

Commitment and regulation. Ethics in research and the human sciences*

Emil A. Sobottka

Although ethical issues have been present since remote times in the academia and in professional organisations, in recent years ethics in research has been doubly highlighted: as a topic and specific field for reflection within the academic community and as an object of evaluation and regulation from outside academia. While reflection has a well-established context in the human sciences, evaluation and regulation developed focusing especially on dilemmas in the biomedical fields. They have expanded from there to the other scientific areas. For research with methodologies that establish more horizontal relations and are open to permanent negotiations, such as participatory research, the regulations that involve vertical knowledge-power relations may present dilemmas that affect both the practice of research and its potential results. However, recognising the specificity of the human sciences regarding this aspect meets with strong resistance. The text discusses these problems based on the experience of participating in a research ethics committee and in a Work Group of the Ministry of Health in Brazil charged with elaborating specific regulations for ethics in research in the human and social sciences.

Key words: evaluation, human and social sciences, reflection, research ethics

* Translated by Hedy L. Hofmann and Luís M. Sander.

Compromiso y regulación.

Ética de la investigación y las humanidades

A pesar que las cuestiones éticas han estado presentes desde tiempos remotos en el mundo académico y en las corporaciones profesionales, en los últimos años la ética de la investigación ha ganado una doble importancia: como tema y campo específico de reflexión dentro de la comunidad académica y como objeto de evaluación y regulación externa a la academia. Mientras que la reflexión tiene ya un lugar vivencial bien establecido en las humanidades, la evaluación y regulación se desarrollaron centradas sobre todo en los dilemas de las áreas biomédicas. Y es desde estas que se expanden sobre otras áreas científicas. Para la investigación cuyos diseños metodológicos establecen relaciones más horizontales y abiertas a negociaciones permanentes, como la investigación participativa, las regulaciones que asumen relaciones verticalizadas de saber-poder ponen dilemas que afectan tanto a la práctica de investigación como a sus resultados potenciales. Pero el reconocimiento de la especificidad de las ciencias humanas en este aspecto enfrenta fuertes resistencias. El artículo discute este asunto tomando como referencia la experiencia de participación en un Comité de Ética de Investigación y en un grupo de trabajo del Ministerio de Salud en Brasil responsable por la elaboración de normas específicas sobre ética en la investigación en ciencias humanas y sociales.

Palabras clave: evaluación, ciencias humanas y sociales, reflexión, ética de la investigación

The place of ethics in research

Concern about ethical issues is nothing new in modern science, although in its youth, in the 18th and 19th centuries, it was enveloped in an idealistic mystique and restricted to select groups that were seen as noble and selfless at the same time (Humboldt, 1982; Weber, 1982, ch. 5), while the potential for conflict of interests and negative consequences of its results were considered small. Well before the experiments with human beings in National-Socialism and the formulation of the Nuremberg Code (Counsel for War

Crimes, 1996), which was done as a reaction to them and indelibly marked research in the field of health, in the human sciences there were already concerns and reflections about research ethics. Max Weber, in his memorable talk to students about science as a vocation in 1917 (1982, ch. 5), warned that the difference in the level of power in the teaching-learning relationship required containment by the teacher in academic activities, leaving personal position-taking to be exposed in the public arena. A more polemical episode involved Franz Boas (cf. Price, 2000). Indignant at the double role of researcher and war spy played by some of his professional colleagues, he questioned the ethicalness of such a hybrid in a text published in a newspaper in December 1919.

Nevertheless, even though the dilemmas to which the scientist's activity can lead, especially when it is subjugated by other priorities,¹ were perceived relatively early as an important matter in the human sciences, the answers found were, at least when seen retrospectively, unsatisfactory. When he turned against political militancy in the classroom and advocated, as an ethical imperative, the separation between the activity of a teacher from that of a citizen, Weber, similarly to Humboldt and following the categorical imperative of their common master, Kant, bet on the correctness of the circumstantial judgment made by the scientist. On the other hand, the American Association of Anthropology, to whose board Boas belonged, preferred to punish the claimant: not only sparing the denounced, but ensuring their right to judge in their own favor. This "solution" appears even more inadequate when one takes into consideration that, according to Cardoso de Oliveira (2010), Boas was the only member of that association who was punished for ethical reasons in almost a century, and that, at least according to David Price (2000), in the United States of America, in emblematic cases,

¹ According to David Price (2000), John Mason, one of the four accused of spying, and the only one of them who did not vote to condemn Boas for the accusation, wrote after Boas's trial "an apologetic letter explaining that he had spied out of a sense of patriotic duty". It appears to be a matter of controversy whether the research activities of Boas himself would resist an analysis in the light of parameters concerning ethics in research (cf. Pöhl, 2008).

anthropological research and spying continued and still continue to be amalgamated.

As the social relations in which research is situated become increasingly complex, especially with the growing interweaving of economic, political and personal career interests with the production of knowledge, the issue of ethics takes on an importance that cannot be ignored. The more science moves from the production of knowledge to the production of technology, the greater the reasons for its presuppositions, procedures and results to be debated in the public sphere and subjected to various modalities of social control, of which evaluation and ethical regulation are only two of many possibilities.

In accordance with these developments, in various disciplines sensibilities were developed that distinguish between procedures considered acceptable and those considered non-advisable or even unacceptable. Based on this sensibility, an entire branch of knowledge was developed: reflection on ethics in research (Johnsson, Eriksson, Helgesson, & Hansson, 2014; Kottow, 2008). Strictly speaking, it concerns itself with matters such as those pointed out based on the examples of Max Weber and Franz Boas. It also seeks to observe scientific activity from a more epistemological-political perspective, in which, besides the problems of dishonest or manipulative procedures (cf. Cottrell, 2014; Lignou & Edwards, 2012), both the purpose of scientific and technological development and its political implications are analysed (Ellul, 1983; Horkheimer, 1988). Despite the importance of this second perspective, which may even be one of the main tasks of the human sciences, the space available only allows the strict meaning to be discussed here.

Shifts and colonisations

While the initial discussions of ethics placed the researcher and their conduct under judgment, in recent years it was the “object of research” that came on the scene, sometimes even as the central focus: the participant who holds the desired information or to whom the experimentation will be applied. This is not, however, only a broadening of the attention to transcend the solipsism of the solitary researcher by including a second participant, nor even the simple shift of the attention from singular individuals to a dyadic relationship in the

sense analysed by Simmel (2006). In recent decades we have seen a complex set of shifts and colonizing expansion of the claims to competence by social groups² and organisations previously considered external to the research activity. In order to perceive how radical these shifts are, it should be recalled that for Wilhelm von Humboldt, acknowledged as the founder of the modern university based on the reform implemented at the University of Berlin in 1810, *freedom* and *solitude* of the academic were the two most elementary requirements for the development of modern science (cf. Forster, 2013).

In the aforementioned Nuremberg Code, the presence of the “object” of research is clear from the first paragraph, when it rules that the “voluntary consent of the human subject is required” in the case of medical experiments with human beings (Counsel for War Crimes, 1996). Although the context of the emergence of this code is highly questionable: the a posteriori justification of the military court of the United States for the condemnations of the Nazi physician-scientists defeated in the war, with a code that was not applied by the very people who drafted it to their previous and later practices, it is a major milestone in several dimensions: in the matter of shifting the focus from the researcher to their “object”, in legitimising social control in the modality of ethical evaluation and regulation, in the preponderant focusing of the ethical debate on the field of health, and in the introduction of a defensive bias as a juridical protection of the researchers.

These shifts are reinforced by another document used as reference: the Declaration of Helsinki. Issued by a general assembly of the World Medical Association in the city that gave it the name, in 1964, this declaration was updated for the tenth time in 2013³ and is constantly referred to in the context of ethics in research. The structuring, the demands and the operation of the research ethics committees in Brazil have this declaration as their main source of inspiration: even though it is directed as an appeal explicitly to physicians, and their observance is encouraged only to “others who are involved in *medical research* involving human subjects” (§ 2). It should be

² The expansion of claims to competency by professional groups has already been treated previously elsewhere (Sobottka, 2014).

³ See in <http://www.wma.net/en/30publications/10policies/b3/>.

emphasised that in the successive updates and reformulations of the Declaration of Helsinki another shift occurred: rather than emphasising the concern with and appeal to an ethical conduct of the physicians-researchers regarding their patients-objects-of-intervention, it began to prioritise, detail and prescribe the social control mediated by institutional committees on research ethics.

The regulation of the external control of research in Brazil has been focused from the beginning on the field of health and is performed by the National Council of Health (Conselho Nacional de Saúde – CNS).⁴ The inaugural document of this Council regarding research ethics dates from 1988, and establishes in great detail “the norms of health research” in general and prescribes the mandatory evaluation of research projects by ethics committees or committees on biological safety, depending on which is applicable. This document expands the focus of regulation of medical activities, which is central to the documents of Nuremberg and Helsinki, to the field of health as a whole. It also does not emphasise the medical profession, instead referring explicitly to ten professions in the field of health regulated at the time. Although it states that its “provisions are of a public nature and of social interest”, in practice the regulation limits control to the health professionals.

The National Council of Health, which has since then been taking the prerogative of regulating and monitoring the ethical aspects of research, is an agency of social control connected to the Ministry of Health. Created in 1937 and restructured several times since then, it has a permanent and deliberative character. Its mission is described as “the deliberation, inspection, review and monitoring of the public policies on health”.⁵ Resolution CNS 466/12, which until April 2016 regulated the subject alone, was issued based on the compe-

⁴ The resolutions of the National Council of Health can be found in http://conselho.saude.gov.br/resolucoes/reso_88.htm. In the United States the Office for Human Research Protections is also connected to the field of health via the U.S. Department of Health and Human Services, and not through the Office of Science or another agency connected to research broadly speaking. The ethical review of research is regulated by the Code of Federal Regulations (45 CFR 46).

⁵ See <http://conselho.saude.gov.br/apresentacao/apresentacao.htm>.

tencies of the Council assigned by Decree nº 5,839, of July 11, 2006.⁶ A comparison between the tasks of this Council in the last decrees that regulate it reveals a shift from a general legislation in 1987, with four tasks, to a much more specific, almost minute legislation, with eight tasks in the present. It also reveals that the assignment of regulating and reviewing the ethical aspects was only established in 2006, and is still explicitly restricted to the “field of health”.⁷ The logic that guides the entire organisation of the Research Ethics Committees, the National Committee on Research Ethics (Comissão Nacional de Ética em Pesquisa: Conep) and the documents that rule their activities have their roots in the field of biomedicine: so far the human sciences and their logic, not even the great multiplicity of social research done with or involving organisations, professionals, managers, users and the social context of health, are taken into account.

The focus is on regulating a specific form of social control: ethical review mediated by Research Ethics Committees. As an *ex ante* procedural control (only projects are evaluated and these from the point of view of the procedures), it is limited in scope and above all in outreach. The spirit that moves it is aimed at partly filling gaps in the social relations established in and by research. The current ethical review goes beyond the limits both by extrapolating the competencies of the original regulating agency and, especially, by intending to impose and control procedures typical of one area upon the other areas of knowledge in general and of research in particular.

There is a key expression in the definition of the scope of this regulation on research ethics: it applies to “research *involving human beings*”. Theoretically, all research projects of this kind should be previously approved by a

⁶ The decree can be found in: http://www.planalto.gov.br/ccivil_03/decreto/1980-1989/1985-1987/D93933.htm and the resolution is in: <http://conselho.saude.gov.br/resolucoes/1996/Reso196.doc>. The following citations are from these sources. In April 2016 a specific resolution for the Human and Social Sciences came into effect; it can be seen in: <http://conselho.saude.gov.br/resolucoes/2016/Reso510.pdf>. It will take a long time to be implemented, because it will require broad organisational adaptations.

⁷ “VII – to follow the process of scientific and technological development and incorporation in the field of health, aiming at the observance of ethical standards compatible with the country’s sociocultural development.”

research ethics committee. There have been many controversies regarding what precisely it would mean to involve human beings; from the amplitude of this interpretation depends which projects should be submitted to prior analysis by the ethics committees and which not.⁸ Since ethical review by committees involves bureaucratic procedures, takes time and, as an external control, may create constraints in an activity that is very zealous of its autonomy, as research has been historically, many conflicts arose (cf. Fleischer, Schuch, Castro, Simões, Seixas, & Universidade de Brasília, 2010), especially in fields of the human sciences that perform experimentation or have an intense interface with the field of biomedicine.

The legal text in Brazil does not expressly limit its applicability to research projects that involve human health; it spells out its validity for the field of health without concerning itself with the clarification of exclusions. Regulation, the institutional structure and procedures are performed without ever taking into account the other areas of knowledge. Some interpretations have extracted from that vague formulation the obligation to submit *all research studies* whose object is human beings to the dictates of external ethical review. This interpretation was received in an ambiguous manner in the 2012 regulation that is currently in effect. On the one hand it prescribes that “research *in any area of knowledge* involving human beings must observe the following requirements ...”. On the other, it states that the specificity of research in the human and social sciences would be considered in a “complementary resolution”. Precisely this specific regulation for the human and social sciences was drafted by a work group with representatives from various scientific associations in this field.

After almost three years of intensive meetings and discussions, there was in the beginning of 2016 an impasse around points considered central by the

⁸ The World Health Organisation delimits it as follows: “activity that entails systematic collection or analysis of data with the intent to generate new knowledge, in which human beings: are exposed to manipulation, intervention, observation, or other interaction with investigators either directly or through alteration of their environment; or become individually identifiable through investigator’s collection, preparation, or use of biological material or medical or other records” (<http://www.who.int/ethics/research/en/>).

participating scientific associations. These associations consider unacceptable, for instance:

- that the regulation about research ethics in the field of the human sciences *be subordinated* to the resolution which is specific of the biomedical area;
- that the risks defined on the basis of biomedical experiments be applied in a unified manner also to the human sciences, leaving out at the same time the specific ethical challenges of these areas;
- that there be a meticulous previous detailing of all research procedures, without any possibility of responsiveness with the interlocutors in the field;
- that the research ethics committees be able to interfere in the methodology planned for research.

This impasse has revealed to what extent, well beyond research ethics, there are matters of prestige and political power of the regulating agencies involved. The growing self-expansion of the tasks of the Ministry of Health and the National Council of Health over all research activities in Brazil intends to subjugate and render uniform, under a biomedical-positivist rationality, a whole set of areas of scientific knowledge that follow completely distinct methods and that, in many cases, have their most genuine contribution to society in the diversity of perspectives of analysis and in their critical potential.

None of the competencies of the National Council of Health allows legislating or regulating areas as distant from its competencies as is research in the human sciences. Its tasks cover only the research involving *human health*: which includes genomics, molecular therapy and other related fields. However, recently the Council went much beyond this and prescribed that “the research funding agencies and the editorial board of scientific journals *must demand* documentary proof of the approval of the project by the CEP/Conep system”. Passages like this not only wish to legally formalise customary practices of the State bureaucracy, but they open doors wide so that the discretion of other agents with which research interfaces can be expanded *ad absurdum* over the autonomy of science and researchers. In April 2016 a

regulation came into effect that takes into account important aspects of the specificity of the human and social sciences: but the organisational structure of control continues to be the same created for biomedical research. Some of the impasses mentioned above could be overcome through negotiations, but in most matters the National Council of Health imposed itself unilaterally.

Thus, besides the already mentioned shifts, in recent years there has been a growing colonization: in the sense defined by Jürgen Habermas (1988a, 1988b), of the different human areas of knowledge by a regulation and monitoring that come from the area of health and are guided by a biomedical logic of optimisation of the means-ends relation that sticks to a paradigm of positivistic science typical of disputes waged in the first half of the last century (Adorno, Albert, Dahrendorf, Habermas, Pilot, & Popper, 1993; Horkheimer, 1992).

Research in the human sciences and its relationship with people

Although the organisational structure for the review of research ethics is presently inadequate for the human sciences, in several cases social scientists are confronted with the demand that their projects be submitted to research ethics committees (cf. Sarti & Duarte, 2013). Funding agencies, academic journals, universities and many organisations from which one needs permission to collect data have made it a condition for this activity to obtain the corresponding ethical approval. Thus, the trinomial which always creates difficulties for researchers: funding, authorisation for field research and submitting a text for publication are the most “convincing” moments to provoke the submission of projects to ethical review. The complicity of the different organisations with the colonising claims of this specific form of control exerted by the external ethical review system, created specifically for the field of health, enabled its expansion to the different academic areas. Almost always, submitting projects is a frustrating experience: projects in the human sciences rarely manage to meet certain requirements made to measure for experiments in the field of health, because they do not belong to their research practices. Often the ethics committees make observations, suggestions or even demands that, from the perspective of a social scientist, are

unreasonable because they completely miss the point or interfere with the researcher's autonomy. There is a considerable scientific production that has already been published about the incommunicability between these two universes.⁹

In an attempt at explaining why the existing regulation does not apply to the human sciences, Luis Roberto Cardoso de Oliveira (2010) distinguishes between research *in* human beings and research *with* human beings. The first separates the subject from the object, separates the active and passive poles in the research relationship, and as a rule its scope is an experiment or intervention provoked by the subject on the object. According to him, this research is to a great extent covered by the current system. The second has in the *research interlocutors* throughout the study; in the dialogue with them, commitments are negotiated that guide the research project; the study becomes a two-way route, along which take place the negotiations and the trust on which a good or unsatisfactory research process will depend. Trust and reciprocity are essential in the interaction that is established in research projects in which the poles are not subject-object, but subject-subject (cf. Gelling & Munn-Giddings, 2011; Vasstrøm & Normann, 2014). In social research, strictly speaking, the researcher: regardless of their will or attitude, is always part of the researched "object", and the "participants" often play a role that goes well beyond the situation of being an "object". There are also specific situations, such as the double insertion as researcher and militant, which imply specific ethical and epistemological issues and cannot be solved by a bureaucratic organisation (Brugge, 2012; Khanlou & Peter, 2005).

Possibly the distinction proposed by Cardoso de Oliveira does not differentiate sufficiently the research projects that should be examined by ethics committees. Genome research, for instance, is rarely seen as "involving human beings", although it clearly does so considering its applicability. Another area that is to a great extent outside the review of the current ethics

⁹ There is an interesting debate that can provide an example of this mismatch. It was based on a polemical text by Zachary M. Schrag (2011): the journal *Research Ethics* dedicated vol. 8, no. 2 (2012) to the topic; Maxime Robertson (2014) takes a position contrary to Schrag, while Stephen J. Humphreys and colleagues (2014) see the entire process of evaluation by research ethics committees critically.

committees is that of *therapeutic procedures*, including the *medical-therapeutic* ones that are only reported a posteriori as “research”, many of which with a high potential risk for the patient. But there is also research in some fields of the human sciences, in a broad sense, that has to do with people’s health and, in this sense, can be included in the sphere of competencies of the National Council of Health. Therefore, it may be appropriate to take a more specific look at what and how the human sciences really research.

I would like to propose, as a complement to the separation between research *in* and *with* human beings, an older distinction, as old perhaps as the social sciences themselves. This is the distinction between research that *is connected with intervention or experimentation* and research that *performs observation* (this in a broad sense, including dialogue, participation, etc.).

In the first case, the research projects contain or are associated with some kind of provocation of changes in the body, in the psyche, or in the habits of its target population *by the researcher*. A few subareas in the human sciences are relatively hybrid: there are some affinities with their area, but they also share methodologies and concerns of other areas. Social work and psychology, for instance, have a broad interface with the field of health; psychiatry is located in health but operates in subareas that are closer to the social sciences. Other areas such as education and administration occasionally also associate experimentation with research. It appears very reasonable to have this concern with systematising rules aiming at a more effective social control of research that is connected with intervention and experimentation with people, including the modality of ethical evaluation. How to do it best is still under discussion (Furukawa & Cunha, 2010).

Experiences of specific ethics committees for the human sciences must be evaluated in depth, but they certainly hardly do justice to the specificities of these areas, as long as the regulation and system to which they are submitted originate in collectives made up mainly of researchers outside the field of humanities. Even if there is a “specific” regulation for the human sciences, as long as it is managed by the current system created for the field of health it will prolong the “dialogue of the deaf” which is now recurrent when human sciences projects, voluntarily or mandatorily, are submitted to this system. An

adequate social control of research in the human sciences requires a regulatory framework, organisations and management guided by logics and attitudes that are compatible with the methodologies that are practiced in them.

However, the vast majority of research projects in the human sciences is of a second type: they are science based on *observation*. Their object of study is not “human beings”; they observe the *actions* of people, the *relationships* between people and the *meaning* people give what they do, and their main task consists of *interpreting* these observations, and *relating* them to characteristics of the context, or else to characteristics that are innate or acquired by people. These studies do not “involve human beings”, but have people as *interlocutors* and, very often, as *partners* in the research (Brandão & Streck, 2006; Sobottka, 2005; Sobottka, Eggert, & Streck, 2005). When the subject-object differentiation exists, it has a very low profile (Cendales, Torres, & Torres, 2005; Silva, 2005; Thiollent, 2011).

These research projects have little in common with the biomedical research model. Many of the documentary and procedural requirements contained in regulation viscerally contradict the *modus operandi* of this other paradigm of empirical science that predominates in the human sciences. Trying to submit these research projects to that regulation not only is beyond the competencies of the National Health Council, involves costs and expenditure of time that are out of proportion with the gain in safety, but it also interferes with the methodology, the content and academic habitus of these areas. Research projects focused on observation and interpretation face different ethical problems, and therefore the ethical evaluation for them must be specific. *Ex ante* ethical review and the bureaucratic logic of the checklist do not do justice to their complexity. Here the commitment of researchers, observation by the community of peers, vigilance of the social groups researched and social control through the public sphere are much more adequate means to ensure the ethicalness of the study, from its conception to the dissemination and use of results.

Criticisms and alternatives for ethical evaluation

An interesting suggestion is made by Sean Jennings (2010) when he contrasts the evaluation based on conformity with the ethically reflexive evaluation. Whereas the first “requires researchers to show how they are complying with a given set of rules or protocols for research”, the second “requires researchers to articulate the ethical issues involved in their research, and to explain and justify the way in which they plan to manage them”. The first model of evaluation focuses on the procedures and on the expectation that they will be strictly observed, whereas in the model proposed by the author the focus is shifted to the researcher. From them would be expected the virtuous attitude of ethical reflexivity throughout the research, described as follows:

To be ethically reflexive in this way would require us to: (1) Make explicit the ethical values and principles governing our research in data collection, analysis and dissemination; (2) justify them, as well as the practical steps we take (or propose to take) with respect to making our practice match those principles; and, (3) weigh up the potential ethical implications of the data collection, analysis and dissemination of the work (Jennings, 2010, p. 88).

Among the reasons that, according to the author, would make this model preferable, two can be highlighted. First, he considers that by needing to justify the conditions of their study argumentatively the researcher would be better prepared to deal with the unexpected situations common in social science research. Second, the discussion with members of the ethics committee would offer the researcher who already takes on an ethically virtuous position a professional space to examine, correct or reaffirm their assumptions. There would be less bothersome forms to fill, the ethical evaluation would become an interlocution open to differences in interpretation, besides driving a recursive process that would extend to the end of the research project, with a kind of rendering of accounts about the ethically relevant circumstances that appeared and the ethically relevant learning which can be provided by the research project.

Despite its intuitive attractiveness, however, this proposal arouses some important issues. It strongly shifts the entire ethical evaluation from the procedures to the researcher's virtues, making it strongly dependent on these same virtues, without being assured of their presence. At the same time, it exposes the researcher to continuous external vigilance, which they must respond to by being constantly ready to render accounts, further undermining the autonomy that researchers, and specialised professionals (cf. Sobottka, 2014), claim to be necessary to perform their activity well. The proposal also presupposes a dialogue, an exchange of ideas between peers with specialised knowledge in the field, with a high level of reciprocal trust and the ability to justify divergences in the appreciation of the subject. In the current academic context in many places, the assumptions of this kind of dialogue still need to be further developed.

Johnsson and colleagues (2014) describe ethical review as the process of institutionalising distrust, which is justified by referring to atrocities of the past and seeks to obtain legitimacy for research by suggesting that those deviations will not be repeated. In their acid criticism of the usual procedures of research ethics committees, they state that "strict adherence to guidelines is also no guarantee that moral responsibilities have been discharged. In fact, if guidelines are used as standards against which performance is measured, responsible conduct will occasionally be punished and blind rule-following praised" (Johnsson et al., 2014, p. 31). Advocating an ethical evaluation more strongly based on principles than on minute detailing, which may encourage a checklist-like behavior, the authors evoke Kant to point to an important aspect regarding the relationship between autonomy, regulation and ethical-moral responsibility: human action may be strictly guided by legality without being (nor encouraging) an ethical-moral action. With a measure of irony they state that a checklist-like system produces a kind of division of the social work: it allows the researchers to dedicate themselves entirely to their research, while others deal with the correlated ethical issues.

Despite their criticism of the ethical review process, the authors do not suggest abandoning this practice, but inserting into it basically conceptual changes. Their first suggestion is that the research ethics committees should have to justify their decisions, thus reinforcing the legitimacy of the review

they perform. Another suggestion they make is that we should stop using the ethical guidelines as regulatory tools, and once again try to conceive the ethical evaluation as a discursive practice. Besides, they advocate a return to the emphasis on the researchers' responsibility and ethical competence, and to a more open interaction of the ethical evaluation with the not strictly academic environment.

Participatory Latin-American research, with its clear option for connecting investigation and involvement, shares with action-research the fact that both are turned to some specific type of deliberate intervention in the reality that is being studied and involve the researchees as protagonists in various stages of the research project. In this way, these two modalities face ethical issues that other research projects in the human sciences, when turned to description and interpretation, do not deal with. The roles of participant and co-researcher, for instance, are not always clearly distinguished, or can even change according to the stage of the research. Further, selecting and obtaining the consent of the potential participants may be very different from procedures common in other research studies.

The participants are often selected "naturally", because they belong to a given group or are involved in a certain situation that is the object of the study. This already involves a pre-selection, at least in terms of exclusion. And asking for consent, besides being easily accompanied by some kind of social embarrassment due to the open and process-oriented nature of this kind of investigation, rarely can be as well-informed as in a research project that follows a closed methodology or experimental protocol. Sarah Maiter, Simich, Jacobson, and Wise (2008) attempt to do this specificity justice, based on a case in a community in Ontario, Canada, by developing the concept of an ethics of reciprocity as a process that extends throughout the entire research until the results are disseminated. On the other hand, regarding the issue of anonymisation, the statement made by Schrag (2011) mainly in reference to ethnographic research applies to it: "Some scholarly endeavours, termed participatory research or action research, seek to include members of a community as full collaborators in a project. When ethics committees insist on anonymity for such participants, they may be stripping co-authors of the credit that is due to them." In this kind of research, in which the relationship

is direct, continuous and sometimes engaging, respect for autonomy and the necessary possibility that the participant may withdraw their consent during the course of the study also present a major risk for the researcher who conducts the project.

As to action-research, Gelling and Munn-Giddings (2011) describe various challenges based on the following topics: value or relevance, scientific validity, reasonable selection of the participants, favorable risk-benefit ratio, independent scientific evaluation, informed consent and respect for the participants involved. These authors claim that action-research does not constitute a specific method, but rather a specific approach to the practice of research, and that it should be submitted to the same type of ethical evaluation as other studies. Even so, the entire text highlights the specific challenges of action-research in each of the topics and the limitations encountered by the current evaluation systems in general in following them. Also Kayleen A. Schumacher (2007) ardently claims that “action research is research” and, therefore, must submit routinely to the standardised procedures of ethical review. Other authors (cf. Löfman, Pelkonen, Pietilä, 2004; Locke, Alcorn, & O’Neill, 2013) prefer to highlight the specificities, and ask how it is possible to take seriously the ethical questions in this research modality.

Beyond the relevant criticisms and suggestions that appear reasonable, it is certainly also important to look at concrete experiences in this field. Debra Diniz (2008) reports an interesting experience regarding ethical challenges in ethnographic research. Together with Eliane Brum, she made an ethnographic film about the abortion of an anencephalic fetus, the child of Severina and Rosivaldo. Besides the emotional, ethical and scientific aspects, that abortion involved political issues, related to the militancy for the liberation of abortions, and a legal issue, insofar as it had been performed in the interstice of three months during which there was an injunction in place allowing legal abortions in borderline situations. Her story emphasises how the transposition of the biomedical model of ethical review is inadequate from some standpoints and limited in others to deal with the questions provoked by research with intensive interaction between researchers and researchees.

Those who take the biomedical model as a factual reference have a problem in perceiving that each methodological research design involves distinct

questions and also enables different ethical sensibilities to which the ex ante evaluation does not do justice. The direct transposition of a technique that may have proved adequate in one field overrules this finding. That is why Debora Diniz and Eliane Brum, according to the story, looked for procedures that were more adequate to the specific situation of the documentary. Consent was not obtained only at an initial formal moment, but was renewed every time filming was done. Besides, the participants were given the right to be co-protagonists in the selection of the scenes during editing, to be the first ones to see the documentary and to veto the results in whole or in parts. A letter of consent was signed after the work was ended and, what seemed very useful, it was conducted by a women's organisation trusted by the main protagonist, "to make sure that the conditions of the free and informed final letter of consent after editing the film were clear and in accordance with Severina's interests" (Diniz, 2008).

This experiment left all of the regulations on ethics in research "involving human beings" outside. However, the commitments negotiated throughout the project are an example of how a dialogued and negotiated ethical evaluation can find solutions that extrapolate the legal provisions tailored to the area of health and allows overcoming difficulties that arise ad hoc when it is conducted by researchers who are sensitive to the context, intellectually capable and committed to basic ethical principles.

Commitments of human science researchers

I once again take arguments from Luís Roberto Cardoso de Oliveira (2010), who lists three commitments of anthropology that can to a great extent be applied also to the other non-experimental human sciences. The first commitment is to *truth* and *knowledge*. Differently from research with a technological orientation, where the main virtue is that it will "work", or from certain professional practices where the ends are incommensurate with the means, the non-experimental human sciences closely connect their methodological procedures, the population on whom they do research and the results of the investigation: all this under the vigilant eyes of the scientific community.

The second commitment is to the *people* who participate as subjects in the research. They are treated and respected as interlocutors throughout the research process and even beyond it. These people not only give their consent at an initial moment in the research, but they renew it constantly through their collaboration, or may also withdraw it. Both in the training of the future researchers and later through the dissemination of the results, the relationship with the research participants is an outstanding topic and a major indicator of the researcher's own professional capacity.

The third commitment is to the *dissemination of the results*. What, how and where to publish is negotiated and renegotiated with the participants during the research project. Further: as a rule the scientific community of the area follows and expects from the researcher proactive interventions in the public disputes in favor of the groups or populations studied whenever threats are based on information other than the truth and knowledge brought to light by their research.¹⁰

As can clearly be perceived from these commitments, in the human sciences the most difficult ethical issues appear during and after the data survey. That is why the effect of an *ex ante* ethics committee, especially when its orientation is of the type that Jennings (2010) calls "compliance focused review", is too restricted to exert any social control. Possibly the resulting gain is even disproportionally small compared to the wear and tear of time, energies and resources.

The Directorate General for Research of the European Commission published an interesting guide on the problems of ethics in research (cf. European Commission, 2010). Besides discussing classical problems of research with a biomedical logic, it contains a discussion on issues of justice and injustice that are provoked by research as non-intended effects. To be included in or excluded from a research may go much beyond the benefits, burdens or evils of an experiment; there may be social implications, such as exploitation and discrimination. Furthermore it discusses how cultural values have implica-

¹⁰ These commitments reveal an improvement in the sensibility of the social sciences, which have distanced themselves from the Humboldtian romanticism of the lone and free researcher and from the illusion of neutrality of science that Merton (1968, p. 585-615) could still have.

tions for what can be considered ethical or unethical in different social contexts. The authors of this text emphasise that it is especially the responsibility of researchers to perceive, evaluate, and draw the appropriate consequences of these findings from conception to publication of the results. In a text with the suggestive title “Beyond the immediate players: Do researchers have moral obligations to others?” Jacques Tamin (2010) argues in a similar way. The situations mentioned in the manual of the European Commission originate mainly in the biomedical area, while Tamin refers to psychosocial studies related to work. In common they focus on the limitation of the bureaucratic proceduralism of ethics committees to detect implications that transcend the immediate routine of research and that require personal ethical commitment from the researcher, even though they are much less skeptical of regulations than other critics (Johnsson et al., 2014).

There have been two usual practices in the humanities to deal with the ethical challenges of professional practice in research. On the one hand, in the immense majority of these subareas, ethics is a constituent part of education, beginning with undergraduate studies. On the other, the community of peers exercises constant vigilance, which is reflected not only in the public reputation of researchers, but also in the spaces granted in the internal public sphere (congresses, publications, etc.) and in the distribution of grants by means of ad hoc consultancies. Certainly, this does not yet satisfactorily solve the challenges of social control with regard to the ethical aspects of research in the human sciences. It brings back to the focus of concerns the social relationship that is established by research, and that research *is* as such. A greater involvement of people and communities that are the aim of research and a more intensive interaction between the academia and the public sphere are dimensions that need to be further developed.

Ethically critical research

Even when the research projects that involve experiments and interventions in the human sciences are set aside, there is research in the human sciences that is critical from the ethical perspective. In them, possibly, besides the self-control learned together with the profession of researcher and the critically

attentive look of the scientific community made up of colleagues in the profession who evaluate the work, in the various circumstances of academic tasks there will be justifiable reasons for the research to be followed by some specialised body. Although I cannot be exhaustive, I list the following research projects that are included here:

- a) Research in which it is necessary to use a hidden researcher: here the research relationships are obviously non-transparent to the people researched and suspend, even if justifiably, a basic principle of professional ethics. With this technique, which became popular for instance thanks to the contribution made by the works of Günther Wallraff (1988) and is often used in marketing, in the social sciences one seeks to minimise the impact of research on the field and access fields that otherwise would be (practically) inaccessible (cf. Davidson, 2006). Both the resistance of businesses and of some public agencies against rendering their social practices transparent and obviously situations of conflict with the law can justify the use of this technique.
- b) Research aimed at generating social technology: Even if in this kind of research the intervention phase is displaced in time, a posteriori, it seems to me perfectly possible to consider it the equivalent of the experimental and intervention research in terms of social control. Many public policies, urban interventions and laws are planned and decided based on results of social research and may have very great (negative) implications in people's lives, some of whom, trustingly, may have given information only because they could not anticipate the consequences of their generosity toward the researchers. Some research studies that intend to establish causal relationships between psycho-bio-physical characteristics and future attitudes or risks, as in the example given by Fonseca (2010) concerning the predictability of people becoming criminals based on their biological constitution, are extreme cases of research designed to generate social technologies. Within the framework of planning public policies, granting exploration rights to private companies and preparing sports mega-events, social information recording systems have been a frequently used means

to generate information that supports gentrification and mass removal actions.

- c) Research done in contexts of conflict: These research projects are done with people or groups where current or potential conflicts arise around the condition that includes them in the research: such as research on remnants of *quilombos* [areas occupied by escaped slaves in Brazil, where their descendants still live], participants in urban or rural squats, ethnics groups, etc.
- d) Research whose final product it not fully aimed at scientific publication, but to restricted use by those who commissioned or sponsored it.
- e) Research on population groups that are in a vulnerable situation: This includes people whose autonomy is restricted, as in the case of soldiers, prisoners, wage-earners, people who have certain diseases that limit autonomy, minors, and also population groups that are fragile or exposed to stigmatisation.

In this kind of research one or more of the following ethically critical situations may occur:

- The purpose clashes, even if only in part, with the commitment negotiated with the research participants.
- The purpose has a high potential to clash with the commitment to the truth and with the good technique to produce knowledge in the field, for instance, by leading to valuing favorable aspects, devaluing or hiding unfavourable aspects.¹¹
- Participation is involuntary or only limitedly voluntary.
- Free and transparent negotiation about what, how and where it will be publicly disseminated is restricted due to commitments of the researcher that are external to the interlocution relationship in the research project.

¹¹ Research on the effects of tobacco, alcoholic beverages and the field of foods that are sponsored, even if indirectly, by interested businesses has been repeatedly reported in the news and does not need to be re-discussed here.

- Research in which the researcher is paid for the task has a high potential for conflict in the relationship with the researchees.

In all these situations it may be advisable to expand social control. But this would have to be done with knowledge about the respective field, not out of dilettantism. The difference that Max Weber describes between the vegetable vendor and the scientist has great parallels with the difference, for the respective sphere of action, between the researcher in a biomedical field who follows a classical positivist epistemology, and the researcher in one of the human areas who observes and interprets people's actions, the relationships people establish and the meaning they assign to what they do. The colonisation of one area by another does not only harm the generation of knowledge; by not knowing the specific problems of each field, at the limit it might have precisely the opposite effect from its stated objective: to reinforce, or legitimise with its approval the vulnerability of those involved instead of protecting them.

Free and informed consent and the human sciences

Free and informed consent is an instrument considered mandatory ever since the Nuremberg Code to confirm the researchee's compliance with the research project. As a rule it is conceived as a formal document based on the logic of contractualism. Carolina F. Fernandes and Livia H. Pithan (2007) make a great effort to undo the image of the letter of consent as a contract of compliance, in order to advocate that it should be seen as the *result* of a communicative process based on trust and aimed at enabling a free and conscious decision by the potential participant. The authors go even further when they claim that "it should be emphasised that the letter *should only be written after the information process*, because otherwise it may be a defensive practice of the physician or hospital providing the service, deviating from the real objective of the procedure" (emphasis mine). It would be enough if the authors looked carefully at the regulations regarding the letter of consent, or else observed the routine procedures of some research ethics committee in a health organisation, to realise that their normative formulation is as utopian as it is far from the legal prescriptions in force. Their article

reveals another complex facet of the discussion regarding the current system of monitoring ethics in research: it moves indistinctly between the description of what “mistakenly” is said to be the letter and the normative language of what it should ideally be. By not distinguishing between description and prescription, the interventions in this dispute may have strategic effects, but do not further the understanding needed for a democratic public sphere.

The contractualist logic seems strange to most of the human science researchers. As mentioned above, research with people involves dialogue, permanent negotiation of reciprocal commitments and of solutions for issues that often appear *during* the interaction-research. There is no way of foretelling these situations exhaustively and, above all, this does not correspond to the self-understanding of the professionals who perform research in this field, as it is not possible to evade the negotiations by a formal instrument like a contract. The relationship of trust and to a large extent of complicity between researcher and researchee would be shaken by a means whose purpose is precisely to create a distance and depersonalisation in the relationship, or even, as indirectly suggested by Fernandes and Pithan, a “defensive practice” against the participant who gives their consent.

There is an additional risk in those studies in which, to protect privacy or for reasons of safety, the source *must* remain anonymous. Demanding a document of reciprocal commitment, in the form of a contract which is ultimately public in the best of cases, makes research impossible because *this* consent is refused. In the worst case the research project would expose the researcher’s interlocutor to uncontrolled risks. What would become of investigative journalism or of research regarding drug traffickers if the sources had to sign a public contract?

The frontiers that delimit the universes of research in the human sciences are, as a rule, guided by socially created characteristics. Their selections of people are always close to randomness: not the random sampling that selects individuals, but the interpretive randomness of the *definitions* that include groupings, typifications, categorisations. To accept or not to participate in a research project involves, therefore, much more consequences for the collectivity than for the individual. A person who agrees to participate is, by the nature of the relationship established, placed in a situation of transcending

themselves and being the representative bearer of characteristics, opinions and traditions; precisely because of the research they become a topically individualised subject of actions that are shared by the collectivity. Reactions in the public sphere, changes in social policies, outcomes of legal conflicts and changes in social recognition, when related to results of research projects, almost always include the collectivity and not the single individual. For this reason too, an individual contract in the form of a free and informed consent may not only be ethically dubious, but unethical.

How the ethics of researchers in the human sciences can be strengthened and accompanied by adequate social control and regulations, therefore, is still an open matter. Even the perception of the magnitude and complexity of the problem is still relatively limited. The expansion of the traditional positivist logic as an epistemology and of the formal proceduralism as a cloak hiding the real challenges of research in the human sciences still has to be overcome. More adequate solutions than the current regulation and ethical review are still necessary for this matter, and they must do justice to the methodological and epistemological plurality, the diversity of experiences involved in research, and also take seriously the question about the purpose of scientific-technological progress.

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About the author

PhD in Sociology and Political Science from the University of Münster, Germany, professor in the Graduate Studies Programme of Social Sciences of the Catholic University in Porto Alegre, RS, General Secretary of the Brazilian Sociological Society (2013-2017) and CNPq researcher. Representative of Brazilian Sociological Society in the working group on Human and Social Sciences of the National Committee on Research Ethics, which wrote the draft of the regulations for this field. A previous version of this text was submitted to *Revista Brasileira de Sociologia*.

Author's address

Rua Prof. Fitzgerald, 192 – Petrópolis
E-mail: sobottka@puccrs.br
90470-160 Porto Alegre, RS, Brasil