Ethics in research in the human and social sciences in health: identifying specificities

Researchers in the human and social sciences (HSS) have been identifying serious inadequacies in the resolutions on research ethics for quite some time. Even though Resolution 466/12 follows a biomedical rationale, its scope was unduly broadening for all areas of knowledge. It has had major consequences such as the rejection or delay of HSS research.

The discussion on research ethics is developed in the scientific field, which, according to Bourdieu (2003), represents a social space marked by specific power relationships. What is at stake is the positivist biomedical hegemony, which supersedes the other research traditions. From this, the definition of the ideal standard of science is derived, with its material and symbolic effects, causing major disputes to arise in this field, including the definition of guidelines for the different paradigms. Bearing in mind how can guidelines on research ethics be drawn up which, duly identifying the inherent disputes, respect the differences without discriminating the approaches, particularly when they do not suit the hegemonic model or paradigm? This is a major challenge for the task of drawing up ethical guidelines for HSS research, especially research that focuses on health, given their complex character as a biosocial phenomenon.

It represents a central problem: if we can initially agree on what are considered to be the sovereign principles, namely autonomy, beneficence, justice, non-maleficence and equity, the way they can be transformed into procedures requires their adaptation to the HSS. It is a challenge faced on the ontological plane, which, due to its complexity, demands respect for otherness and interdisciplinary dialogue. Illustrating just one of the principles alluded to the concept of autonomy is not a consensual point since it implies preconceptions about what is meant by being human, an individual or a person.

Furthermore, when considering these principles, it is necessary to assess both the social value and the scientific rigor of research. The dominance of biomedical research has unfortunately led to the lack of recognition of the social value of HSS research in not only improving health in the broadest sense, but also in fostering the capacity for critical thinking of its users, including health professionals. All research benefits from critique ethically and scientifically. This critique, however, can only be constructive if it is performed within the philosophical paradigm from which it is derived. Thus the scientific community, including research ethics committee members, must understand and respect a diversity of scientific and philosophical traditions.

Resolution 466/12 is indeed an advance, as it acknowledges that the HSS has specificities which highlighted the need for a specific resolution. To develop this resolution, the National Commission for Ethics in Research (CONEP) set up a Working Group (WG), which is composed of 18 national scientific associations, encompassing almost all of the disciplinary fields of HSS; the HSS Forum; the Ministry of Health and the National Health Council. This process culminated in the recent presentation of a draft of a specific resolution still under discussion that will shortly be put to public debate.

In this issue, organized by two researchers who are members of the CONEP HSS WG, several core issues discussed during the WG meetings are presented. They have all been examining the complexity and challenges of developing ethical guidelines for HSS that will aid in enhancing the knowledge of and respect for HSS research that are essential for equitable ethical review.

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