

O que é ética em pesquisa

Dirce Guilhem and Debora Diniz

DOI: 10.3395/reciis.v2.Sup1.215en

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The topic of research ethics has been the target of debate among researchers around the world and has also been receiving more and more attention from Brazilian scientists (Guilhem et al., 2006, 2007a, Diniz 2007, Guerriero et al. 2008). The adoption of ethical measures as a way of protecting the research participant's rights is now common consensus in the scientific community. Nevertheless, during the 20th century, many abuses occurred because scientists did not respect the participants' fundamental human rights.

The book "What is Research Ethics", which was launched at the last 2008 Meeting of the Brazilian Society for the Progress of Science, by authors Dirce Guilhem and Debora Diniz, has two main goals: to describe the historical trajectory of the happenings that culminated in the protection of the rights of people involved in scientific studies and to present the current challenges in this area of knowledge. The book, which is part of the "Primeiros Passos Collection", a traditional Brazilian collection aimed at the training of university students, professionals, and other people that are interested in understanding new concepts and disciplinary fields, fulfills its role by presenting, in a didactic yet dense way, a panorama of research ethics, concepts, and tools.

Guilhem and Diniz present the main ethical abuses that were committed during the last century and the resulting consequences in rich detail. The first part of the book explores the scientific experiments conducted with human beings not only in the Nazi concentration camps but also in universities and health institutions situated in developed countries. Cases such as the Tuskegee study, a study with black Americans who had syphilis and were deprived of access to available medicines, are



São Paulo: Brasiliense, 2008. 105p.
(Coleção Primeiros Passos).

ISBN: 978-85-11-00145-7

analyzed and allow us to understand the limitations that researchers had in respecting the participant's rights. Also, the authors present the repercussions that were raised by abusive studies inside as well as outside the scientific community. The first part of the book ends with the presentation of the impact caused by government measures, international accords, and the writing of documents that established guidelines for research with humans. The book discusses the significance and impact of the Nuremberg Code, the Helsinki Declaration, and the Belmont Report in the 20th century and their effects today.

The second part of the book presents the institutionalization of research ethics through multidisciplinary committees aimed at revising these protocols. In this part, the authors dedicate themselves to an analysis of the Brazilian research ethics system, which is different from existing systems in other countries. In Brazil, the research ethics system was created by the National Health Council, an organ bound to the Health Ministry and composed of representatives from the civil society, universities, and the State, through Resolution 196/1996. The Brazilian research ethics system is constituted of the Brazilian National Commission for Ethics in Research (Conep in Portuguese) and the Research Ethics Councils (CEP in Portuguese) that are distributed throughout Brazil and are located in academic and health institutions (Guilhem et al. 2007a). Until February 2008 there were 584 CEP subordinate to Conep, which centralizes and controls the ethical review for Brazilian research. It is through Conep that Brazil creates specific regulations that delineate guidelines involving, for example, multicentric studies and vulnerable populations, as is the case with indigenous participants.

The Brazilian system of research ethics is inspired by the Helsinki Declaration and counts on the support of several disciplinary fields, scientific editors, universities, and health institutions. Nowadays, it is almost impossible to conduct studies in Brazilian health institutions or even publish in Brazilian periodicals in the biomedical areas unless the researcher has submitted the research project for analysis by a CEP and has fulfilled all of the existing ethical guidelines. The specificity of the Brazilian research ethics system is still little understood by researchers in other countries in which, generally, the research ethics committees are located in research centers and there is no national organ that controls all of the ethical review processes.

The Brazilian research ethics system was strongly influenced by the methods and notion of risk present in biomedical studies. The consequences of this influence in the current Brazilian model are analyzed in the third part of the book where the authors discuss the contemporary challenges of research ethics. Currently, there is intense debate among researchers who do not consider it appropriate to apply all of the demands of biomedical studies on research in the social sciences (Victora et al. 2004, Diniz 2007, 2008, Guerriero et al. 2008). The authors are able to confidently identify the main

challenges put forth by social sciences for the Brazilian research ethics system. The book also presents inherited initiatives that have arisen in Brazil, as was the case with the first CEP that aimed exclusively at analyzing research projects from the Human Sciences, Social Sciences, and related fields. The authors indicate strategies capable of creating CEP that are sensitive to the epistemological and methodological specificities of distinct disciplinary fields from the biomedical areas.

Another example of possible change presented in the book is the adoption of an oral consent in place of the traditional written consent form. Despite the diversity among the different fields of knowledge, the academic community shares the need to adopt ethical measures. The book provokes the different fields of science to think of new possibilities for exercising social control on the evaluation of research projects. The current debate that exists among social science researchers shows how research ethics is a growing topic of interest in the Brazilian scientific community and indicates necessary changes to strengthen the system.

The question of a *double standard* is the other point that is explored in the third part of the book since it is directly related to the reality of developing countries, as in Brazil. Guilhem and Diniz explain that *double standard* was an expression that arose in the 1990s to describe the phenomenon of the relaxation of ethical standards in studies involving poor countries or developing countries that are usually conducted by rich countries. This type of relaxation occurs because researchers in developed countries use people in poor countries, with an absence of resources and in vulnerable situations, to conduct scientific studies that do not worry about the protection of human rights. The poor or developing countries are considered strategic loci for the development of some scientific experiments which would never be accepted in developed countries, where ethical vigilance and the defense of human rights is consolidated.

The topic of the exploitation of people in vulnerable situations has been the target of bioethical analyses and has already been explored in cinematographic works (Guilhem et al. 2007b). Some researchers defend the idea that given the context of scarcity existing in poor countries, the studies do not go against the physical and moral integrity of the people who are already on the margin of access to health services, medications, and other types of rights. Nevertheless, this position has been strongly combated by researchers in developing countries. Brazilian researchers had an outstanding role in international meetings for revising the Helsinki Declaration (Garrafa et al. 2008). All of the proposals to alter the declaration in favor of a *double standard* were refused as an acceptable ethical procedure if it depends on the social context in which the research participants are located. In posing the question of the *double standard*, the authors show how Brazil has occupied a leading position in the international discussion on research ethics.

In relation to the conceptual aspect, at the end of the book, the authors present a glossary with common

expressions from the ethics field and refer to the theories produced by the field. Besides the glossary, throughout the work, other concepts central to the evaluation of research projects and the protection of participants are also explained. One of the concepts discussed by the authors is that of “vulnerability”, which is fundamental for understanding how situations of exploitation are configured; that is, how participants could be exploited due to their personal and social characteristics. In virtue of the introductory character and target public of the book, the authors do not go into depth with the conceptual discussion of research ethics; however, at the end of each chapter, bibliographic references that found the discussions are presented. The reference lists can be considered a good starting point for readers who are interested in broadening their studies of the topics discussed in the book. It is possible to observe that the literature review that contributed to the writing of the book is up to date and broad. The references provided at the end of each chapter are classic texts or articles published during the last five years in Brazilian and international periodicals with recognized scientific merit in the discussion involving research ethics.

The message left by the book is that research ethics is a conquered right and needs to be recognized as well as respected by the different fields of knowledge. According to the data presented in the book, in fact, the ethical review system and accompaniment of research projects needs to be improved to attend the epistemological diversity that characterizes studies with human beings in Brazil and around the world. For this job researchers

must stop being critics of the system and begin presenting proposals that are capable of contemplating the evaluation of different types of research and the preservation of the participants’ human rights.

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