Charis Thompson
Good Science. The Ethical Choreography of Stem Cell Research.
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Stem cell research has attracted a great deal of scholarly reflection, both in the field of Science and Technology Studies and in bioethics. This is mainly due to the high level of public and political debate surrounding its regulation, triggered primarily by the complex ethical issues related to the use of the human embryo for deriving a particular kind of stem cell (namely human embryonic stem cell – hESC). The controversy over the legal and the ontological status of the human embryo, and its contested usability, has represented the main ethical, political and social issue in this field of biomedicine. Several scholars highlighted the overarching role of the embryo question, which would have overshadowed an entire range of concerns, problems and challenges in stem cell research and clinical application. Although prevailing, the embryo question is not the only controversial societal challenge qualifying stem cell research. Accordingly, STS and social studies of biomedicine have explored a variety of other challenges: quality control, clinical safety and effectiveness in therapeutic applications; standardization and validation in biobanking practices; social justice in access, affordability of available stem cell therapies and issues related to the procurement of embryos, eggs and cell lines (e.g. health risks for egg donors, inequalities and exploitations between the North and the South in the circuit of biomaterial supply). Therefore, the multiplex ethical, legal, political, social and cultural issues at stake, and their dense intertwinement with bioscientific practices and objects, make the field of stem cell research, and its regulation as much, a paradigmatic case of the ways in which science and society are mutually constitutive.

Charis Thompson in this book explores these overshadowed challenges in stem cell research, in order to outline what she calls "good science" or a science that has ethics – rather than a science that is simply dealing with ethics or constrained by ethical limits. After a decade of debates over the status of the human embryo in research on pluripotent stem cells (i.e. stem cells able to develop into any cell type of the organism, usually derived from the inner cell mass of an embryo), there is a tacit agreement on a fundamental disagreement on the embryo question, which turns the attention to other ethical issues.

According to Thompson, we face "the end of the beginning of human pluripotent stem cell research", where this research field is becoming to be normalized and standardized and thus new bioethical topics are emerging. It is time, then, to explore these topics and the "ethical choreography" of the process of consolidation of hESC research. Exploring the

ethical choreography means taking into account what kind of concerns emerge and gain public, political and regulatory attention, while others remain less visible. For attaining this goal, Charis Thompson develops an analytical framework based on the notion of "triage". Triage is the practice by which, in a hospital emergency department, patients waiting for treatments are classified and prioritized according to the seriousness of their condition and to the urgency of an intervention. Her approach aims at exploring how and why some issues come to the fore and are largely discussed while others are "left in the waiting room" (p. 12).

Her second goal is offering suggestions for establishing a good science in stem cell research. As Thompson argues, the book "takes a methodological and theoretical turn toward a more normative, policy-relevant approach to analyzing science and technology in society" (p. 9). In this sense, she criticizes the ELSI approach (ethical, legal, and social implications) in the governance of scientific research: problems related to the procurement of embryos and eggs for stem cell research are not implications, but preconditions. Similarly, questions arising from donation of biomaterials, standardization of procedures, access to therapies or participation in the value chain of this (bio)economic sector, as well as definitions of the role and rights of research subjects (as donors, patients, animal models or individual recruited for clinical trials) are part and parcel of the research itself. Charis Thompson invites to frame the ethics surrounding stem cell research into "the overall picture of health care" (p. 19) in order to better deal with ethical, social and economic issues arising in this field of biomedicine.

She notices that research on human pluripotent stem cells has taken place in what she calls the "pro-curial" frame, which (a) operationalizes the ethical problem within the procurement of biomaterials (i.e. human embryos, eggs and derived hESC lines) and thus solutions rely on ethically acceptable ways of procurement; (b) develops curatorial protocols and practices for managing the process of procurement; (c) deploys a procures rhetoric driving innovation and investment in this field (p. 29). Thompson discusses how the U.S. and Californian debate on human pluripotent stem cell research (the main case study of this book) has framed ethical issues in terms of procurement. What are the acceptable biomaterials (spare embryos leftover IVF treatments, embryos created for research purposes, stem cells derived from somatic cell nuclear transfer, adult stem cells, existing hESC cell lines)? And what should be the necessary bureaucratic procedure for attesting and securing the acceptability of these materials?

The strong point of Charis Thompson's work is that she shows how the problem of procurement does not rotate only around the embryo question. Problems related to donation of biomaterials, the exigencies of disabled people, disparities in access to health care, forms of benefit sharing of research outcomes, geopolitical differences in stem cell research and clinical applications represent issues that should be not only taken

into account, but also addressed to establish a "good science" in this biomedical field. For example, she explores and discusses the multiple issues related to the donation of biomaterials (e.g. embryos and eggs for somatic cell nuclear transfer) from the point of view of the health of women involved. She also addresses the well-known issue of property in donation: donated tissues enter in a value chain where donors have not a participation in the revenues and where the return in term of access to future therapies is not clearly defined. She discusses the problems related to the prohibition of compensation for donating eggs: while this prohibition is thought as promoting altruism, it clashes with the parallel market of gametes in IVF. This, in turn, may create a sort of market failure in biomaterial supply, which may be solved through a flow of biomaterials from countries with less strict rules on procurement and thus with exploitation of donors from these countries.

In addition, being this field of research supported by public funding, the return to taxpayers in terms of social justice and equity in the access to cure is a relevant issue, but scarcely debated and not sufficiently implemented into regulations. Thompson criticises the adoption of classical informed consent model for donation – which presupposes that the donor has rights neither in defining the research trajectory nor in the sharing of possible commercial outcomes. She, instead, claims that the emerging personalized medicine, and the development of epigenetics, calls for a strong and continuous interaction between donors and researcher. Thus, privacy and confidentiality appear as untenable. Similarly, the notion of withdrawal of consent is unfeasible in stem cell research: once stem cell lines are generated, it is impossible to predict what kind of pathways research and clinical application will take. Hence, Charis Thompson explores different consent models, where the interaction between donors and researchers is open-ended and forms of benefit sharing are envisaged. The author, thus, claims for a greater involvement of concerned subjects (donors, patients, investors, etc.) in every phase of human pluripotent stem cell research, in order to set up rules, procedures and practices answering to the multiplex ethical, social, economic and health care demands arising in this field of bioscientific research and future medical applications.

Although human pluripotent stem cell research in the U.S. and California is the focus of the book, another good point of Thompson's analysis is her exploration of different geopolitics of stem cell research, and her discussion of how the internationalization of this field and the competition among nations creates hierarchies that, in turn, could generate disparities and other ethical concerns. Despite the efforts of emerging international scientific organizations in the field (such as The International Society for Stem Cell Research) to establish international rules for quality and safety, phenomena such as that of stem cell tourism (i.e. ill people travelling to countries in which untested stem cell therapies are available) testify how the geopolitical pattern of stem cell research does not create a

horizontal international world, with a progressive standardization and harmonization of ethics and science practices. A world vertically stratified – not only in merely economic terms but also in access, affordability and safety of health care outcomes – emerges from her analysis.

Finally, in a very interesting chapter, the author addresses the issue of substituting animal models in research with in vitro cellular models. Using stem cells to study diseases and test drugs, indeed, implies not only the abandonment of exploiting animals or particular classes of individuals (e.g. prisoners or poor people through the clinical trial outsourcing in developing countries), but it could better fit the expectations of personalized medicine. In sum, besides the embryo question, a high variety of ethical issues are at stake in stem cell research, which should be addressed by regulations.

In conclusion, this book is a highly valued exploration of multiplex ethical and social issues and concerns involved in stem cell research, which are usually scantily discussed in public and regulatory debates (although they are not unknown in recent STS work on stem cell research). Its normative approach is undoubtedly useful to improve public and political discussion on this field of biomedicine and scientific research and, in general, for regulation and policy-making. However, in some cases, the book simply lists a set of ethical and social issues to be addressed, instead of proposing practical ways to implement them into regulations and into research and clinical practices. Furthermore, the analytical approach based on the notion of triage sometimes seems inadequate to produce analyses and explanations for the different attention gained by issues and involved groups' interests. In the book, it is not always clear why some issues are scantily debated and others gain prominence: Does it depend on cultural legacies, which prioritize some topics and silence others? Or does it rely on the power of involved actors in shaping the public and political agenda? The book, thus, seems more oriented to open a discussion with policy-makers and actors involved in regulatory processes, rather than scholars searching analytical frameworks for analysing and explaining the socio-technical dynamics shaping the making of a techno-scientific field.

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