method of presenting the data or if other strategies are necessary, such as talks, seminars or texts in simple language.

Sarmento (2008, p. 252) affirmed that, "if the right to knowledge, information and to the results of the studies is increasingly restricted, to the same degree, the right to political participation is also limited." The presentation of the research results can also provide benefits for the people who, at some time, find themselves in a situation of vulnerability. To understand the situation in which they find themselves living can help individuals to demand their rights and struggle for better living conditions. The democratization of information emphasizes the pedagogical dimension of Social Work, which assists the formation of a new culture, contributing to the creation of new forms of sociability (ABREU, 2004). The observation of ethical care in data collection and in the promotion of the results of a study prevents disrespect for the rights of participants in the studies, especially if they are in a situation of vulnerability.

Final considerations

This study showed that authors who published in *Revista Katálysis* from 1997 to 2011 made advances in the adoption of ethical care aimed at the protection of the rights of research participants. Before 2006, none of the articles resulting from studies involving people presented information about the guidelines contained in the Helsinki Declaration or in Resolution 196/96. The only ethical care mentioned before 2006 was anonymity, and in two cases, the return of data to the participants. Since 2007, there has been a change in this situation. The authors came to mention the norms, and the attainment of free and informed consent, submission of the study to a Research Ethics Committee, voluntary participation and the return of data.

The debate about ethical care has advanced in the field of the social and human sciences, including Social Work, where there is an increased number of studies involving human beings. Social workers have a commitment to the preservation of the rights of these participants. If the integrity of the person studied is not respected, the promotion of the data obtained by the study can cause harm. The journal *Revista Katálysis* has had an important role in the education of authors and readers by emphasizing the importance of ethical care when conducting research. The adoption of measures that protect participants and their rights can be seen as a central ethical commitment, given that the studies are conducted with people in situations of vulnerability.

Another challenge raised by the debate about research ethics in Social Work is that of analyzing the limits of Resolution 196/96 and the best way to overcome them. The text of the resolution offers ethical guidelines that are still not very sensitive to the specificities of qualitative research. In this sense, Social Work, as a disciplinary field, must advance in the critical analysis of the resolution and indicate new means for evaluating research projects, which are more suitable to the particularities of the human sciences in Brazil.

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Notes

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2 We confirm that before 2006 there were articles that mentioned the use of ethical care, such as anonymity. Nevertheless, the articles did not mention that this ethical care were adopted because of knowledge of specific guidelines about ethics in research contained in the Helsinki Declaration or in Resolution 196/96.

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