

Scientific disputes that spill over into Research Ethics: interview with Maria Cecília de Souza Minayo

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This is an interview with Maria Cecília de Souza Minayo, by university lecturers Iara Coelho Zito Guerriero and Maria Lúcia Magalhães Bosi. It reflects the heat of the current debates surrounding implementation of a specific protocol for evaluation of research in the Human and Social Sciences (HSS), vis-à-vis the current rules set by the National Health Council, which have a clearly biomedical bias. The interview covers the difficulties of introducing appropriate and fair rules for judgment of HSS projects, in the face of a hegemonic understanding of the very concept of science by biologists and medical doctors, who tend not to recognize other approaches unless those approaches adopt their frames of reference. In this case, the National Health Council becomes the arena of this polemic, leading researchers in the human and social sciences to ask themselves whether the health sector has the competency to create rules for other areas of knowledge.

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1. Iara Coelho Zito Guerriero (ICZG) and Maria Lúcia Magalhães Bosi (MLMB): Taking into account your experience as an anthropologist of health, and an investigator who, when you were a member of the National Health Council, voted in favor of Resolution 196/96 (now repealed by 466/12), and as an author of publications on the subject, and currently a member of the author of the Conep HSS Working Group (GT CHS/Conep) responsible for preparing a resolution for HSS, we would like to hear opinions from you on the importance of that Resolution, and what justifies it.

Maria Cecília de Souza Minayo: I think it's fundamental to have clear rules for the human and social sciences, because, on the one hand, it's not right that the biomedical areas should colonize another field and subordinate it to their logic. On the other, the HSS also need orientation, and cannot consider themselves to be above any law or rule: their history shows many successes and contributions, but also some mistakes – some of them classic mistakes – in relation to the populations with which they work.

Yes, I was a member of the National Health Council in the name of the SBPC, and I voted in favor of Resolution 196/96. At the time, it was a new development for all of us, and the health area was under the effects of some accusations. There were reports of collection and illegal sale of the blood of indigenous Brazilian populations; and, also, a certain negative influence from the work of the anthropologist Nancy Scheper-Hughes about “selective maternal negligence” – an interpretative category that she had created to refer to the behavior of poor mothers in Recife who, according to her interpretation, allowed their ill and weak children to die, giving priority to the stronger and healthier ones, due to personal powerlessness and the lack of social and health support to take care of them all (this interpretation turned out to be not only superficial, but also unjustified, and cruel to the women referred to; the research survey had taken place what any social control or supervision by any public bodies).

Over time, and with the day-to-day practice in presenting projects to be evaluated by ethics committees, I and the majority of my colleagues in the social sciences and the humanities, principally those that work with health subjects, began to realize the inappropriateness of the instruments proposed by Resolution 196/96 for analyzing the ethical aspects of empirical research in

the human and social sciences, particularly in the case of anthropology.

2. ICZG and MLMB: Could you comment on some aspects of this ‘inappropriateness of the instruments’ that you refer to, based on problems that you have witnessed?

MCSM: The difficulties for researchers, like myself, who work in qualitative and anthropological investigation – which by nature include inter-subjective relationships as the kernel of the process of comprehension – come prior to the procedures demanded by the Ethics Committees with a biomedical focus, and go back to the established academic discourse of the ‘hard’ sciences, which only recognizes as science whatever can be quantifiable. This hegemonic logic is present in the Ethics Committees, in the form of rules.

I will give three examples of difficulties that I have encountered:

(1) The demand to explain in advance the number of participants of a given survey, when the concern should be to know whether the universe proposed is sufficiently broad-based (for example, whether different actors that are part of the same question being studied will be heard, in a quest for a process of ‘saturation’ moving toward illumination of the problem and also of the context). In the insanity that accompanies each demand there are people who decide, in advance, that if there are not at least 30 interlocutors, the research will not be representative. Where did this magic number come from? What criteria is it based on? There is no theoretical grounding – neither in anthropology nor in the various theories of social research – to justify it.

(2) The requirement for individual signature for groups or people who only give their testimony if this does not involve any signature on paper, such as cases that involve situations of transgression.

(3) Demand for signature for processes of participatory observation, when what one is trying to achieve is spontaneity of communication, which seeks to achieve a triangulation between interviews, focus groups, or, in many cases, establishing a confrontation between the theory and the practice of official discourses.

I could continue giving examples, but I would like to reiterate the difficulties of coexistence between the biomedical model and a proposal that includes appropriate rules for the HSC are part of the incomprehension and the de-valuation of the nature of this scientific field by the biomedical sciences.

3. ICZG and MLMB: One question that is always present is the dissatisfaction of researchers in the human and social sciences with having to follow the resolutions that have been in force up to now, which, as well as being oriented by the biomedical model, are approved by the National Health Council (CNS). Although everyone recognizes the importance of the CNS, they question the legitimacy of the health area to make rules for ethics in research for all the areas of knowledge. One can ask, for example, why does a researcher who studies religion have to follow these rules?

MCSM: In a way, I have already answered that question, and I fully agree that the health area does not have the right to impose its vision on other fields of knowledge. For this reason, it's my view that the CNS has taken a very important step, through the National Research Ethics Committee (Conep), in creating a work group to discuss the questions brought up by the HSS, bringing together anthropologists, sociologists, psychologists, historians, teachers, social assistances, law scholars and others, all supported by their respective scientific associations. I think this joint participation is very important, since the Health and Social Sciences are not a specific discipline - they practice a reading of the phenomenon of health/illness from the perspective of the HSS, and at the same time take the health sciences as a reference - one might perhaps say, an interdisciplinary hybrid.

The human and social sciences, in the strict sense, constitute the field that generates both the philosophy and the ethics of the various disciplines. However, in the overall context, it has been the health sector that has made the call to conceptualize a protocol that is appropriate for the ethics of the social and human sciences. It could have been another area - which, perhaps, did not feel authorized to make this call. I believe, however, that whoever is making this call cannot think of themselves as owner of the right to think about, formulate and make rules for - in some cases, censure - what another field of knowledge, in strict observance of its basic principles, has established.

4. ICZG and MLMB: Would it be more relevant if the CNS were to make rules for HSS surveys only in health? What would be the advantages and disadvantages of this as an option?

MCSM: I think that the option of the CNS making rules only for HSS work in health would resolve the problem internally for those who work in the sector and suffer from lack of understanding and disputes with the biomedical area, always trying to apply their logic in a homogenous way to the whole of the field of the life sciences. But this would be a contingent solution, since as I said above, the human and social sciences in health do not constitute a field per se. They are part of the wider logic of the HSS, on which they base both their philosophical and ethical principles. For this reason, the ideal solution would be to build a common code in which all the disciplines of the HSS find a response for their language, method and needs, including for the human and social sciences in health.

5. ICZG and MLMB: Preparation of a resolution for the HSS in the ambit of the CNS creates a process with singular characteristics. The representatives of the field of law that are members of our working group warn that on the points where a specific resolution for HSS turns out to have omitted something, Resolution 466/12 will take effect. Since Resolution 466/12 is visibly centered toward the biomedical area and assumes a positivist conception of science, the working group opted to prepare the draft by comparing each item with Resolution 466/12, so that there would be no omissions. This resulted in a text that was long, and difficult to adapt to the whole paradigmatic and theoretical-methodological diversity of the HSS. If it had not been for this, we could have considered the possibility of preparing broad general principles, without this level of detail. We would like to hear your comments on this.

MCSM: I think that the difficulty in establishing and maintaining the necessary dialogue has reached the point of becoming an arena of political dispute in which the HSS seek space in a field dominated by the biomedical logic. From my point of view, going into too much detail on the questions only creates casuistry and makes procedures in each individual area more difficult. However, given the overall context, the comparative exercise could be a step towards showing the inappropriateness of the domination by one

field over the other. Considering this hegemony to which you refer, and that the attribution of the CNS is specific to the field of Health, it would be more appropriate that the preparation of the directives/guidelines for surveys in HSS, and also the management of the Research Ethics Committees, would be made by another instance, that would include all the areas of knowledge, such as for example the CNPQ/MCTI. But this last proposal is only an opinion which, I believe, will not be likely to win over others at the present moment.

6. ICZG and MLMB: One of the points of dissonance between Conep and our working group relates to maintaining the work group in such a way as to accompany the actual application of the resolution in the processes of review. This is because we believe that the guarantee in the discourse, even though fundamental, does not ensure the consolidation of the processes, especially when it involves creation of a new culture, as appears to be the case. As to this, there has yet to be established a guarantee of a parity-based, or at least equitable, composition, between researchers with different areas of focus. How do you see this specific aspect?

MCSM: I fully agree that it is necessary, at least temporarily, that the work group of the HSS should accompany the application of the specific rules established for the research surveys of individual areas. As I said in answer to the first question, it was in our work practice that we began to see the inappropriateness of the rules established by Resolution 196/96 for the Human and Social Sciences in Health. In the vigilance over what is prescribed and the practice, directions taken are corrected and formulations are improved. There are no unbreakable rules, nor rules that are able

to be applied in isolation. As to the composition of the Conep, I think that equitable presence of representatives of the HSS is absolutely fair.

7. ICZG and MLMB: As well as the aspects that we have selected in the questions we have asked you, what would you like to add, in relation to the complex process that is underway?

MCSM: I would like to give a reminder – although I believe that for most of the readers of the magazine this may be well-known – of what I have written in the articles that I have published together with you, Yara. Ethics is not something that one injects into a project so that it will be approved, nor is it to be confused with procedures. It should be an intrinsic part of the behavior of a research investigator all the way from decision on his subject to the publication of the results. Thus, although a Committee can only act based on the information that it has, the research investigator's commitment goes beyond the technical shape of his or her investigation: the researcher needs to look at and take into account the meaning and the significance that his/her investigation will have for society, and, especially, for the group that he/she is studying in inter-subjectivity; fair and correct relationships with the financiers; and the way of dealing with and describing his/her team – including the students in it – for example, giving a credit to all those that take part in the work.

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