Alireza Bagheri Jonathan D. Moreno Stefano Semplici *Editors*

Global Bioethics: The Impact of the UNESCO International Bioethics Committee



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Volume 5

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Global Bioethics: The Impact of the UNESCO International Bioethics Committee



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ISSN 2212-652X ISSN 2212-6538 (electronic) Advancing Global Bioethics ISBN 978-3-319-22649-1 ISBN 978-3-319-22650-7 (eBook) DOI 10.1007/978-3-319-22650-7

Library of Congress Control Number: 2015953502

Springer Cham Heidelberg New York Dordrecht London © Springer International Publishing Switzerland 2016

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Printed on acid-free paper

Springer International Publishing AG Switzerland is part of Springer Science+Business Media (www.springer.com)

In the last twenty years, I believe this is perhaps UNESCO's greatest achievement – our relentless determination to link ethics with science, to never let scientific development outstrip our ability to weigh it critically against the only standard that matters.

Irina Bokova Director-General of UNESCO.

Preface

Since the beginning of the twenty-first century, discussions about 'global bioethics', its definition, methodology and application have generated a large body of literature in bioethics.

The UNESCO International Bioethics Committee (IBC), established in 1993, quickly became a major influence in advancing the global dialogue in bioethics and continues to advocate a more balanced and culturally less biased approach to bioethics. Since then the IBC has played a leading role in developing normative instruments as well as promoting a broader concept of bioethics. The members of the IBC have worked to bring global and local perspectives closer together and to present a shared understanding of the main values and principles of bioethics. UNESCO's international declarations, guidelines and reports have been instrumental in shaping the global bioethics discussion and have inspired member states to embrace the spirit of these instruments in national legislation, bioethics-related guidelines and public policies. Those normative instruments are seen as fulfilling the standard-setting mission of UNESCO.

Although there are various other international standards for bioethics-related practices, such as the World Medical Association's Declaration of Helsinki for human research ethics, the IBC has been the only regular, sustained forum for the interaction of persons from several dozen member states. The benefits of this interaction are not always tangible. Although they do not technically "represent" their countries, IBC members have established an informal network of collegiality and friendship that opens up a unique forum for the exchange of views and an enhanced appreciation for the challenges facing bioethics workers in different cultural milieus.

This book presents a review of the evolving global bioethical discussions and describes the reflections of the IBC on the most critical topics as well as the positions taken by the IBC in leading the global bioethical discussions. The contributors are mostly members or former members of the IBC, and the topics cover the conceptual premises of a universal framework for bioethics and the IBC's efforts in bioethical normative setting at the global level. Several chapters look at current IBC initiatives and discuss the impact of IBC initiatives on bioethics capacity building at

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national and regional levels in different parts of the world. Yet other chapters present new frontiers requiring thoughtful bioethical discussions.

In the first chapter, Henk ten Have elaborates on the achievements of two decades of the IBC's involvement in bioethical discussion at the global level. He argues that more important than contributing to the adoption of normative instruments, the IBC has played a leading role in promoting a broader conception of bioethics that is more appropriate to current processes of globalization. By explaining why an international organization such as UNESCO should be involved in global bioethics, the author presents some new bioethical challenges which the IBC should tackle in the next 20 years.

In Chap. 2, Michèle Stanton-Jean examines the importance of UNESCO's declarations on different bioethical issues in global bioethics. As an example, she elaborates the Universal Declaration on Bioethics and Human Rights by examining its elaboration, implementation, promotion and contribution to knowledge construction. The author concludes that the declarations provide value to global discussion and practice, especially in countries where bioethical infrastructures were previously absent.

By elaborating the key points in the success of the IBC's contributions over the past 20 years to bioethics at the global level, Nouzha Guessous emphasizes that the defining characteristic of all successful initiatives is the overarching multidisciplinary and pluralist approach of the IBC.

The article highlights the leadership of UNESCO and the IBC in global bioethics discussions and suggests a list of priorities for the UNESCO bioethics programmes.

Chapter 4, by Richard Magnus, discusses the universality of the Universal Declaration on Bioethics and Human Rights. The article explains how this declaration has shifted the main focus of bioethics from respect for individual autonomy to consideration of the good for the larger society. He advocates that we must think even more broadly to look at the consequences to humanity and beyond, including our future generations, the environment and other living beings. The author further submits that the declaration has broadened the scope and impact of bioethics by integrating international human rights law into the field of biomedicine.

In Chap. 5 based on the Universal Declaration on Bioethics and Human Rights Sheila McLean focuses on the importance of informed consent in global bioethics. She argues that while the declaration seeks to establish a normative framework, the IBC's further work contained in the report on consent helps guide states in appreciating how these norms might be translated into their culture and laws.

Next, in Chap. 6 Stefano Semplici emphasizes the "social dimension of bioethics" and elaborates on the broader scope of bioethics. He argues that inasmuch as bioethics is about health and healthcare, it is at the very crossroads of all the determinants of human development and well-being. The author reflects on a sustainable holistic approach in which global bioethics should be understood as social bioethics and everyone should act accordingly, whether at the domestic or international levels.

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In Chap. 7, Emilio La Rosa reflects on the report of the ICB on Traditional Medicine Systems and their Ethical Implications and presents ethical challenges in the application of traditional medicine. He argues that traditional medicine must not be an alternative for the poor, nor should it be a pretext for failing to improve access to the best diagnostic techniques and treatment. He further submits that traditional and modern medicine can coexist provided bridges are built between them. The author criticizes efforts to develop a two-tier healthcare system; rather, there should be one system that is easy to access and inexpensive for all.

Chapter 8 touches upon the complexity of ethical issues in biobanking. Ewa Bartnik and Eero Vuorio outline some ethical concerns in the systematic collection of human samples and data in biobanks. After providing a balanced account of the risks and benefits of biobanking, the authors offer practical approaches to population bioethics as well as how to deal with incidental findings.

Alireza Bagheri examines some of the ethical issues in organ transplantation and trafficking in Chap. 9. By elaborating the risks of stigmatization in organ procurement as well as the risks of discrimination in organ allocation, the author recalls the report of the IBC on the Principle of Non-Discrimination and Non-Stigmatization and outlines some practical measures to prevent stigmatization and discrimination in organ transplantation.

Abdallah Daar and his colleague examine the topic of nanotechnology, specifically the ethical, economic, environmental, legal and social issues concerning its development and application in Chap. 10. In reviewing the advances in nanotechnology that are most likely to benefit low- and middle-income countries, they examine the most relevant ethical challenges and warn about the "nano-divide" between high-income countries and the developing world. The authors propose potential approaches to address these challenges based upon the foundations of equity, justice, non-discrimination and non-stigmatization as advanced in the report of the IBC on the Principle of Non-Discrimination and Non-Stigmatization.

Jean Martin, in Chap. 11, examines Article 19 of the Universal Declaration on Bioethics and Human Rights, which calls for the establishment of ethics committees at various levels. He elaborates the conditions and rules necessary for national bioethics committees in order to comply with the requirements of independence, multidisciplinarity and pluralism.

In Chap. 12 Christiane Druml examines the influence of UNESCO's bioethics initiatives in Europe and elaborates on the interaction between the IBC and the network of ethical advisory bodies in Europe as an example. The author argues that such influence should be evaluated in a different way compared to other regions. She emphasizes the importance of the interaction and influence of the European members of the IBC with their various national ethical bodies as well as academia in Europe.

Olga Kubar and Jože Trontelj present a review of bioethics development in Central and Eastern Europe in Chap. 13. They make the case that the great historical and economical changes over the last 20 years – coinciding with IBC activities – have created unique opportunities for capacity building in bioethics. The authors argue that the formation of the Commonwealth of Independent States, uniting 11

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regional countries, gave rise to a dynamic legislative and administrative collaboration in biomedical ethics with special efforts focusing on the implementation of IBC declarations.

The impact of the UNESCO bioethics programmes on the development of bioethics in Arabic countries is the topic of Chap. 14. Ben Ammar and his colleague examine how these programmes have shaped and impacted bioethics development in the Arab region. The authors argue that the core bioethical principles which have been emphasized by the UNESCO bioethics declaration are in harmony with Islamic values.

Chapter 15 authors Claude Vergès De Lopez and colleagues discuss the impact of the IBC activities on bioethics development in Latin America. They emphasize how the IBC's central focus on respect for cultural diversity, pluralism and human rights has been an important contribution to Latin American bioethics. The authors explain the positive impact of the Universal Declaration on Bioethics and Human Rights on bioethical issues and especially its influence on the interpretation of laws relating to health services in Latin America.

In recent years, Africa has become the focus of UNESCO's programmes. In Chap. 16 Monique Wasunna and her colleagues describe how IBC initiatives and documents in this area have been helpful in bioethics capacity building in Africa over the last two decades. The authors conclude that UNESCO bioethics initiatives and programmes have contributed immensely to the development of bioethics in Africa by supporting the establishment of national bioethics committees, strengthening the capacity of these committees, training teachers in bioethics and providing ongoing direction in addressing bioethics issues in the life sciences.

In Chap. 17 Myongsei Sohn elaborates on the development of bioethics in East Asia and the impact of the IBC's work on that region. He explains how the region, once an importer of Western bioethics, has developed its own bioethics discourse and has become a global contributor to the bioethics discussion.

In his address on the occasion of the inauguration and first session of the International Bioethics Committee, Federico Mayor, Director-General of UNESCO, pointed out the task to perform: "...the IBC is envisaged first of all as a forum for the exchange of ideas. It will also, as a corollary, be the inspiration for practical actions to be carried out in the field. Far from being set up as a monitoring agency to censure and stigmatize, its central task will be to facilitate understanding of the changes currently occurring, taking account of cultural differences. It will endeavour to heighten awareness and to inform the public and finally, will seek to foster dialogue between the representatives of specialist circles throughout the world, without losing sight of the fact that bioethics is something that directly concerns public decision-makers". Twenty years later, this commitment is still key for all those who want to contribute to foster the awareness as well as the instruments to respect, protect and fulfil the fundamental unity of humankind.

Finally, the editors would like to thank our IBC colleagues for their scholarly contributions to this book. They have successfully provided an in-depth analytical review of the IBC activities as well as its leading role in global bioethical discussion.

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Our thanks are due to the anonymous reviewers whose comments were very useful to improve the quality of the discussion in each chapter. We also would like to acknowledge the help of the IBC Secretariat in translating two articles into English.

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Chapter 1 Globalizing Bioethics Through, Beyond and Despite Governments

Henk ten Have

Abstract This chapter will review the role of UNESCO and in particular the International Bioethics Committee (IBC) in the field of bioethics over the past two decades. Three questions will be addressed. The first question is what has been achieved. It will be argued that more important than contributing to the adoption of normative instruments the IBC has played a leading role in promoting a broader conception of bioethics that is more appropriate to current processes of globalization. Another question is why an organization such as UNESCO is involved, and should be more involved in the global development of bioethics. The last question that will be discussed concerns the challenges that will lie ahead in the next 20 years.

1.1 Introduction: What Has Been Achieved?

It is easy to enumerate the list of unique achievements of the bioethics program of UNESCO. The adoption of three normative instruments, the establishment of the IBC (with independent scientific experts as members) and the Intergovernmental Bioethics Committee (with governmental representatives as members), the creation of national bioethics committees in several countries, the promulgation of the core bioethics curriculum in universities around the world, and the setting up of the Global Ethics Observatory with data on bioethics experts, ethics entities, ethics teaching programs, and ethically relevant legislation in various Member States are all major achievements that help to promote and sustain bioethics across the world.

Without the activities of UNESCO these achievements would not exist today. However, these results and activities are the manifestations of a deeper concern that is closely related to the mission of UNESCO: the intellectual and moral solidarity of humanity that is the only guarantee that progress in science will contribute to human flourishing, peace and security. Against this foundational background that

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© Springer International Publishing Switzerland 2016
A. Bagheri et al. (eds.), *Global Bioethics: The Impact of the UNESCO International Bioethics Committee*, Advancing Global Bioethics 5, DOI 10.1007/978-3-319-22650-7_1