

# Ethics in social research: challenges to the biomedical model<sup>1</sup>

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## Abstract

This article analyzes the main challenges involved in the ethical review of social research projects that use qualitative techniques for gathering data. The Brazilian ethical review system was constructed having biomedical sciences as the main reference. This article goes over some of the main points of ethical tension in social research by discussing five classic cases in human and social sciences. It supports the possibility of social research being included in the current ethical review system, as long as there is a sensitization of the ethics committees regarding the methodological particularities imposed by qualitative techniques. Finally, the need for specific ethical guidelines for social research is also considered.

## Keywords

social research; qualitative techniques; research ethics; research ethics committee; ethnography

## Wide frontiers of social research

The field of social and human sciences is vast and diversified. Its disciplinary frontiers are defined by the research techniques it uses and by the knowledge produced (Denzin & Lincoln 2008a). A study on social representations conducted by a nursing team can be understood as a study in sociology or social psychology, as well as in public health, depending on how the authors want to insert themselves into the academic debate or on how they build the argument. A study can be classified in a field based on the researchers' academic community of origin, on the research techniques used for the study's

design, or on the argumentative ambitions of the authors. The result is that a study with qualitative techniques for gathering data may produce an academic article, a literary piece, a video art, or a journalistic report.

For the purposes of this article, social research will represent this disciplinary diversity brought together by a set of qualitative techniques for gathering and analyzing data (Hoeyer et al. 2005).<sup>2</sup> Despite the researcher's disciplinary origin or the research project's academic insertion, social research will be defined here as that which uses qualitative techniques for gathering data, such as participant observation, ordinary observation, open or

closed interviews, ethnography, auto-ethnography, and focal groups; or as that which applies qualitative analytical procedures, such as grounded theory, feminist perspectives, depth hermeneutics, and content analysis.

Social research brings a series of challenges to the current ethical review system in Brazil (Guerriero 2006; Diniz 2008; Guerriero & Dallari 2008; Minayo 2008). With the international consolidation of ethical review systems in the 1980s, a heated discussion began between the biomedical and social fields on the application of the rules for review adopted by ethics committees to the humanities and, more specifically, to the studies that use qualitative techniques for gathering data (Plattner 2003; Bosk 2004; Bosk & Vries 2004; Haggerty 2004; Hamilton 2005; Hoeyer et al. 2005; Feeley 2007).

Anthropology in particular was a field that prematurely reacted to the biomedical model of ethical review, considered inadequate to evaluate the specificities of the ethnographic method – the main research technique adopted by anthropologists in fieldwork (Chambers 1980; Thorne 1980; Wax 1980). There was intense resistance to the deductivist standards of ethical regulation systems, whose inspiration is expressed in the sections of a research project to be evaluated by the committees before the data collection, especially the hypothesis and the written informed consent form (Marshall 2003; Haggerty 2004; Morse 2008).

The ethical review by committees based in institutions did not emerge as a result of a broad discussion between the disciplinary fields in the universities or research centers. On the contrary, it was a political movement that imposed on researchers, in all areas of knowledge, new rules on how one should do research with ethics. The international political process was, on the other hand, the result of academic debates and political discussions in the professional associations of the biomedical areas, particularly medical research. The Declaration of Helsinki, a document authored by the World Medical Association and nowadays a regulatory reference for the field of research ethics in all areas of knowledge, is one of these examples (World Medical Association 2008). Recurrent situations of scientific malpractice since World War II led countries and professional associations to deliberate on this topic (Guerriero 2006; Emanuel et al. 2008; Guilhem & Diniz 2008). In this process of almost half a century between the appearance of the first declarations and the debate between the biomedical and social fields on the current regulations, the methodological and ethical particularities of social research were not well considered, and the researchers that mostly use qualitative techniques rarely participated in the normative deliberations.

Qualitative techniques challenge the research ethics committees review rules basically for two reasons. The first is the epistemological statute of knowledge production: subjectivity and reciprocity are values to be considered in a research design with qualitative techniques for gathering data (Ribbens & Edwards 2000). The research meeting involves investigators and participants in social

relationships, a symbolic game that is different from the one established in the routines of biomedical studies. The second reason is about how knowledge in social research is produced: different than with quantitative techniques, it is from the interaction between theory and empirical scene, that is, from the meeting between the researcher and the social world, that knowledge is generated (Denzin & Lincoln 2008b). A large part of social research does not have hypotheses; that is, these studies do not anticipate research findings, but rather get closer to reality in search of new ideas (Diniz 2008).

This article analyzes some of the challenges imposed by social research with qualitative techniques to the current process of ethical review in Brazil. The fact that the regulation model was inspired in the methodological and epistemological particularities of biomedical knowledge brings a series of questionings on the pertinence of the evaluation rules for qualitative techniques. The presupposition of this article includes the possibility of the current model of ethical review incorporating qualitative techniques, thus the creation of an alternative system being unnecessary. The proposal is to broaden the debate by raising awareness about the peculiarities of qualitative techniques, and about specific guidelines for the ethical review of social research. However, so that this inclusive spirit translates into practices that are fair and sensitive to the diversity of knowledge, it is necessary that the committees establish new ethical review practices. If, on the one hand, the ethical principles are universal in the research scenario, on the other hand, its translation into procedural rules for the committees' work must be diverse. The topic of this article spins around this exercise of translating universal principles into ethical rules that are sensitive to disciplinary diversity.

## A little of the history between ethics and social research

The Brazilian debate about the frontiers between research ethics and qualitative techniques is recent. The first publications date from the 2000s and are markedly about resistance to the incorporation of social research into the ethical review system instituted by CNS Resolution 196/1996 (Brasil 1996, 2007; Victoria et al. 2004; Guerriero & Dallari 2008; Minayo 2008). Internationally, particularly in the United States, the discussion began in the 1980s, when some biomedical authors on research ethics came closer to the ethical questions launched by social research. The main topics on the agenda for discussion in this first phase of ethics in social research were the model for the informed consent form as a contract, the challenges associated with the technique of disguise for data collection, especially used in social psychology, and the notions of the risks and benefits of social research when compared to biomedical research (Beauchamp et al. 1982; Sieber 1984).

The book *Ethical issues in social science research* may be considered an initial milestone for the debate about the ethical evaluation of social research (Beauchamp et al. 1982). Composed of nineteen chapters, the book,

whose summary anticipates the main issues in thirty years of future debate, resulted from a collective work, in which the vast majority of authors were social scientists, lawyers, or philosophers. All assumed for themselves the commitment not only of recognizing the importance of ethics in scientific research, but also of challenging the biomedical model that was in force after the Belmont Report, the principlist theory, and the rise of the model of ethical review by institutional boards. Despite the authors' diversity of arguments and positions, the tendency of the book was to recognize that social research should be submitted to the ethical review system: the knowledge diversity between the researchers was reaffirmed, but the centrality of ethical review for the promotion of science was also reassured.

But this attempt to include social research in the ethical review system did not happen without doubts about which evaluation rules would be fair. Almost simultaneously, the US National Institutes of Health (NIHs), the main supporting institution for the consolidation of the ethical review system in that country, promoted a great debate on the topic of ethics in social and behavioral research. Unlike *Ethical issues in social science research*, whose authors were from the humanities and which had as one of the central topics of discussion the operationalization of the ethnographic method in light of the new rules for ethical review, *NIH readings on the protection of human subjects in behavioral and social science research* assumed another tone (Beauchamp et al. 1982; Sieber 1984). The agenda concerned behavioral research in psychology, especially the studies that used disguise techniques. While the first book intended to challenge the limits of the ethical review model in light of the particularities of social research, the second one was a guide for the job of the committees, though little sensitive to the state-of-the-art of the debate between the biomedical and social fields.

These two pieces are exemplary for indicating the polarization of the research ethics debate in the last thirty years. On the one side are the authors and researchers that are skeptical of the ethical review model inspired in biomedical research as valid for all knowledge. On the other side are those who ignore the particularities of social research and support the view that the rules adopted by the ethics committees are able to translate the principles that should guide scientific research in any area of knowledge. This tension between these two points of view stimulates reflection, for it questions the postulates considered to be universal, and challenges the consolidation of the field of ethics in social research, since it complicates review actions in the current system, for there is no consensus that social research should submit itself to the committees for review.

In general, the topic of ethics in social research has not occupied the agenda of social investigators. Even in international events on research ethics and bioethics, the challenges of social research are tangent to the discussions. In Brazil this is still a question of social researchers working in the threshold between the humanities and

biomedical knowledge, in particular for those who study the world of health and disease. What actually made the first social researchers seriously confront the topic of research ethics were the impositions of the review system from the agencies that sponsor research, of the health institutions where data would be collected, and of the periodicals in the interface between biomedicine and the humanities.

## Discursive fields

Research ethics organizes itself around three discursive fields. The first is the one of national and international norms and regulations. In Brazil, the ethics committees review the research projects according to CNS Resolution 196/1996 and other complementary resolutions from the National Health Council (CNS), which also correspond with other international documents, such as the Nuremberg Code, the Declaration of Helsinki, or the CIOMS/WHO Guidelines (Emanuel et al. 2003). There is an argumentative effort around revising these documents and making them more adequate for the regulation of research in every country and for multicentre international studies.

The second field is that of the argumentative construction about which ethical principles should base the committees' rules and review procedures. There is an extensive debate occurring on the boundary between moral philosophy and applied ethics on confidentiality, privacy, secrecy, vulnerability, protection, and responsibility, in a broad theoretical agenda in bioethics. This is the field that brings research ethics the closest to the national and international forums on bioethics. The third field is that of case studies and experiment reports. The genealogy of research ethics is marked by paradigmatic cases that challenged the tranquility of biomedical research: the Nazi experiments, the studies reported by Henry Beecher, and the Tuskegee Study are some of the most well-known (Emanuel et al. 2003; Guilhem & Diniz 2008).

A genealogy of the field of ethics in social research has been designed in a similar way, with some cases already documented. Few social investigations were the object of ethical controversy during the phase of data collection because, in the majority of cases, the dilemma arose after the publication of the results (Bosk 2001; Bosk & Vries 2004). This phenomenon points out one of the ethical particularities in social research: unlike biomedical research, its main challenges are not in the protection of the rights and interests of the participants during the fieldwork. As a general rule, a large part of social investigations involve "minimum risk" to the participants, that is, a risk similar to that pertaining to any social relation outside of the study's context (Bankert et al. 2006). It is after publishing the results that the greatest ethical challenges lay, such as the guarantee of anonymity and secrecy, ideas about fair representation, sharing the benefits of the study, returning the results, etc.

It is due to this particularity of social investigations – the existence of minimum risk during data collection, although followed by ethical questionings about the

publishing of results – that five studies are known as classic cases of ethics in social research: the study on social life in a suburb in the US by William Foot Whyte (1993, 2005); the study on kinship and genetics among the Yanomami by Napoleon Chagnon (1968) and Borofsky (2005); the study on homosexual practices in public spaces by Laud Humphreys (2008a); the study on genetic counseling and a health team by Charles Bosk (1992, 2001); and the study on social movements for animal rights by Rik Scarce (1994, 1995). Some of these studies had been conducted many years before the ethics debate began, leading to a retroactive discussion on practices and conduct during fieldwork, as was the case with Whyte and Chagnon; in others, the ethical controversy occurred in an unusual phase, that is, before the official publication of the results, when the participants had access to the research reports, as happened to Bosk; and, in Scarce's case, the controversy arose as a result of judicial actions.

These studies were isolated cases in the universe of social research. A large part of the qualitative techniques used for data collection is found in observations and interviews. In both, the risk of harm to the participants is minimum, which does not presume that minimum risk is the same as the inexistence of ethical questioning. However, the unique character of these five cases is what facilitates the identification of some of the main ethical challenges in social research. It is exactly the exceptionality of these cases that promotes thinking about the ethical challenges of social research.

## Social research cases

### Street Corner Society

Whyte's study was conducted in a suburb in Boston in the end of the 1930s. This was a moment for the discovery of ethnography as a method of qualitative social research in urban groups. It was also a time for great advance in anthropologic ethnography in indigenous or aboriginal communities, with Bronislaw Malinowski's fieldwork (1976) as a milestone of this period. The book *Street Corner Society* was published for the first time in 1943 and is still a piece of dense ethnography in urban societies (Whyte 2005). Whyte had lived in the suburb from 1936 to 1940, and the book is a report of the life of young men that organized themselves into groups known as street gangs. Whyte's key informant was Doc, a pseudonym for an Italian-American that not only introduced Whyte to the community of immigrants, but also taught him about basic rules of survival and social relations.

Doc had a central role in Whyte's ethnography. He was the one who explained to the community the reasons for a researcher belonging to another social class to live among them and ask questions about their behaviors and beliefs. In many ethnographic studies that require a long stay in the field, there is not any initial institutional acceptance, but rather previous contacts with key informants, who can guarantee entrance into the group to

be studied. In an analogy with biomedical research, Doc played the role of a hospital director that agrees to the entrance of investigators in the institution. But, in this analogy, there is no way to present a formal term to Doc, as is required for hospital directors, prison wardens, or school principals. Doc did not represent the community's interests; he was only Whyte's key informant. But he was someone who, at the same time, assured the entrance of the ethnographer and protected him from community suspicions. Whyte studied an illegal practice: the formation of groups into gangs.

In later editions of his work, Whyte introduced annexes in which he discussed some of the methodological and ethical challenges faced during his fieldwork. One of the most original ideas of his work is exactly in these new pieces, where he exposed some of the impasses that he had faced due to the contingencies of qualitative research with a long stay in the field. The subject of a special number in the *Journal of Contemporary Ethnography* in 1992 was Annex A of his work. In it, Whyte revealed some of his misconduct in the field and told how he returned to the suburb almost 30 years later (Adler & Johnson 1992). The report is colloquial and assumes a literary tone because of the lightness of the stories told by the young ethnographer. The voice, however, is one of a mature sociologist speaking of his past as a researcher: he tells how he saw himself compelled to cheat in the community elections, voting more than once for his group's candidate; how he learned to listen more than ask questions; and the mistakes he committed in designing his research (Whyte 1993).

From the ethical point of view, however, some commentators provoked him in two ways. The first was the fact that he cheated in the elections, because "I violated a fundamental rule of participant observation: I tried to influence the events" (Whyte 2005: 231). Whyte justified this misconduct as an unplanned act on his part, a naïve impetus instigated by the fraternal relationships that he had established with his informants. Voting innumerous times for the same candidate was a practice shared among the street corner boys, which made him imagine he also had that duty as a participant-observer of the group. The public enunciation of this incident opened an important discussion among ethnographers about how participating should be an observation. How can one establish limits without breaking the trust relations and solidarity between the ethnographer and his informants? How can one stay in the researcher's position in order not to create the false impression of being just another member of the community?

Whyte's objective in this public confession was firstly to open the debate about the tenuous affective and ethical limits established between researchers and informants during fieldwork, rather than presenting definite answers on how an ethnographer should construct a relationship with informants. There are no absolute answers to this dilemma, but the enunciation of the challenge was a new issue in the debate. Whyte's position was summarized in the idea that "I had to learn that,

in order to be accepted by the people within a district, you do not need to do everything the way they do it”, a criticism already extensively enunciated by anthropology about the false pretension of “becoming a native” (Whyte 2005: 314-5). The richness of the technique of participant observation in fieldwork is exactly the permanent negotiation of this ambiguity related to the researcher’s role: it is like someone external to the community, but who lives in it, wanting to understand it, in which data are collected.

The second ethically controversial issue was the fact that Whyte broke Doc’s anonymity in the 1981 edition and did not share the benefits of the book with his key informant. Since Doc had died, Whyte felt safe to expose ethnographic details, such as the real name of his main informant. There is no evidence as to what damage this break of anonymity could have caused Doc or his family, even though the book is a report on how gang boys acted, that is, to a certain degree, illegal practices were involved. The topic of anonymity is so connected with expectations about representations of the group that one of Whyte’s informants questioned him, in a conversation after having read the book: “All that you described about what we did is totally true, but you should have pointed out that we were only young people back then. That was a phase that we were going through. I have changed a lot since then” (Whyte 2005: 343).

Whyte says that, during almost thirty years, the book only brought him financial losses, firstly because he had to pay to publish it, but also because of the derisory character of sales. If the book gave him any financial benefit, it was belatedly and after large investments of time and resources. Nonetheless, one of Whyte’s commentators questioned if Doc, for having been the key informant and translator of social life, did not deserve the status of co-researcher and sharing of the benefits produced by the study (Adler & Johnson 1992). This is, in fact, a question that raises doubts about what the status of a key informant should be – that of participant, co-researcher, or co-author? There is almost a consensus in recognizing him as a participant, but, depending on how one understands the relationship of reciprocity established during fieldwork, it is possible to impute ethical deviations of the ethnographer-author after leaving the field. The challenge of ethnographic research is exactly in this ambiguity between the affective bonds that are genuinely formed during fieldwork and the narrative authority of the author, a new point which appears after the researcher leaves the field.

### Yanomami: a fierce people?

The Yanomami blood case came to international attention after the publication of Patrick Tierney’s book (2002), *Shadows in the Eldorado: how scientists and journalists devastated the Amazon and raped the Yanomami culture*.<sup>3</sup> The story dates back to the 1960s, when a group of American researchers began a genetic, epidemiological, and anthropological study with different Yanomami groups in Brazil and Venezuela. In this case, at least 12,000

Yanomami blood samples were collected, part of which is still stocked in different universities in the United States. Recently, some samples were returned to the Yanomami leaders for destruction (Albert & Oliveira 2006).

Tierney’s book presented serious accusations against two well-known scientists: James Neel, geneticist, and Napoleon Chagnon, anthropologist, whose works and ethnographic films were studied by a generation of anthropologists. Neel and Chagnon were a team of socio-biologists whose main goal was to investigate the genetic bases for violence and its relationship with reproductive practices. The Yanomami were an ideal population for this type of study given their description as a violent and savage people and for the deep isolation in which they lived, which guaranteed the group’s genetic homogeneity. The social construction of the Yanomami as a primitive people was an additional attraction for testing the frontiers between biology and culture in human societies: the search for the violence gene and its relationship with reproductive behavior could be a hypothesis tested for the first time on a specific population.

Chagnon is the author of one of the most well-known and popular books on the Yanomami, *Yanomamö: the fierce people* (1968). The main idea of the book, which sold more than three million copies, a considerable number for works in anthropology, is that violence occupies a central role in Yanomami societies (Borofsky 2005). In partnership with Neel, Chagnon supported the thesis that violence has a genetic basis: the Yanomami had a genetic propensity for violence (Chagnon 1988; Neel 1994). This characterization of the Yanomami people as violent had a dual appeal: on the one hand, it was a reference to the idea that was still in vogue at the time that indigenous societies were primitive groups that represented part of an evolutionary process; on the other hand, it was a manifestation of the belief that the Yanomami were savage due to structural violence. Savagery would be the result of a genetic propensity for the use of physical force, as well as an expression of the evolutionary process of indigenous societies.

A cultural trait of the Yanomami people is that a person’s name is not revealed in public (Albert 2005). To say someone’s name aloud is a serious insult. In general, the response of a Yanomami to the question “What is your name?” is a lie. The discourtesy is not in lying, but rather in the insistence of a non-Yanomami in needing to know some information that is socially considered to be a secret. An even more serious insult is to ask the name of a person who has died. Proper nouns are like very pejorative codenames that describe bodily marks, disabilities, or stigmas. It is expected, for example, that the name of a Yanomami child with a leporine lip would make reference to her body. But the name is not only a description of the person’s physical condition: it is also a depreciative enunciation of the person. As such, names are secret and their disclosure is considered an insult (Albert 2005).

In this social and cultural context with names as insults, it is easy to imagine the challenges of a genetic

study in which the reconstitution of family genealogies presupposes the identification of each person in a family tree. It was necessary to collect information not only on individuals, but also on the extended family. Given that genetic research traditionally raises these data through proper names, the fact that names were a cultural taboo demanded that Neel and Chagnon either interrupt their study or use culturally sensitive strategies for data collection on Yanomami kinship. Chagnon's choice, however, was to ignore the Yanomami's values and maintain traditional parameters for genetic research with urban groups: the genealogies were mounted by recovering the names of individuals and their kin network, including the Yanomami who had died.

Chagnon was the researcher in charge of gathering these data (1968, p. 8). But instead of using his ethnographic knowledge to identify possible strategies for gathering data without offending local values, Chagnon opted for two research techniques: 1) he offered presents to children so that they would reveal their names and the names of their family members; and 2) he offered gifts to the Yanomami's enemies so that they would inform the Yanomami's names (Chagnon 1968; Tierney 2002). To test the veracity of the information, the name of the person was said aloud and Chagnon evaluated the intensity of indignation that the enunciation provoked. In his own words, "[...] I made use of the fights and local animosities to select my informants [...]" (1968: 12). With this dual strategy, Chagnon recovered a large part of the Yanomami genealogies.

The data presented spoke of secret information and cultural taboos, as in the case of proper names. Chagnon not only acquired these data through the use of strategies considered to be controversial, but, even worse, made them internationally public through films and books. It is necessary to note that one of Chagnon's methods for collecting such information was to recruit children in exchange for presents. This situation permits one to question the validity of the data collected, since the children who wanted presents could have lied in order to obtain them. With the proper names recovered and the genealogies constructed, Neel's team began the collection of blood samples for research, but everything indicates that he said the collection was part of a preventative procedure for public health.

Finally, one of the most recent questions about the case of the Yanomami blood is about sharing post-study benefits. As a general rule, studies in social science are not profitable like the biomedical studies sponsored by pharmaceutical companies. Nevertheless, in exceptional situations, it is possible to earn money, benefits, and prestige from research. Chagnon is an example of a social scientist who earned a lot of money because his books and films were widely read and watched in many countries around the world – it has been estimated that he made more than one million dollars from his copyrighted material (Borofsky 2005). Is there a moral obligation to share these financial and symbolic profits with the groups that were studied? If so, how should

the researcher go about doing this? Should post-study obligations be on the agenda of discussions in human sciences, or should this be a topic that is restricted to the biomedical sciences?

### Homosexual practices in public spaces

"My research in tearooms required such a disguise. Does it, then, constitute a violation of professional ethics?" (Humphreys 2008a: 167). Humphreys was conscious of the ethical challenge to his methodological strategies during field work: concealment and disguise. His study was conducted in public bathrooms in the United States with anonymous men who met with other men by chance for sexual practices. Humphreys gained the confidence of the men who would go to the bathrooms by assuming the place of a *voyeur* in the erotic game, but his role in the observation was also to announce the arrival of strangers or the police. For months he wrote in his diary about the stories, practices, habits, and routines of men in public bathrooms practicing fellatio. The second part of his fieldwork consisted of interviewing 134 men in their homes. For this, he registered his subjects' license plate numbers, and with the help of a police officer was able to obtain access to their addresses. With a sample of 100 men in his hands, he registered to be a volunteer for the public health services in the region and participated in a large survey about male health. With authorization from the coordinator of the survey, he was able to include his own questions and personally interview 50 of the men from the public bathrooms and 50 men from a control group.

Humphreys was a young sociologist whose doctoral thesis resulted in the publication of *Tearoom trade: impersonal sex in public spaces* in 1970 (Humphreys 2008a).<sup>4</sup> His dual training – as a priest and sociologist – and his continuous affirmation that he did not participate in the homoerotic scenes opened a torrent of ethical discussions about his research techniques. The first part of his fieldwork required concealment. Humphreys assumed the place of one of the characters in the secret encounters in the bathrooms: that of *voyeur*. As *voyeur*, he considered himself as a participant-observer in the sexual scenes. In the second phase of his fieldwork, to protect himself from being identified by the anonymous men, the researcher used disguises: "I changed my hair style, attire and automobile. At the risk of losing the more transient respondents, I waited a year between the sample gathering (in the tearooms) and the interviews" (2008a: 179). The first part of the study took place in public bathrooms, and the second was in the men's houses. His defense for the use of these research techniques was the allegation that only concealment would give him access to the secret world of the homosexual practices in public spaces, and that only with the disguises would he have access to the men's domestic life for the interviews. These two techniques together offered sufficient data for his analyses, which were politically motivated to break down homophobia.

Some people consider that Humphreys' motivations for his research justify the use of concealment and

disguise. Others defend his techniques since the observation took place in public spaces; therefore, there was no violation of privacy. Nevertheless, a large part of the debate around his work occurred because the techniques of concealment and disguise in social research restrict freedoms and can violate the privacy and intimacy of the participants (Glazer 2008; Hoffman 2008; Horowitz & Rainwater 2008; Humphreys 2008b; Warick 2008). In the field of social psychology, the techniques of disguise are still recurrent strategies for the simulation of daily or private social situations with the intention of compiling data that would not be able to be collected through ordinary observations. In the 1990s, James Korn estimated that 50% of the studies in this field used disguise techniques (Korn 1997: 2). In other areas of social research, nonetheless, these techniques have provoked intense ethical controversies for decades (Roth 1962; Erikson 1967; Haggerty 2004).

Many commentators on Humphreys' work organized the ethical controversies according to the phases of the study. In the first part of the fieldwork, the fact that the objects of observation were anonymous encounters in public places protected Humphreys from the accusation of violation of privacy; however, the same justification was not sufficient to justify the second part. Humphreys entered the men's homes, knowing about their intimate affairs, and went on to ask questions about their conjugal, familial, and affective lives. Some commentators consider there was such a strong violation of privacy that, immediately after the study's publication by the media and the opening of a disciplinary action against Humphreys, several men went to the author's university because they felt threatened by a possible release of their names and stories (Glazer 2008). Humphreys defended himself by thoroughly describing how he planned each step of the study, how he burned the original field notes, how he took out anything that could identify the men from the interviews, ultimately, how he had planned each phase of the fieldwork in such a way that he preserved the anonymity and privacy of his informants (Humphreys 2008). None of the men were identified, even after the intense public contestation that the book provoked.

One of the central questions provoked by his work was: to what point can scientific curiosity advance in the study of issues related to people's private lives? Humphreys was part of a generation of sociologists who believed in the importance of investigating all of the spheres of social life, especially what was known as "deviant behaviors" in the 1960s. The gay world was one of these unknown and secret aspects of society. In this context, Humphreys, who received the C. Wright Mills Sociology Award for his academic rigor, was a hero, because of the way he protected his informants, and because of the daring of his work. However, other sociologists believe certain spheres of human life can only be shared with scientific scrutiny if explicitly consented to by the participants. This does not mean that there should be secrets hidden from scientific curiosity, but that the secrets can only be unveiled with the consent of the detainer.

## Genetic counseling and health teams

Charles Bosk (1992) followed the tradition begun by Whyte of confessional words in the appendix of *All God's mistakes: genetic counseling in a pediatric hospital*, an ethnography about the medical work of genetic counseling in an intensive therapy pediatric unit in the United States. The book was written ten years after the fieldwork, so it is a combination of memories and reports from the field. The 1980s marked the resurgence of clinical genetics as a medical specialization guided by the principle of respect for autonomy, a turning point from the eugenic Nazi past. But, unlike a large part of the ethnographic tradition in medical anthropology, Bosk chose to have the medical team itself as a participant in the study. Including the doctors as informants meant moving them from their traditional social roles in a study to a new one: that of research participants. This displacement brought a series of ethical challenges while publishing results, something common in research with urban elite groups who have access to the ethnographic reports (Bosk 2001; Hoffmaster 2001).

Starting at the hospital was unusual – an invitation from a medical team to accompany and understand the work of doctors during genetic counseling. In other words, Bosk was invited to be an ethnographer for genetic counseling. Some rules were agreed to in this invitation: the confidentiality of the participants would be guaranteed, there would not be any identification of the hospital, and the focus would be on the professionals, not the patients. The hospital was described as a reference center for genetic counseling and called Nightingale, which demonstrates his commitment in establishing a group of descriptors that would come close to the reality being studied, but which preserved the anonymity of the institution and the informants.

If for other ethnographers social and cultural distance between researcher and social group is permanently announced by racial, linguistic, or gender markers, in the case of Bosk, "I was just another white, male doctor, in a tie, asking questions and taking notes" (1992: 173). The symbolic proximity between ethnographer and participants associated with entering the field through an invitation from a group of doctors strengthened the expectations of complicity in the ethnographic narrative: ethnography should not cause surprises from the point of view of the team about itself, but should be a strengthening of its sense of identity and of belonging to the quasi-sacred character of the trade.

This was not what happened. Inspired by the idea that a good ethnography is one that discerns what is not said by the social order that one lives in, "making the latent manifest" (2001, p. 209), Bosk was faithful to his ethnographic commitment: the medical team was his research group, so their routine, jargon, ironies, and disputes were described. One printed version of the book was presented to the director of the hospital, his key informant in the study, before its public release. The reaction was immediate: "A Mop-Up Service, Janitors, Shock Absorbers'... Oh no... Bosk, you can't say this", said Bill. The assistant

responded, "But why not, you say it everyday". Bill told her, "That's different. I say it to you, to the walls of my office, to the conference room. It's one thing for you all to know what I think. It's another to put it out there for everyone to see. How will I work with these people?" (Bosk 2001: 208). Bill was a pseudonym for the director of the hospital, Bosk's key informant who began to challenge him about the borders between being a member of a team and an external observer. Where was the informed consent form for each dialog, each encounter, each field note? Yet, the pertinence of this question is debatable. Not even in biomedical research is the informed consent form requested before each procedure; there is only one authorization to be included in the study.

Bosk began a great argument with the hospital team. The research project had been approved by an ethics committee from his university and had received the informed consent from the whole team of geneticists. It was an initial consent to enter the hospital, with clarifications about the objectives of the study and the long stay of the researcher in the service of intensive therapy, but not for each social scene registered in his field journal. During the dispute about not publishing the manuscripts, one of the arguments launched by the director of the hospital was to try to translate the consent form for ethnography in terms of the one for biomedical studies: the consent should have been for a specific set of technical procedures, such as blood exams, tests of medications or other clinical procedures, which would mean that, for ethnography, there would be no general consent, and consent for pre-determined social scenes would be required. This analogical reasoning would mean the impossibility of ethnographic research itself, since a routine of continuous ruptures to announce the consent form would modify the social order and impede the fluidity of social phenomena.

This controversy led Bosk and the director of the hospital to an agreement: details that could allow identification would be replaced; errors that were by chance in the description of diseases or diagnostics would be corrected; nevertheless, the interpretation would belong exclusively to the researcher-author and would not be shared with the team of participants (Bosk 2001). The controversy with ethnographic research did not happen during the fieldwork, since the questions were not disturbing; the permanent presence of the ethnographer did not cause estrangement; and his habit of taking notes was not a matter of greater concern. The controversy was related to who had the right to interpret the data, which Bosk had assumed to be his exclusively. It was from that point on that the team began to review the conception of "research zone" in which the ethnographer lived. For the research participants, that was their private life at work; for the ethnographer, that was a research situation. The health team did not identify errors in the ethnographic description, but felt uncomfortable, and even humiliated, by Bosk's precise reports.

This research incident brought Bosk closer to bioethics and caused him to begin writing about the ethical

challenges of the biomedical method for ethnography, and also about the ethical particularities of ethnography (Bosk 2004; Bosk & Vries 2004). If the rules of ethical review were considered the same for all of the fields, there would be no way of keeping the ethnographic method as a valid research technique. Bosk's question "How can we expect our subjects to intuit our objectives, to see the world clearly from our point of view?" (2001: 214) is still worrisome, if ethics in social research were to be considered by the participants' degree of satisfaction with the ethnographic report. This, normally, would not happen. Because of this, a great part of the ethical controversies in social science occurs while releasing data, especially when the study is conducted with groups that have access to the results of the study, as occurred with Bosk (Erikson 1967; Hoeyer et al. 2005). Certainly, this contains an ethical challenge which accompanied the proper genesis of the ethnographic method; however, since the first studies were conducted with groups who did not have access to the ethnographic reports, this question did not arise during the work of the first generations of ethnographers.

### Social movements and animal rights

The story of Rik Scarce is unique in the field of ethics in social research, especially regarding the freedom to conduct research. Still a doctoral student in 1993, Scarce was arrested for 159 days for not handing over his tapes and field journals to the police (Scarce 1994, 1995). As he did not accept collaborating with police and judicial investigations against one of his informants, the ethnographer was considered a suspect for having privileged information about a case that had happened at his university. As a journalist, Scarce had been the author of a book about environmental movements that promoted civil disobedience and property damage for the liberation of animals in captivity. Scarce was already a specialist in social movements for the defense of animal rights when he decided to dedicate his doctorate in sociology to the theoretical questions related to the movements. By coincidence, during his fieldwork a "rescue attack" took place on the Washington State University campus, where he belonged. Coyotes, rats, and ermines were freed in a nocturnal attack. The case was widely published in the newspapers.

Scarce was indicated as a specialist to collaborate with the police investigations, not only because of the book he had published as a journalist, but also for having interviewed the leaders of the political movements during his doctoral research. Scarce was notified that he should compulsorily inform the courts and the police of what he knew about the "rescue attack" and the suspects to the university. Yet, Scarce did not violate the confidentiality and secrecy deal that he had established with his informants before the interviews. In all of the judicial inquiries, he only answered the questions about information that was obtained through other means, not through the interviews granted under the promise of secrecy.

After a long trial, Scarce was indicted as a “recalcitrant witness”, whose sentence was up to 18 months of prison. He stayed in prison for five months for refusing to testify against his informants. Scarce’s resistance during the depositions was so great that there is almost no information about what he could or could not have known about the “rescue attack” at the university (Scarce 1995). He took a stance of total silence in response to the questions about the political leadership of the movement or about the events investigated. For not knowing that social research should be reviewed by an ethics committee, Scarce’s study had not been submitted to his university’s board before the beginning of the interviews.

The case opened an intense discussion in US sociology about academic freedom, ethics in social research, and confidentiality (Cecil & Wetherington 1996; Gordon 2003; Katz 2006; Dash 2007). As a journalist, Scarce would have had the right to protect his sources; therefore, he would have guaranteed the secrecy regarding the origin of his data against a police investigation. But as a sociology student, he did not have the protection of confidentiality for research. Journalists and sociologists can use the same research techniques – interview and observation; nevertheless, only journalists have the right to protect their sources. In the ethical review model in the United States, there is a device known as “certificate of confidentiality”, which researchers request in order to guarantee the protection of their participants and not be forced to present their data in police investigations (Palys & Lowman 2000, 2002; Katz 2006). Scarce had not requested the certificate of confidentiality and did not act as a journalist in the study, despite his training in the profession. Either he had to hand over his data or be considered an opponent to the investigation, so he was arrested.

In almost every country, there is no guarantee of privacy for social science researchers. This is also the case in Brazil. The delicacy of the research topic does not matter; when there are judicial or police investigations, the researcher may be obliged to reveal his/her sources. There are few methodological reports of how researchers protect themselves from possible risks of violating privacy, but methodological precautions, as the ones explained by Humphreys (2008a), are established case by case. In many studies, the guarantee of confidentiality is a necessary condition for the possibility of conducting the study; otherwise, the informants would not be disposed to participate, running the risk of being imprisoned or having their privacy violated. Important topics for public safety, such as illicit drug trafficking, for public health, such as abortion, or for the protection of youth, such as pedophilia, need to be studied by observation or interview, but how can one conduct this type of study without imposing risks on the participants?

The boundary between social research and journalism is established not only by their different levels of protection in the exercise of the profession, but also by their ambitions in relation to the results. In the same way, social research should not be confused with police investigation: is it possible to do research on illegal topics

without putting the participants at risk? Do researchers have the right to study illegal practices? If so, what guarantees can the committees offer the researchers? What guarantees of protection do the researchers offer the participants? Today these are guarantees of methodological safeguards, such as the destruction of tapes, the use of pseudonyms, or the promise that, in cases of litigation, the data would not be handed over to the police or the courts. Another possibility would be the removal of whatever information that could identify the participants from the research files. As such, what could be solicited by the courts would always be anonymous.

## The main challenges

As in the debate about biomedical research, these cases assume a privileged role to potentiate the limits of ethical reasoning. The vast majority of social research does not threaten the integrity or the safety of the participants, as could have happened in Humphrey’s study; does not impose feelings of humiliation on those interviewed, as Bosk’s report provoked; does not deal with illegal topics, as Scarce’s study did; or does not violate the basic precepts of social life, as Chagnon did. This does not mean that the committees should impede studies with risks or studies whose ethnographic reports could provoke ambiguous feelings in the participants. On the contrary, what these cases show is the importance of analyzing each study from the phenomenological particularities involved. Humphrey’s same study, for example, could have been conducted by a gay ethnographer, whose close relationship with the participants would offer them safety and not threaten their privacy. Whyte’s study, on its turn, would not have been the object of great controversy if there had not been a break in the anonymity of the key informant, no matter how much time had passed after the completion of the fieldwork.

But the cases explained here have the role of imploding the ethical safety of social research: as the risks are less than those present in biomedical studies; as the techniques of social research simulate daily social relationships, such as doing interviews; or as some techniques do not impose disturbances on daily scenes, which is the case with ordinary observation, it is believed that the topic of research ethics should not reach social research. But the resistance should not be in making social research and ethical review closer, but in considering the norms and practices of biomedical knowledge valid and legitimate for social research. A large part of the international debate about social research and research ethics resists the classification of social research in the biomedical fashion of methods, techniques, and results (Citro et al. 2003; Marshall 2003; Bosk 2004; Bosk & Vries 2004; Haggerty 2004; Hamilton 2005; Hoeyer et al. 2005; Ells & Gutfreund 2006; Katz 2006, 2007; Dingwall 2007; Feeley 2007; Guerriero & Dallari 2008; Morse 2008). The fields are different, and the richness of the ethical analysis will only be seriously considered when the disciplinary and methodological specificities are equally recognized.

Among the challenges faced by the committees, two summarize the rumors and the tensions shared by social researchers when they submit their projects for ethical review. The first is the model of deductive reasoning expected in a research project. Not all social research projects have the same sections as a biomedical project, with specifications about problem, hypothesis, sample, criteria for inclusion or exclusion of participants, and pre-established risks or benefits. There are many social research protocols that arise from one question, and it is from the interaction between theory and reality that the research question is delineated. A large part of the visual ethnographic narratives, for example, is found in this format (Diniz 2008). For these investigation formats, it is particularly challenging to interpret the regulations of Resolution CNS 196/1996. The result is either the complete rejection of the ethics committees by social researchers or the presentation of projects-for-approval, which are disassociated from the daily practices of the researchers' knowledge. These could be projects evaluated under the criteria of "simplified evaluation", as has been instituted by various international ethical review systems (Bankert & Amdur 2006).

The second challenge is the requirement of the written informed consent form before data collection. Many social investigations use interview techniques, which comprise a formally defined research setting, thus allowing the presentation of the form before the beginning of the social interaction between researcher and participant. It is in this style of fieldwork that most of the studies done in the interface between the humanities and health are found, specifically for social researchers coming from the biomedical fields. Nevertheless, the same requirement renders impossible ethnographic research with other cultural groups, with illiterate populations or even with communities in which *rapport* is a condition for the researcher to get close to the participants (Gubrium & Holstein 2002; Plattner 2003; Hoeyer et al. 2005; Alasuutari et al. 2008; Morse 2008). Without *rapport*, there is no confidence, and without confidence there is no reciprocity for the research. Also, without *rapport*, there is no way to present the informed consent form, which resembles a contract between people with interests that are in dispute, where risks, benefits, damages, and protections are defined. A great part of social research has a minimum risk, and for this an oral informed consent is sufficient to guarantee that the meeting is genuine and voluntary between the parties. The other possibility is to use the informed consent form at the end of the fieldwork.

If the intention is to assume that social research should be evaluated by ethics committees, this movement will demand a review of the members' revision practices. The first change will be a turnabout in the way of looking at research, an amplification of what is understood by research. The challenge will not be to include all of the fields under the category of research, as defined by Resolution CNS 196/1996, but seriously begin a debate between the fields about how they desire to be understood for the purpose of ethical review. Should a play, a documentary, or a journalistic piece

that demand interviews or observations all be evaluated by a committee? If so, under what criteria? If not, how would the interests and rights of the participants be protected for these research initiatives? The statement that any study with participants presupposes a review by committees is not a sufficient answer to subordinate all fields and techniques to the committees that were inspired by biomedicine.

The second change presupposes an extensive sensitization of the committee members regarding social research. It is not enough to have the disposition for an interdisciplinary point of view; the committees need specialists in the different techniques and methods that they need to analyze. The creation of committees specialized in social research is one way out, as was proposed by the University of Brasilia in 2007. The elaboration of specific guidelines about research ethics in human and social sciences, which could assist social scientists as well as members of research ethics committees, is another strategy.

## Notes

1. Debora Diniz was responsible for writing the paper and Iara C. Z. Guerriero included her contributions.
2. This does not mean that social research with quantitative techniques does not exist. The concept in this article is instrumental for representing the fields and methods that use qualitative techniques for gathering and analyzing data.
3. This case was originally presented in a more detailed version in Diniz, 2007.
4. Tearoom is an English informal expression to indicate homosexual meetings in public bathrooms.

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