Ethical procedures, ethics, and bureaucracy in a research experience with indigenous population'

Trâmites éticos, ética e burocracia em uma experiência de pesquisa com população indígena

Christine Ranier Gusman

Universidade Federal do Tocantins . Palmas, TO, Brazil. E-mail: christine&uft.edu.br

Douglas Antonio Rodrigues

Universidade Federal de São Paulo. Departamento de Medicina Preventiva. São Paulo, SP, Brazil. E-mail: doug.xinguægmail.com

Wilza Vieira Villela

Universidade Federal de São Paulo. Departamento de Medicina Preventiva. São Paulo, SP, Brazil. E-mail: wilza.villela@gmail.com

Correspondence

Christine Ranier Gusman 606 Sul, Al. Bruno Giorgi, QI 7, lote 24, Plano Diretor Sul. Palmas, TO, Brazil. CEP 77022-064.

Abstract

Based on an experience that occurred during a doctoral research, this article aims to discuss the bureaucratic procedures of social research in Brazil and some of its practical implications. We raise some questions regarding location and the decision--making power granted (or not) to an indigenous individual or population, as well as reflections on the resolutions approved by the National Committee for Research Ethics, their applicability and the (in)adequacy of forms and models used in social research. The article focuses on ethical issues, analyzing operational flows from and among agencies responsible for regulating research carried out with indigenous populations. It also includes reflections on the trace left by the tutelary condition of indigenous people and how this condition continues to limit research guidelines. By sharing this experience, this article intends to incite debates on the ethical implications of situations in which neutrality is replaced by bonds, as well as to demystify the idea that simplifying overly bureaucratic procedures would be a threat to ethical principles.

Keywords: Research Ethics Committees; Indigenous Populations; Ethics in Research.

¹ Funded by a post-doctorate grant offered to the first author by the Coordination for Higher Education Staff Development (CAPES)

Resumo

A partir de uma experiência vivenciada durante uma pesquisa de doutorado, pretende-se discutir os trâmites burocráticos da pesquisa social no Brasil e algumas implicações práticas. São levantadas questões como o lugar e o poder decisório concedido (ou não) ao indivíduo ou povo indígena, bem como reflexões acerca das resoluções da Comissão Nacional de Ética em Pesquisa, sua aplicabilidade e a (in)adequação dos formulários e modelos para as pesquisas de caráter social. Este artigo levanta as questões éticas, analisando os fluxos operacionais dos e entre os órgãos que normatizam pesquisas com indígenas e inclui reflexões sobre como o rastro deixado pela condição tutelar de povos indígenas ainda baliza as normativas em pesquisa. Pretendese, ao compartilhar a experiência, contribuir para o debate das implicações éticas nas situações em que a neutralidade é substituída pelo vínculo, bem como desmistificar a ideia de que a simplificação de processos excessivamente burocráticos seja uma ameaça aos preceitos éticos.

Palavras-chave: Comitês de Ética em Pesquisa; População Indígena; Ética em Pesquisa.

Introduction

This article aims to share experiences and reflections on the process necessary to obtain authorization for entering indigenous land and ethical appreciation for a doctoral research involving indigenous women. The process was long and we were constantly affected by questions regarding rules and protocols to defend research ethics and vulnerable subjects. These same questions were consistent with the bibliographic production. Therefore, here we have the bureaucratic procedures necessary for social research in Brazil and some practical implications, as well as location and the decision-making power being granted (or not) to the indigenous individual or population.

It is noteworthy that while this manuscript was being written, representatives of the Human and Social Sciences (CHS) were able to approve Resolution 510/2016 (Brasil, 2016). This resolution addresses the ethical specificities of research projects that use methodologies from this area of knowledge. Therefore, the experience described herein predates this resolution and, considering that this achievement is neither definitive nor final, we still believe that sharing this experience can contribute to discussions in the field of ethics and the operational flows that strive to guarantee it in all research.

One must consider the necessary existence, importance and seriousness of the agencies responsible for approving research in the Country, but also the negative counterbalance in the disarticulation between agencies, slow processes and the lack of clarity shown by some conceptual issues raised by a social research.

In Brazil, before Resolution 510/2016, research in/with human beings (regardless of knowledge area, technique or method) should follow the rules established by Resolution 466/2012 (Brasil, 2013). The most current resolution, however, fails to consider indigenous populations. Thus, research involving these populations are included in "special thematic areas", and are contingent on the approval of: the local Research

Ethics Committee (CEP), the National Committee for Research Ethics (Conep), the National Indian Foundation (Funai), the National Council for Scientific and Technological Development (CNPq), in addition to approval by indigenous leaders. If the research seeks to access traditional indigenous knowledge, this process must also include approval by the Institute of National Historic and Artistic Heritage.

International society's new perspective on human dignity, which occurred after the end of World War II, led to the creation of new protective rules for any research participants. The Nuremberg Code (1947), created to assist the judgement of Nazi criminals, and the Helsinki Declaration, which establishes guidelines for clinical research since 1964, are milestones that serve as basis for documents and resolutions dealing with research ethics in several countries (Guerriero; Minayo, 2013).

The first Brazilian document to establish national ethical guidelines for research involving human beings was the Resolution 196/1996 of the National Health Council (CNS) (Brasil, 1996), updated in June 2013, with the new Resolution 466/2012 (Brasil, 2013). Based on these resolutions and using an online platform, the CEP/Conep system evaluates, monitors and approves research involving human beings in Brazil, through specific electronic forms (regardless of the nature of the research) that the researcher must complete before starting any research.

The historical origins of the resolutions and their basis in documents issued by institutions whose focus and attention are clinical and experimental research, we readily accept that they are necessary in order to preserve life and ensure the dignity and integrity of the participating subjects. Generalized in these terms, it seems to be an unquestionable requirement. However, there are far more ethical subtleties than one might first assume from this assertion, and that should not be ignored. Science is not only produced through bodily intervention, nor is ethics guaranteed by generalized forms or standard protocols.

Methodology

The idea to share the experience of dealing with Funai and the CEP/Conep system through an article came to us as we traversed this road. Considering the first hurdles, such as conflicting information, doubts when filling online forms and a perspective of more elastic deadlines, a revision of the research schedule was the first step. Firstly, the doctoral research was our priority and dedicating time to a new subject was out of the question. However, at some point, reflecting on this subject became inevitable, the tensions of the ethical procedures and their practical implications in the study on the forefront of our minds. Diving deeper in to this question become essential for the continuance of the doctoral research.

Despite a detailed study of the decrees and resolutions, there was still a need to find authors that dove into the inconsistency of the single model form and uniformed rules adopted by the CEP/ Conep system for any research involving humans, which failed to distinguish or consider the peculiarities of all the different areas of knowledge. We started keeping a field diary to document the obstacles and difficulties of each step, thus creating a guide to which subjects needed attention and future discussions.

Beside our experience with the CEP/Conep system, the diary was also enriched by the exchange of information, correspondence and documents with Funai. Attempting to understand how the organizational structure of this foundation worked, the information flow between the agency and Conep, and the attributions of sectors through which the research project was being processed, we ended up with a collection of information obtained through articles, decrees, regulations, phone calls and requests put through the online transparency site.

The purpose of this study is not limited to sharing information collected along the way; its main focus is contributing to the debate on the specificities of non-biomedical research in Brazil, the bureaucratic obstacles involved and some practical consequences for fieldwork, all based on our experience. It is not our intent to delve into the epistemological reflections of bioethics, and that is this article's first limitation. Taking into consideration the complexity of the CEP/Conep system (and its innumerable regional particularities) and the unstable policies directed to Funai, we believe that the reported experience cannot serve as a parameter for other social research with indigenous populations.

Protection of body and subjectivity in research

Protecting subjectivity or traditional knowledge is as important as protecting the body. Though, the protection tools for the first are not the same as the latter. A research project that has its course defined by relationships and interactions will be unable to list all the risks, damages, and benefits involved. So the question remains, how to ensure ethics despite forms and protocols?

The concepts of "research" and "research involving human beings", according to the CNS resolutions, are well defined. However, other concepts lack clarity, such as the particularities involved in all the different fields of research, the various ways of participating in a research and the ethical implications of the multiple methodological approaches (Brito; Peres; Vaz, 2011). This means that the resolutions follow the biomedical model of science, in other words, the experimental/clinical model, commonly used for research in biology and medicine. As will be discussed below, even biomedical research has to deal with controversies, feeding the strong debate that oscillates between the protection of ethics, bureaucracy and commercial interests.

The term "bioethics" dates back to the 1970s and has undergone successive modifications since it emerged. Garrafa (2012) considers that it was coined as a comprehensive term, meant for the observation of life in general through ethics, and later suffered a significant narrowing of the term, thus being limited to the biomedical field. Both the Resolution 466/2012 and the protocols listed on the CEP/Conep system platform are primarily focused on biomedical research. However, the publication of

Resolution 510/2016 contemplates a review of the protocols and procedures of research.

For Oliveira (2004), the non-distinction between research "in" humans and "with" humans is a serious misconception. Choosing a single biocentric model for the practice of research or one view of ethics that places all areas of knowledge, researchers and research subjects on the same level, imposes a limited way of doing science. Ethical care is essential for those testing a new drug or surgical procedure, but it is also indispensable for those investigating the effects of advertising on family consumption, for example. It is clear that research of different natures, with different impacts and risks, do not fit into the same form, or even under the same logic.

This is only one of the many issues involved when dealing with social research in Brazil. For Víctora (2011), it is fundamentally important to discuss the chosen research techniques, the insertion and participation of the researcher in the different research contexts and the procedures of data analysis and interpretation. According to the author, these aspects are necessary and fundamental debates to strengthen ethics in social research.

The research that triggered this article has a social aspect, using a qualitative method of collecting and analyzing data, and techniques derived from the CHS. Although some objectives focus on unveiling how a specific public policy affects the production of care and health, no body intervention is involved.

Filling the online form (*Plataforma Brasil*) of the CEP/Conep system proved to be a challenge, especially regarding: the number of subjects, free and informed consent form and risk prediction. Establishing the number of subjects prior to the beginning of the research is mandatory, as well as offering a detailed description of the division of groups (including the interventions to which these groups will be exposed). In social research, that is not always possible. Initial interaction with informants, the community and the situations experienced in the field can lead to the inclusion of other, unplanned subjects. In addition, the researcher can choose to skip dividing subjects into groups or

decide not to include any interventions aside from the interview and/or observation.

By putting into perspective how the number of subjects is defined (or interviews, focus groups, informants, etc.) and their relationship with ethics, Víctora (2011) defends that it much more important "what" and "how" the researcher converses with the subjects, than the number of people involved in the research. The author also emphasizes that "a larger or smaller sample size does not multiply or divide the ethical questions of the research" (Víctora, 2011, p.101).

This assumption leads us to reflect that an ethical qualitative research requires specific criteria for choosing the target population or the time chosen to interrupt the search for subjects and information, much more than defining the number of subjects. These were the issues that first guided data collection in our research and caused redirections. The subjects of the survey were indigenous women of the Krahô ethnic group, from different villages. The way daily life's social relationships occur within this group, like the constant presence of husbands or sisters in conversations, and the bond built between researcher and subject are elements that certainly helped define the number of subjects. The time for completing the study is also not the same; it depends how long it takes to create and refine relationships, which makes planning (such as number of villages, which and how many subjects will be visited/interviewed) harder to define.

Another challenge is the consent form, which has proved inadequate in social research (Guerriero; Dallari, 2008, Sarti; Duarte, 2013, Víctora et al., 2004), since the creation of Resolution 196/1996. One of the main achievements of the new resolution is the expansion of techniques and recording tools used to obtain informed consent; however, the submission of this project is prior to the new document. As initially postulated and maintained in Resolution 466/2012, the free informed consent form requires that all participants of the research be informed and clear regarding all possible consequences of their participation, including risks, protection measures and anticipated benefits. The researcher

is responsible for minimizing these risks and restituting in case of damages. It is a document that must be produced and signed by both parties before the start of any research involving humans. Again, it is noteworthy that the free informed consent form follows a model anchored on clinical and experimental research, directly assuming imminent risk to human health.

For Diniz (2010), reimagining the contractual model of the consent form is fundamental. Except for exceptional cases, social research only involves risks that are similar to those linked to daily social relationships, which are considered minimal.

According to Víctora (2011), for qualitative research, the consent form model should be less concerned with risks and benefits of the biomedical research, and more focused on the researcher's commitment with contextualizing the data collected during the interpretative process. In our experience, most of the changes Conep requested related to risk description, prevention methods, possible damages and possible repair. Ethics should always walk hand in hand with the researcher. Nonetheless, after a few months of fieldwork, we observed that the nuances of conduct and what could or could not be considered risk or damage only become clearer after the fieldwork was underway. Moreover, the critical and ethical sense weighs much more when one is outside of it. The way the researcher handles the relationships built (even after fieldwork has ended), data selection to determine what will be divulged and the way it will be interpreted can influence the subjects more directly than any assumed prior risk.

After the adjustments, the consent form document proved to be extensive. First meetings with the leaderships were challenging, the written language not prevailing in the indigenous culture and a considerable part of the Krahô people not having full control of the Portuguese language. Thus, the consent form seemed inconvenient for a first meeting; dialogue and the need to find out a little more about the other was clearly more urgent and important for both parties. Gathered in conversation, there was no attempt to formally read the consent form, since it would create an artificial environment and potentially compromise bonds of trust. Thus, the strategy was to share the content of the consent term informally during this gathering. It became clear that those assembled had little interest in the document and what it contained, the desire was to get to know the other, to talk about themselves and the village collective, the skills, the children and the animals that were also part of the conversation.

This seems to be one of the biggest advances of the new resolution. As long as the research fits the parameters of a social research, art. 4 (Brasil, 2016) clarifies that consent can be obtained and registered at any point of the research, as well as withdrawn at any time, without prejudice to the participant. The article also states that consent and assent can be obtained through oral, written, sign language (or other), and becomes valid for various forms of registration, such as writing, sound, magnetic (or others). It remains unclear whether research with indigenous populations will partially benefit from the new resolution or continue to be linked to the previous resolution.

Research (in)operational flow involving indigenous nations

We must consider that the purpose of the resolutions, norms and operational flows for the development of research is to preserve human dignity and health, safeguarding ethics and developing and advancing science. Organizing data and services is secondary. In other words, the rules, flows and forms should not be an end-in-itself, but operate for the benefit of both the participants and the researchers, seeking the production of knowledge. It does not seem that this matter has been well resolved in Brazil, since divergences between researchers is not uncommon.

In August 2015, the newspaper Folha de S.Paulo published an open letter to the then President of Brazil, criticizing the excess of bureaucracy that prevents the advance of clinical research in the country, and requesting a revision of the norms by Conep. The indignation of

the researchers who signed this letter highlights another obstacle that is not the biocentric look of the CEP/Conep system, since clinical research would normally fall within its normal parameters. For them, "the cause is one: the bureaucracy" (Carta..., 2015, A7). They use terms such as delay, prejudice and technological and commercial dependence to argue that ethics has been used as an "excuse for bureaucracy" (Carta..., 2015, A7). On the other hand, Palácios and Rego (2015) warn that clinical research is subject to the commercial interests that usually accompany them and must be debated, less these interests overlap the interest and protection of the participants, or disqualify the CEP/Conep system.

Bureaucratic hindrance is not exclusive to clinical research. If the survey involves indigenous individuals or people, the path is equally long. It is the CEP of the institution that supports the researcher, which gives first approval to the project and sends it to Conep, via the online platform. At this stage, we experienced an impasse. The CEP that analyzed the project, approved it. However, an authorization to enter indigenous land was required to continue the process. Funai, responsible for issuing this authorization, had to await the approval of Conep to grant it. We became stagnant. The project was able to continue in the CEP/Conep system after a little over four months and two degrees denying the progress of the project.

The experience should not be generalized, let alone be taken as a rule - it was probably an exception -, but it illustrates how a process can be hindered by these particularities. There are over 620 CEPs linked to Conep. They are interdisciplinary and characterized by volunteer work (Batista; Andrade, Laurentino, 2012). The Circular Letter No. 002/2011 Conep/CNS (Tannous, 2011), in which the chair of the committee calls for institutions to consider the social relevance of the services provided by the CEP and to recognize their workload as a research activity. This letter shows us the frailties involved in the scientific production of Brazil.

The authorization to enter indigenous territory follows a path parallel to Conep, but interdepen-

dent. The document that regulates entry to indigenous land for research purposes is the Normative Instruction No. 1/PRESI, 1995 (Brasil, 1995), issued by Funai. The documents required must be sent directly to the presidency of the institution and, according to the regulations, be analyzed by the General Coordination of Studies and Research (CGEP). In our case, the final authorization took 11 months.

Stating the long time it took to acquire authorization, without context, is not coherent. Authorization depends on documents from other institutions, such as the "merit analysis" issued by the National Council for Scientific and Technological Development (CNPq) and ethical approval by Conep. The consent of the indigenous leaderships is mandatory; Funai consults with these leaders with the participation of the researcher. More important than to breaking down miscommunications and ambiguous guidelines, we must consider some organizational issues.

The CGEP was extinguished in 2009, by Decree No. 7056/2009 (Brasil, 2009), which was later repealed by Decree No. 7778/2012 (Brasil, 2012), but maintained the extinction of the coordination. No other coordination or sectional institution is mentioned by the decrees, replacing the CGEP. In response to a question posed to the transparency site, Funai reported that the Counseling for Ongoing Studies and Research (AAEP), upon request, offers direct council to the presidency regarding entry into indigenous lands for research purposes. The AAEP is a unique structure, without a fixed composition, and its servers are busy with many indigenous demands. This may have contributed to some delays, notably the process of consulting with the indigenous leaders.

In paper, Funai is responsible for the authorization process, but after six months no meeting took place, mainly due to budget cuts and limited use of the vehicle, reserved for emergency situations. This situation required a new bureaucratic process for temporary entry into indigenous territory.

Arriving to the indigenous territory is interesting to describe. Temporary authorization in hand, issued by Funai, we were there to consult with the leaderships. We were told it would be necessary to bring this document to the regional branch, located in the municipality where the research would be conducted. The place is a simple house, in poor condition, chipped paint, scarce furniture; it is hard to identify it as a public building. After explaining our objectives, the responsible official did not request the document, but merely wrote on an A4 sheet of paper that the researcher had dropped by and had the necessary documentation.

The media has reported an unfavorable situation for the institution, with a decrease in the number of staff members and the annual budget, higher tensions in land demarcations, as well as a decrease in the decision-making power, which occurred after a period of two years (2013-2015) under interim presidency (Arruda, 2015; Greenpeace, 2015; Pellegrini, 2015). The institution is the official indigenous organ of the Brazilian State, playing a fundamental role in establishing and executing policies directed at the indigenous population, as well as promoting and protecting their rights.

There is no need to highlight isolated causes, institutions and/or people responsible for the excess time spent trying to conduct research with indigenous populations. Some cares are undoubtedly essential. However, recognizing the impact these disarticulations of institutions and sectors cause, as well as operational weaknesses within the research process is a basic condition for the advancement of science.

Indigenous people as vulnerable research subjects

Resolution 466/2012 states that all research involves risks in different types and nuances. The researcher would then be described as responsible for the integrity and well-being of the participants, since the resolution defines vulnerability as:

The state of a person or groups who, for any reason or motive, have their capacity for selfdetermination reduced or impeded, or are in any way prevented from offering resistance, especially with regard to free and informed consent (Brasil, 2013, II .25).

Taking these definitions into consideration, while considering social research, we are faced with a paradox, since the idea of a fragile and passive participant in contact with an active and responsible researcher reduces the research subject to a mere object of study, denying the politicizing character that tends to permeate research of this nature (Schuch, 2010).

"Vulnerability" encompasses a range of meanings not contained within the resolution. Individuals or groups may be considered vulnerable under one or several aspects of life in society; the idea behind the term is that there is a greater fragility than other groups in society. Thus, determining indigenous populations as vulnerable deserves some consideration.

Studies involving indigenous populations are included in "special thematic areas", alongside new invasive therapies, human reproduction, genetically modified organisms, genetic manipulations, fetal medicine, among others. Vulnerability is the implied criterion that led indigenous communities to be included in the special areas list, even though that is not explicitly stated. The mention of these populations as protected, in the item IV.6.e corroborates this (Brasil, 2013). Therefore, the concept of vulnerability present in the resolution is consistent.

Allowing indigenous communities to be viewed as "individuals or groups that have their capacity for self-determination reduced or impeded" (Brasil, 2013, II.25) goes against the longtime struggles and claims of citizenship of these communities.

Lima (2014) makes sense in this context:

If the tutor has the task of instructing, he acts simultaneously in order to be eternalized as the sole source of authority, transmission of knowledge and correct ways of belonging to a wider community. The thought of the mentee, his actions, beliefs, alternatives and judgment capacity are permanently disavowed in their difference, since they are viewed as constructed based on an imperfect knowledge of

the social reality in which they must exist (Lima, 2014, p. 28).

The author recalls that the Brazilian Empire and later the republican administration were the ones responsible for categorizing them as insufficient for civic life, alongside madmen and married women (among others), and thus indigenous populations were included in the Civil Code of 1916 as relatively incapable and subject to the tutelary regime.

The Federal Constitution of 1988, by defending the cultural differences of the indigenous communities, represented a great advance. The protection of their interests was then viewed as dependent on the promotion and maintenance of their cultural patrimony, opening the possibility of the indigenous communities themselves defending their rights (Souza; Barbosa, 2011).

It is not our intention to deny the importance of Conep or Funai in safeguarding the dignity and integrity of indigenous or non-indigenous individuals and groups that may participate in research, but rather to question the epistemological bias that supports the rules meant to guarantee their protection.

Milmaniene (2010) analyzed the rights of indigenous communities and social research, and recalls that recent years have seen the subjects of research assuming the roles of their own defense, and in some cases, stipulating conditions and rules for research activities. This does not always sit well with researchers. The author points out that: "this complex process of claiming their individual and collective rights makes it possible to identify them as political subjects" (Milmaniene, 2010, 295).

The report issued by the 5th National Conference on Indigenous Health (2014), in 2014, is an example. The document recognizes the importance and the need for inspection and close follow-up of researches by the competent institutions, like Conep, Funai and others. However, indigenous communities wanting to participate in other stages of the research and to take some control over research activities is clearly described in the report, under item 110 of sub-chapter 2.1:

Public and private institutions of education and research interested in researching the health and interests of indigenous populations should first consult the indigenous communities and their respective organizations, respecting the rights guaranteed by the Convention 169 of the International Labor Organization (OIT). Subsequently, submitting the research project to the CEP-Conep/CNS system, CLSI, DSEI/Sesai and Funai (Souza et al., 2014, p. 100).

The socioeconomic and cultural vulnerability of the majority of indigenous populations do not seem to legitimize the concept of vulnerability as described in Resolution 466/2012 (Brasil, 2013). We must also acknowledged that there are several indigenous communities whose particularities expose them to vulnerable conditions, to a greater or lesser extent, no matter what kind.

It is not possible to describe herein the long and complex historical process that marks the interaction with and between indigenous communities, nor the indigenous policies that followed this interaction. Nonetheless, we must state that the multiple conceptions that the Brazilian society and the Brazilian State maintains of the indigenous populations, their different vulnerabilities, as well as the ambiguous situation of protected vs. free citizen, find roots in this history.

Resolution 510/2016: advances and uncertainties

During the pilgrimage to approve the research project, we uncovered an interesting occurrence. CHS representatives had been mobilizing for some time with associations and the Conep itself in search of specific ethical rules for research in this area of knowledge. Public consultation, debates and confrontations, non-consensual minutes and the pressure of non-biomedical researchers seemed to encourage this process. While this manuscript was finalized, Resolution 510/2016 was approved by the National Health Council.

The advances go far beyond the new ways of registering the free informed consent form; the replacement of a narrow and simplistic concept of vulnerability by a criterion of vulnerability and the non-issue of judgments regarding methodological designs (as long as the methodological procedures not involve risks) are examples of some concrete advances.

The research with indigenous populations is not clearly contemplated in the new resolution, except in its art. 13, which cites indigenous communities, for example, the necessary consent of the community authority or leadership. With the exception of this brief quotation, art. 32 is clear in its single paragraph: "In situations not contemplated by this Resolution, the ethical principles contained in the Resolution CNS No. 466 of 2012 will prevail" (Brasil, 2016). In case of a research from the CHS, however, with an indigenous group or individual, which resolution would prevail?

It is possible that these deadlocks will be resolved as the tools and forms are added to the CEP/Conep system. A new resolution with the classification and levels of risks is contemplated, as well as the possibility of creating our own forms and then feeding them to the online platform, as soon as the system is updated. This new system of analysis and ethical merit will be consolidated as it goes, but surely a fundamental observance will manage which, how many and what kind of forms will be adopted, in order to avoid what the system has so firmly tried to sidestep: the bureaucracy.

In cases of research involving indigenous communities, a partnership between Conep and Funai could encourage a minimally necessary number of documents, available to both institutions simultaneously.

Final remarks

Certainly, that an ethical posture should permeate all research is a consensus, including the steps after fieldwork is through. However, while the CEP/Conep system continues to ignore the many particularities of social research, it will only strengthen the idea of an ethics linked to consent given or to filling out forms and approving research in regulatory instances, reducing it to specific moments.

The risk, it seems, is that ethics will be known as a bureaucratic process, manufactured and aligned with interests and objectives that make no sense outside the logic of its creators.

There is a fine line between irreparable harm and commercial interests in some clinical research, and protective measures are absolutely pertinent. Still, safeguards should follow a broad debate that goes beyond bureaucratic control. Palácios and Rego (2015) remind us that Brazil is internationally admired for having an integrated system of ethics committees, maintained by social control and the democratic participation of different institutions, organs and health services. Therefore, we have a fertile and promising system for the development of some limitations, like the recent new resolution. This achievement highlights the necessity of a balance between professionals of the two major scientific areas (Biomedical Sciences and CHS) in both Conep and the CEPs. This would allow projects to be evaluated by members knowledgeable in the area of study.

Though the resolution is a major breakthrough for the field of ethics in social research, there seems to be no short-term prospects for the debureaucratization of the process as a whole. The creation of a new pathway within the CEP/Conep system, with specific forms, has been planned and should occur soon, as well as a specific resolution for risk classification and assessment. These are advancements that may bring more coherence and simplify the process. May, but not necessarily will.

The simplification of extremely bureaucratic processes should not be considered a regression or a threat to ethics. On the contrary, protecting individuals who participate in research may be more assured when responsibility for ethics is clearly shared, bypassing forms and documents.

Silveira and Hüning (2010) are openly opposed to the idea of institutionalizing ethics, most specifically, the committees: "In our opinion, an ethics committee is unnecessary (if democratic) or a mistake (if authoritarian). We consider ethics as produced through singular processes carried out by those involved in them" (p.390).

Though not in full agreement with the radical idea proposed by the authors, the experience clearly showed that ethical or non-ethical postures are experienced through the singular and subjective processes, despite what may be registered in forms. The authors do not consider forms and committees as dispensable, but defend that debureaucratization necessarily entails helping the researcher realize the weight of his own behavior, even though there is an official document of ethical approval. Obvious, it seems. Nonetheless, something that can easily be lost in the absence of reflections, either by the committees or by researchers.

Tomanik (2013) also chooses an alternative path. The author recognizes the importance of the CEPs in times when pressure for productivity can overrun important processes and procedures. He believes that broadening the role of committees, institutionalizing discussions and reflections on ethics in research projects and reports, can strengthen both the field and the institutions themselves.

The most central questions raised by this article finds in the medical certificate attesting that the individual has no contagious disease, demanded by Funai, its best representative. Considering that the researcher can acquire contagious diseases at any given time, what would be the practical purpose of a certificate issued months or years before he encounters indigenous populations? The researcher should judge whether his state of health permits his entry into the field at a given time. In other words, the ethical issues that matter most (and with the greatest potential for damage) will always be present in the course of research, oftentimes away from the monitoring eyes of the system.

There are other, more subtle forms of nonobservance of ethics that may be long-term. For example, inadequate use of data or even nondisclosure of information that could benefit research participants. How to measure and repair these damages? Ramos et al. (2010) conducted a review of ethics in qualitative research and found an expressive number of published articles that

failed to mention any ethical issues, implicitly or explicitly. The authors consider that these finding do not necessarily mean flaws in the ethical procedures, only that they were not mentioned. This gap suggests that discussion of ethics in social research is still a work in progress. Also, it required a broad debate and a differentiated and careful look at a form of research that negates neutrality; on the contrary, assumes a relationship of trust and bonds between both parties. In this sense. when an article suppresses the ethical aspects and dilemmas experienced during the research, it loses the opportunity to broaden the discussion on damage, repair, risk or non-risk in social research. A favorable horizon for the re-signification of ethics in research gains more visibility, which means sharing ethical information in scientific articles is a very relevant tool for favoring the discussion of this issue.

References

ARRUDA, R. Dilma reduz estrutura da Funai e tem menor demarcação de terras desde 1985. *O Estado de S. Paulo*, São Paulo, 15 fev. 2015. Disponível em: http://bit.ly/2eLE8ab. Acesso em: 8 out. 2015.

BATISTA, K. T.; ANDRADE, R. R.; LAURENTINO, N. O papel dos comitês de ética em pesquisa. *Revista Brasileira de Cirurgia Plástica*, São Paulo, v. 27, n. 1, p. 150-155, 2012.

BRASIL. Resolução nº 196, de 10 de outubro de 1996. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial [da] República Federativa do Brasil*, 16 out. 1996. Disponível em: http://bit.ly/2ekI03. Acesso em: 3 nov. 2014.

BRASIL. Resolução nº 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial [da] República Federativa do Brasil*, Brasília, DF, 13 jun. 2013. Disponível em: http://bit.ly/1mTMIS3 Acesso em: 10 jan. 2015.

BRASIL. Resolução nº 510, de 07 de abril de 2016. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais. *Diário Oficial [da] República Federativa do Brasil*, Brasília, DF, 24 maio 2016. Disponível em: http://bit.ly/2fmnKeD>. Acesso em: 20 jun. 2016.

BRASIL. Decreto nº 7.056, de 28 de dezembro de 2009. Aprova o estatuto e o quadro demonstrativo dos cargos em comissão e das funções gratificadas da Fundação Nacional do Índio e dá outras providências. *Diário Oficial [da] República Federativa do Brasil*, Brasília, DF, 28 dez. 2009. Disponível em: http://bit.ly/2ekH2UV. Acesso em: 5 mar. 2015.

BRASIL. Decreto nº 7.778, de 27 de julho de 2012. Aprova o estatuto e o quadro demonstrativo dos cargos em comissão e das funções gratificadas da Fundação Nacional do Índio. *Diário Oficial [da] República Federativa do Brasil*, Brasília, DF, 30 jul. 2012. Disponível em: http://bit.ly/2fCwvVo. Acesso em: 5 mar. 2015.

BRASIL. Fundação Nacional do Índio. Instrução Normativa nº 1/PRESI, de 29 de novembro de 1995. Aprova as normas que disciplinam o ingresso em terras indígenas com finalidade de desenvolver pesquisa científica. *Diário Oficial [da] República Federativa do Brasil*, Brasília, DF, 13 dez. 1995. Disponível em: http://bit.ly/2fyo7mM. Acesso em: 10 jan. 2014.

BRITO, B. N.; PERES, J. G.; VAZ, N. M. S. A questão da vulnerabilidade no caso de pesquisas em seres humanos: algumas reflexões sociais e jurídicas a partir do quadro normativo. Âmbito Jurídico, Rio Grande, v. 9, n. 93, 2011. Disponível em: http://bit.ly/2eUcUfn. Acesso em: 15 ago. 2015.

CARTA aberta dos cientistas brasileiros à Exma. Sra. Presidente da República Dilma Rousseff sobre o atraso na pesquisa clínica no Brasil. *Jornal Folha de S.Paulo*, São Paulo, 6 ago. 2015. Poder, A7. DINIZ, D. A pesquisa social e os comitês de ética no Brasil. In: FLEISCHER, S.; SCHUCH, P. (Org.). Ética e regulamentação na pesquisa antropológica. Brasília, DF: UnB: Letras Livres, 2010. p. 183-192.

GARRAFA, V. Bioética. In: GIOVANELLA, L. et al. (Org.). *Políticas e sistemas de saúde no Brasil.* Rio de Janeiro: Fiocruz, 2012. p. 853-868.

GREENPEACE. Governo nomeia novo presidente da Funai. *Greenpeace*, 17 jul. 2015. Disponível em: http://bit.ly/2eLvfou>. Acesso em: 20 out. 2015.

GUERRIERO, I. C. Z.; DALLARI, S. G. The need for adequate ethical guidelines for qualitative health research. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 13, n. 2, p. 303-311, 2008.

GUERRIERO, I. C. Z.; MINAYO, M. C. S. O desafio de revisar aspectos éticos das pesquisas em ciências sociais e humanas: a necessidade de diretrizes específicas. *Physis - Revista de Saúde Coletiva*, Rio de Janeiro, v. 23, n. 3, p. 763-782, 2013.

LIMA, A. C. S. Revisitando a tutela: questões para se pensar as políticas públicas para povos indígenas. In: TEIXEIRA, C. C.; GARNELO, L. (Org.). Saúde indígena em perspectiva: explorando suas matrizes históricas e ideológicas. Rio de Janeiro: Fiocruz, 2014. p. 27-58.

MILMANIENE, M. P. La comunidad indígena y sus derechos: debates en torno a la ética de la investigación en ciencias sociales. *Anuario de investigaciones*, Buenos Aires, v. 17, p. 287-297, ene./dic. 2010. Disponível em: http://bit.ly/2eUeoaH. Acesso em: 8 set. 2015.

OLIVEIRA, J. P. Pluralizando tradições etnográficas: sobre um certo mal-estar na Antropologia. In: LANGDON, E. J.; GARNELO, L. (Org.). Saúde dos povos indígenas: reflexões sobre a Antropologia participativa. Rio de Janeiro: Contracapa Livraria: ABA, 2004. p. 9-32.

PALACIOS, M.; REGO, S. A proposta de regulamentação ética da pesquisa clínica apresentada ao Senado Brasileiro não interessa aos participantes de pesquisa. *Cadernos de Saúde Pública*, Rio de Janeiro, v. 31, n. 8, p. 1583-1585,

2015. Disponível em: http://bit.ly/2fDJx0a Acesso em: 18 ago. 2015.

PELLEGRINI, M. A relação do governo com os índios se assemelha à da ditadura. *Carta Capital*, São Paulo, 19 abr. 2015. Sociedade. Disponível em: http://bit.ly/1JVoVdD>. Acesso em: 27 set. 2015.

RAMOS, F. R. S. et al. A eticidade na pesquisa qualitativa em saúde: o dito e o não dito nas produções científicas. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 15, n. 1, p. 1673-1684, 2010.

SARTI, C.; DUARTE, L. F. D. (Org.). *Antropologia e ética*: desafios para a regulamentação. Brasília, DF: ABA, 2013.

SCHUCH, P. Comentário: multiplicando perspectivas e construindo verdades parciais. In: FLEISCHER, S.; SCHUCH, P. (Org.) Ética e regulamentação na pesquisa antropológica. Brasília, DF: UnB: Letras Livres, 2010. p. 91-98.

SILVEIRA, R. A. T.; HÜNING, S. M. A tutela moral dos comitês de ética. *Psicologia & Sociedade*, Belo Horizonte, v. 22, n. 2, p. 388-395, 2010.

SOUZA, M. N.; BARBOSA, M. N. Direitos indígenas fundamentais e sua tutela na ordem jurídica brasileira. *Âmbito Jurídico*, Rio Grande, v. 14, n. 85, 2011. Disponível em: http://bit.ly/2ekIN4h. Acesso em: 10 de jul. 2015.

SOUZA, A. A. et al. (Coord.). *Relatório final da 5ª Conferência Nacional de Saúde Indígena*. Brasília, DF: Rebidia, 2014. Disponível em: http://bit.ly/2fCOc4t >. Acesso em: 18 abr. 2015.

TANNOUS, G. S. *Carta circular nº*oo2/2011CONEP/CNS. 2011. Disponível em: <
http://bit.ly/2fDLE4N>. Acesso em: 18 ago. 2015.

TOMANIK, E. A. Debatendo os comitês de ética: controle burocrático ou laissez-faire? *Psicologia em Estudo*, Maringá, v. 18, n. 1, p. 175-180, 2013.

VÍCTORA, C. G. Uma ciência replicante: a ausência de uma discussão sobre o método, a ética e o discurso. *Saúde e Sociedade*, São Paulo, v. 20, n. 1, p. 104-112, 2011.

VÍCTORA, C. et al. (Org.). *Antropologia e ética*: o debate atual no Brasil. Niterói, RJ: UFF, 2004.

Authors' contribution

All authors participated during the inception, the writing and the critical review of this text.

Received: 03/30/2016 Approved: 10/03/2016