

"What Does the Future Hold? Introduction"

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DOSSIER

BIOETHICS WHAT DOES THE FUTURE HOLD?

VARDIT RAVITSKY

CRÉUM

What does the future hold for bioethics? This young field of research and practice, which emerged in the 1960s, is now coming of age. Looking back, one cannot ignore its significant achievements. Bioethics helped establish the centrality of respect for the autonomy of patients and research participants. It has transformed the norms of medical care and the standards underlying bio-medical research involving human participants, thus contributing to the protection of vulnerable populations. Bioethics also led to the formulation of certain crucial guidelines that lay down fundamental principles in the area of ethics and health, documents that have garnered wide consensus and have shaped Western societies¹.

As it embarks on its 6th decade, bioethics may seem fully established. With its own academic journals, professional societies, university programs, graduate degrees, and even a variety of possible careers in industry and government, the future of bioethics may seem secure. Yet, the field is undoubtedly in its adolescent stage: it suffers from growing pains and its identity issues are far from resolved. Questions still abound: What is bioethics? Is it an academic discipline or an interdisciplinary field of study? Does it have agreed-upon theoretical or conceptual frameworks, research methodologies, or analytical tools? Or is it simply a set of questions posed by advances in the biomedical sciences and health technologies and answered in an unsystematic manner by a loosely-knit group of researchers who share similar interests²? And what is a “bioethicist”? While some embrace the title, others passionately reject it, sticking to their more traditional disciplinary backgrounds. Despite these ambiguities, bioethics is moving forward and expanding its areas of specialisation. So what challenges will it face in the coming decade?

Bioethics will have to do more of the same, but in a changing environment. It will have to pursue its traditional role of protecting individuals and promoting respect for autonomous decision-making, in the face of new threats to this autonomy. While the culture of paternalism within medical practice has largely changed, threats to individual autonomy now emerge from systemic pressures to increase the cost-effectiveness of the healthcare system. One expression of this new type of threat can be found in routinized opportunistic testing that does not meet the well-established norms of informed and voluntary consent. This challenge is addressed in Davis’ contribution to this issue and is certain to remain the focus of bioethical attention in coming years.

Furthermore, the norms underlying research involving human participants have changed, and elaborate systems have been implemented world-wide to protect the interests of research participants (and communities). However, a new research environment is emerging based on large-scale bio-banks and health information databases, often involving open ended longitudinal studies, international collaborations and transfer of information across borders. In this new environment, individual autonomy may once again be threatened in the name of pursuing knowledge that could benefit society and future generations. However, new rationalizations emerge to justify limitations to individuals' control over their information. This time, the principle of respect for autonomy is being countered by principles such as reciprocity, mutuality, and solidarity³. In this new research environment, new principles (some focused on appropriate governance mechanisms) sometimes overshadow the old and well-established principles of research ethics (such as respect for persons, beneficence and justice). Striking the right balance between the old and the new is a major challenge facing bioethics in the decade to come.

Bioethics will have to pursue a new path on which it recently embarked. After decades of focusing on the protection of individuals within the healthcare and the research systems, bioethics has finally turned its attention to the context of public health. Recognizing that the effective promotion and protection of health requires interventions and initiatives that go beyond the level of the individual, to the level of populations, public health ethics is beginning to address some of the unique ethical challenges emerging from the tensions between individual rights and liberties on one hand, and the protection of groups and populations on the other. Taking on this challenge has led, in the past decade, to a burgeoning literature and the development of fresh conceptual frameworks and new perspectives. Hurst reflects on this challenge in her contribution to this issue, and argues that public health ethics is certain to keep bioethics scholars very busy in the future.

Moreover, as Hurst insightfully points out, public health ethics is facing the "next-generation challenge" of ethical tensions not just between individuals and collectives, but also between different types of collectives. To date, public health ethics has attempted to cope with the tension between the individual and the collective (community, nation), based on the notion that there is a collective interest in promoting the health of all. The recognition that health is significantly shaped by the actions and interests of private collectives as well, expands the debate. Private sector interests do not necessarily coincide with the objectives of public health, as in the case of companies whose products have proven negative health outcomes (such as cigarettes). Challenges thus arise from the recognition that public health ethics must address not just two, but rather three points of view, as the role played by the private sector adds complexity to the more familiar tensions between individuals and populations.

Finally, another major challenge facing bioethics in the future stems from its own success. In 1991, David Rothman wrote the first historical account of the development of bioethics and titled it “Strangers at the Bedside”. Today, bioethicists are no longer strangers. They have successfully integrated into what used to be the hermetically sealed world of medical decision-making and research, becoming collaborators and even reshaping these environments. Bioethicists teach ethics in medical school, are members of or chair clinical and research ethics committees, and provide consulting services in hospitals, industry, and the public sector. Yet, their successful integration also raises questions regarding bioethicists’ ability to remain objective — even external — ‘watch-dogs’ who can operate with independence, integrity and “speak truth to power”. Some argue that bioethics needs its own code of ethics⁴. Will bioethics successfully meet these “internal” challenges? And how will it evolve as a field of study, even one with relatively fluid boundaries, in new emerging contexts? Although only time will tell, it is clear that the future of bioethics holds many surprises.

NOTES

- 1 The Declaration of Helsinki 1964, last updated 2008 : <http://www.wma.net/en/30publications/10policies/b3/17c.pdf>; The Belmont Report, 1978: http://videocast.nih.gov/pdf/ohrp_belmont_report.pdf; UNESCO's Universal Declaration on Bioethics and Human Rights, 2006 : <http://unesdoc.unesco.org/images/0014/001461/146180e.pdf>
- 2 Leigh Turner. 2009. Does bioethics exist? *Journal of Medical Ethics*, 35: 778-780. Daniel Adler and Randi Zlotnik Shaul. 2012. Disciplining Bioethics: Towards a Standard of Methodological Rigor in Bioethics Research. *Accountability in Research*, 19:187–207.
- 3 Bartha Maria Knoppers and Ruth Chadwick. 2005. Human Genetic Research: Emerging Trends in Ethics. *Nature Reviews Genetics*, 6: 75-59.
- 4 Robert Baker. 2009. The Ethics of Bioethics, in Ravitsky, Fiester & Caplan (Eds.), *The Penn Center Guide to Bioethics*, Springer Publishing Company.