Global Justice and Bioethics

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CHAPTER 1

Introduction

Global Justice and Bioethics

JOSEPH MILLUM* AND EZEKIEL J. EMANUEL

Kosnatu and her sister have traveled all day from her village in rural Sierra Leone to the maternity referral hospital in Freetown. Kosnatu is pregnant and about to give birth. Following serious complications with the birth of her first child, a community health worker told her that she must have a cesarean section if she became pregnant again. The government recently introduced free health care for pregnant women, breast-feeding mothers, and children under five. Kosnatu's family is very poor; she is hoping that the government's promise will be honored and she will not be charged "fees." For now, they sit in a hallway waiting. There are many patients but very few hospitals, hospital beds, or qualified health care personnel.

Nguyen Van Long is an ex-heroin addict who lives in the outskirts of Ho Chi Minh City, Vietnam. Five years ago, he contracted HIV by sharing needles and since developed AIDS. Each month, Van Long goes to a government clinic where his condition is monitored and he collects the antiretroviral drugs that have halted the progression of his disease and allowed him to return to work. His doctor is now worried. Over the past two months Van Long's viral load has increased, and the doctor suspects that the virus is developing resistance. Second-line antiretrovirals exist

* The ideas and opinions expressed are the author's own. They do not represent any official position or policy of the National Institutes of Health, Public Health Service, or Department of Health and Human Services.

but are far too expensive for normal Vietnamese like Van Long. The doctor suggests that he make inquiries into a drug trial being conducted in a city hospital by a U.S. research group. It is rumored that the trial provides free treatment in exchange for research participation.

Each of these medical encounters can be described in terms of the interactions between individuals. But such descriptions, like the ones above, do not paint a complete picture. Kosnatu has to travel so far to get to a hospital because Sierra Leone's health care infrastructure is so weak. Government corruption and years of civil war have impeded development and mean that millions rely on subsistence farming to survive. The civil war was launched from neighboring Liberia and funded by international sales of diamonds from Sierra Leone's diamond fields. It was ended by intervention from regional powers, the United Nations, and finally the British army (the UK having once colonized the country). The government's announcement of free health care for pregnant women was possible only because of funding from the UK government and loans from the International Monetary Fund. Whether it will be sustained depends on them. A long wait for medical attention is inevitable in a country where there are so few health professionals; targeted recruiting and better wages mean that over 50% of the health care workers trained in Sierra Leone emigrate to neighboring countries, such as Ghana, and to the West.

Nguyen Van Long's generic antiretrovirals are imported from India, whose intellectual property laws were, until recently, substantially weaker than in the West. The cost of AIDS drugs has been brought down by competition from generics, and protracted negotiations between multinational pharmaceutical companies and civil society groups and politicians. Moreover, for thousands of Vietnamese, treatment for HIV/AIDS has been possible only because of the funding provided by the U.S. government through its President's Emergency Plan for AIDS Relief (PEPFAR). The more recent generation of antiretrovirals needed by patients like Van Long are still protected by patent laws and therefore much more expensive than the first-line treatments. And though he might receive treatment by enrolling in a clinical trial, this depends on the research needs of international organizations that sponsor treatment trials, and it forces these organizations to decide whether and how to treat Van Long.

Kosnatu's and Van Long's situations only really make sense from a global perspective that takes in the structures that affect people's lives around the world. It is only from a global perspective that we can properly explain how these people's complicated medical encounters arise. And it is only from a global perspective that options for addressing their difficulties can be identified.

In this book, twelve scholars working at the intersection of philosophy, economics, and bioethics critically examine pressing global issues in medicine and ethics. The book is organized into three parts. The first part focuses on questions of ideal theory—that is, questions related to the ultimate global order at which we should be aiming. The writers in this part answer questions related to the normative significance of state boundaries for bioethics, rights to essential medicine, and the duty to ensure that everyone has access to health care. The last part of the book focuses on non-ideal theory—that is, questions about what the various actors engaged in biomedical research and care (individual researchers, research funders, foreign ministries, nongovernmental organizations, pharmaceutical companies, and others) ought to do in the face of an unjust world in which others do not do as they should. Here the problems include working out what medical researchers ought to do for research participants and host communities that lack access to health care outside of clinical research; addressing cultural differences in providing health care to people who are very poor; and mobilizing consumers and investors to improve global health. Joining the two parts are two papers that address more theoretical issues concerning the nature of non-ideal theory and its relationship to ideal theory.

This introduction provides a brief overview of the burgeoning field of global justice and bioethics. We begin historically, trying to explain why the types of issues addressed by the contributors to this volume have become so pressing. For those readers unfamiliar with international political theory or bioethics, we then provide some basic factual and conceptual background. Finally, we survey some of the key themes and problems that connect global justice to bioethics and analyze the strategies used in this book to address them.

BIOETHICS AND POLITICAL THEORY

Traditionally, the central subject matter of bioethics has been the ethics of individual interactions—between physicians and patients, and between researchers and research participants.[1] For the most part, this ethical analysis has also been relatively parochial, with U.S. bioethicists, for example, focusing on ethical problems arising within the context of U.S. clinical care and research. However, over the past decade or so, the purview of bioethics has greatly expanded.

The expansion of bioethics has at least two aspects. First, there is increasing recognition of the importance of the *systems* within which health care and research operate, which shape people's options and health

care decisions, and which determine the resources available to them. Bioethicists now concern themselves with, for example, the development of health policy, the organization of health care providers, the institutions that govern medical research, and the social determinants of health. Though never wholly absent from bioethical discourse, these broader concerns are much more prominent than before. Systemic concerns like these naturally raise questions about the justice of the systems. Second, the reach of health systems is increasingly *international*. For example, increasing amounts of clinical research take place at multiple sites in multiple countries.[2] Faced with the disparities between the care that is available at home and the care received by their participants, Western researchers working in developing countries are dramatically forced to face the question of what they owe their participants during and after clinical trials. The levels of development assistance fall short of what is needed to combat health problems, raising questions about priority setting. Shortages of physicians, nurses, and pharmacists in developed countries, and recruitment of these providers from developing countries, raise questions about global distribution of health care personnel. With rapid travel, diseases are no longer localized but have global impact. And the implementation of the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement, along with other bilateral and multilateral agreements, means that intellectual property protection is international—affecting the development and pricing of medical technologies and treatments everywhere.

Like bioethics, political philosophy has until recently had a rather domestic focus. Indeed, it is only a small exaggeration to describe the history of political philosophy as a history of theorizing about the state. The central problem for modern political philosophers has been working out the conditions under which the state's coercive power over its citizens can be justified. Indeed, even for Plato, the answer to the question "What is justice?" turned out to require a detour through a description of the political order of an ideal state.[3] One reason for this focus on the state is the perception that it is the source of many of the social conditions that determine the quality of people's lives. As John Rawls writes: "The basic structure [of society] is the primary subject of justice because its effects are so profound and present from the start."[4] But this justification for focusing solely on the state no longer seems viable. Recent growth in international communications, collaboration, finance, and commerce, and the institutions that regulate them, means that the life prospects of citizens from every country are dependent on events happening outside their country's borders. Such international effects are no more chosen by the people who experience them than the effects of national or local institutions; indeed, generally less so. Justice is a global concern.

The facts of globalization mean that a responsible bioethics must address problems of international scope. But the expansion of the scope of both theories of justice and the problems of bioethics into the global arena means that the concerns of the two now intersect to an unprecedented degree. Consequently, it is now impossible to engage with many of the most pressing problems of bioethics without also engaging with political philosophy (if, indeed, it ever was possible).

BACKGROUND: SOME KEY FACTS

A proper understanding of global bioethics and how considerations of justice relate to it is not possible without having some idea of the context in which bioethical issues of global scope arise, including the distribution of wealth around the world, the global burden of disease, and the key international political institutions.

Despite the massive increases in global productivity since the Industrial Revolution, the majority of the world's 6.8 billion people remain very poor.[5] More than 3 billion live on less than $2.50 a day, and over 80% of the world's population lives on less than $10 a day.[6] Though the amount of absolute poverty has fallen in the past three decades, the majority of this reduction is accounted for by China, where 600 million people have been brought out of poverty during its dramatic economic growth. In the rest of the world, the number of people living in absolute poverty—that is, suffering an absolute deprivation of their basic needs—has fallen only slightly.[7] Meanwhile the distance between the wealth of the richest and the poorest people in the world has dramatically increased. Disparities in wealth are reflected in disparities in consumption. For example, the wealthiest 20% of people account for 76.6% of consumption, while the poorest 20% account for just 1.5%, and 12% of humanity is responsible for 85% of human water use.[8]

It is often convenient to divide countries into rich and poor (or "developed" and "developing"), but such a simple division misses several important features. First, the differences in wealth between countries that are considered developing are immense. Mali has a gross domestic product (GDP) per capita of around $1,000, whereas Brazil's is closer to $10,000.[9] Second, disparities within countries can be very great. Though Equatorial Guinea had a GDP per capita of $30,000 in 2007—roughly the same as Italy—the majority of its people remain subsistence farmers, while a tiny ruling elite controls the country's substantial oil revenues. Consequently, Equatorial Guinea's average life expectancy is just 50 years (compared to Italy's 81) and nearly two thirds of its people lack access to clean water.[10]

Poverty and poor health frequently go hand in hand. People living in poorer countries tend to suffer greater morbidity, have lower life expectancies, and are less likely to be able to access modern health care. However, there are exceptions to all of these associations. For example, the high life expectancies found in relatively poor communities in countries such as China, Costa Rica, Cuba, Sri Lanka, and the Indian state of Kerala indicate that poverty *per se* need not lead to poor health. In fact, these places are characterized by their focus on the broad determinants of health of their citizens. For example, Kerala introduced universal free primary and secondary education in the early 20th century, has invested in maternal and child nutrition, provides universal access to free health care and family planning, and is culturally and politically committed to the empowerment of women. As a result its performance on key population health indicators—such as mortality rates for mothers, infants, and children, numbers of underweight children, and life expectancy—is dramatically better than other Indian states, even though it has a low per capita income even relative to India as a whole.[11]

As well as disparities between countries (and within them) in terms of wealth and health, there are significant differences in the sources of morbidity and mortality. While some noncommunicable diseases, such as heart disease and stroke, cancer, and mental illness, are severe health problems in almost all countries, the burden of infectious diseases is far greater in South Asia and sub-Saharan Africa. HIV/AIDS, malaria, tuberculosis, and diarrheal diseases kill millions of people in these regions but very few people in developed countries. On the other hand, diabetes is a growing problem in populations rich enough to overeat, and Alzheimer's and other dementias are a serious health burden in populations with long life expectancies.[12] There are also important differences in the causes of injuries and in environmental health hazards to which people are exposed. For example, the indoor air pollution caused by cooking with solid fuels such as dung or wood is responsible for 1.6 million deaths each year in developing countries.[13] Differences like these affect whether research into new health care interventions responds to the global disease burden. For example, since the purchasing power of the global poor is very low, there is little financial incentive for private companies to develop treatments for diseases that burden only them, nor to develop delivery mechanisms for treatments that are designed to operate in resource-poor environments.

In terms of institutions, the nation-state is still the most important political entity on the world stage; however, there are a number of significant transnational institutions. The UN is a political organization comprising 192 member states whose stated purpose is the promotion of

international peace, cooperation, development and human rights.[14] The UN system also includes the World Health Organization (WHO), an agency of the UN devoted to international public health. The WHO conducts and supports research and monitoring, sets international health standards, and provides countries with technical support.[15] The World Trade Organization (WTO) deals with the regulation of trade between its 153 member states through the negotiation of binding agreements. Compliance with WTO trade agreements is backed by the threat of economic penalties. Other, mainly economic, transnational institutions also have profound impact. The European Union now comprises 27 countries, from Germany and Sweden to Romania and Cyprus. It has its own parliament, single market and currency, and an annual budget of over €120 billion.[16] The World Bank offers financial loans and credits and technical assistance to developing countries to fight poverty. In 2010 it provided over US$45 billion and is now involved in over 1,800 projects, ranging from microcredit to large infrastructure development.[17]

These global institutions are responsible for a number of global agreements that are of direct relevance to bioethics. The UN established the International Bill of Rights, which comprises the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights. Among other entitlements, the International Bill of Rights includes a right to freedom from discrimination, to freedom of movement, to health, and to an adequate standard of living. The WTO now oversees some 60 trade-related agreements, perhaps the most famous of which is TRIPS. TRIPS aims to standardize world intellectual property protection at the high levels found in the United States, the European Union, and Japan. This process is expected to be complete in 2016, when all signatories, including the "least developed countries," are required to have implemented the WTO's intellectual property provisions. Intellectual property rules play an important role in determining which health care interventions get developed and how much they cost.

BACKGROUND: SOME KEY CONCEPTS

Political theorists who discuss justice are usually concerned with the evaluation of public policies or social institutions. This requires that they consider questions of *distributive justice*—how policies, institutions, or a social system as a whole distributes some set of benefits and burdens. For example, social institutions are responsible for the allocation of property, opportunities for work, political rights, and so forth. All of these

allocations may be properly assessed to determine whether they are just. In analyzing theories of distributive justice, or when assessing the justice of a particular institution, there are several ways in which it can be helpful to conceive of justice. One way is to think of justice as equal treatment.[18] Different theories of justice can then be understood as different theories about what equal treatment consists of, and an institution can be criticized if it fails to treat people as equals. An alternative is to think of justice in terms of justifiability. An institution is then just if and only if its structure and its actions can be justified to each of the people it affects.[19]

Domestic and Global Justice

Discussions of justice used to be limited to the state. But we noted above that many of the reasons to be concerned about domestic distributive justice now seem to be reasons to be concerned about global distributive justice too. These include the imposition of institutions like the WTO. People have no more choice about their country's WTO membership than they do about most of its domestic institutions. The effects of global factors like international trade and finance on a country's economic growth and stability, as well as its people's life prospects, are immense.[20] One of the foundational questions we may ask about global justice is how morally important the boundaries of the state are. Philosophers have offered a continuum of possible answers to this question, ranging from a *cosmopolitan* denial that state boundaries have any intrinsic significance, to what we may call a *statist* view that the existence of the state is a necessary condition for requirements of distributive justice to apply.[21]

The idea of justifying principles of distribution to those they affect can be helpful when assessing particular global institutions rather than the global system as a whole. For example, property claims (over both physical and intellectual property) are now held against everyone in the world, and almost all the world's physical resources are owned. This suggests that the global institution of property ownership requires justification to all; it should have a form that everyone can accept.[22]

The borders of the state are often thought to make a normative difference: different duties are owed to fellow citizens than outsiders. But people often claim that other associations are morally significant, too, such as shared national, ethnic, or religious identities. Such groupings may be important because they ground special duties between people who share the group identity. Modern nationalists, like Will Kymlicka and David Miller, point to such aspects of identity to explain why we should care more about fellow nationals than other people, and why national groups

have a claim to form their own state.[23] The question of whether associations like the nation make a normative difference is distinct and additional to the previous question about the normative significance of the political state. It is possible to downplay the relevance of state borders to distribution while still thinking that co-nationals should be preferred. Likewise, someone may think that the existence of a state transforms the normative relationships between its citizens while denying that this is connected to characteristics they have in common (other than co-citizenship).

Others argue that there are moral duties to respect the internal workings of other people's associations, such as families, religions, and nations. This respect might be instantiated by a presumption against intervention, or it might be argued that (in at least some instances) there is no impartial position from which to criticize a practice from another culture. Lisa Fuller considers some of the complexities of intervening in societies with very different value systems in her chapter on international nongovernmental organizations (INGOs).[24]

Ideal and Non-ideal Theory

The papers in this collection are categorized according to their focus on ideal or non-ideal theory. *Ideal theory* concerns hypothetical institutional arrangements that are just, known to be just, and whose requirements are largely complied with by those to whom they apply.[25] The central task for ideal theorists, therefore, is working out realizable conceptions of just institutional arrangements. Conversely, *non-ideal theory* deals with the obligations that arise either when institutional arrangements are not just or when some of the individuals subject to the institutions do not comply with them. These correspond to two branches of non-ideal theory: transitional theory and partial compliance theory. In this volume, the proper taxonomy of non-ideal theory is critically explored by Gopal Sreenivasan, and one aspect of the relationship between ideal and non-ideal theory is analyzed by Robert E. Goodin.[26] Here we make a further analytical point that may be helpful.

A binary classification into ideal and non-ideal theory is not always the most helpful way to think about specific policy questions or institutions. This is because when we evaluate actual or proposed institutions, we can idealize the context in which we consider them to varying degrees and along different axes. Suppose we are trying to answer the question of what rules should govern the pricing of medicines around the world. Given the vast disparities in purchasing power in the actual world, we might think it useful to address the question as a matter of transitional justice: what

should the rules governing the pricing of medicines be, assuming the world's wealth and health disparities remain more or less as they are? Our answer to this question might tell us how the governments of rich industrialized countries should act, what the WTO ought to agree, and so forth. But the answer to this question is an idealization: it assumes full compliance with the demands of transitional justice, and so it is, as it were, a type of ideal non-ideal theory. We may also be interested in what an individual actor, such as the UK government, ought to do if other governments do not follow our recommendations about the right transitional system for pricing medicines. Our theorizing will then be non-ideal along two axes, since we will assume that the global distribution of wealth remains unjust *and* that not everyone is going to do what he or she ought; hence it will be a matter of both transitional theory and partial compliance.

A lot of the work that bioethicists do falls into this intermediate zone between ideal and non-ideal theory. Depending on the purpose of one's analysis, it may be very helpful to idealize along some, but not all, dimensions. Liam Murphy has argued that considerations of fairness constrain certain moral duties under conditions of partial compliance, so that they do not require more of us than we would be expected to do if everyone did his or her share.[27] Thus, according to Murphy, working out what each individual ought to do under conditions of full compliance might tell us what a fair division of duties is. Were this argument sound, it would suggest that we can work out our *actual* duties by means of analyzing our *ideal* duties. Sreenivasan takes precisely this route in considering what Canada's minimal obligations of global redistribution are.

PRESSING PROBLEMS OF GLOBAL JUSTICE AND BIOETHICS

Bioethical problems that can be resolved only by paying attention to questions of international justice are liable to arise whenever institutions with global reach affect health or health care. These institutions themselves may be the subject of ethical appraisal—for example, when international treaty obligations appear to conflict with a government's supplying cheap drugs through its public health system. In other cases, the institutions or their effects provide a backdrop of injustice against which bioethical issues arise—for example, when clinical researchers in a low-income country have to decide how to deal with research participants who do not have access to health care.

Table 1.1 lists a broad but not exhaustive sample of important international bioethical problems divided into four categories: clinical care, research, health policy, and theory. Of necessity, it is a simplification; for

Table 1.1. SELECTED PROBLEMS IN GLOBAL JUSTICE AND BIOETHICS

Subject	Problem	Key Question
Clinical care	Health tourism	Is it permissible for wealthy people to use the health systems of other countries for faster or cheaper care?
	Organ trafficking	Is international trade in organ transplantation permissible?
	Access to medicines	How should access to essential medicines for everyone be ensured?
Research	Responsiveness	Must health research be responsive to the needs of the community in which it is carried out?
	Benefit-sharing	How should the benefits of research be shared with the different groups who contribute to it?
	Standards of care	What standard of care should be offered to participants in trials when the prevailing care in their community is less than the global best?
	Ancillary care	What treatment ought researchers to give their participants over and above the treatment that is required for the scientific design and safety of their trial?
	Post-trial access	Should research participants and communities be guaranteed access to successful interventions after the trial?
Health policy	Parallel health systems	Should NGOs and private providers run health care systems independent of public health care systems?
	Intellectual property	How should the international intellectual property regime be structured as it applies to health interventions?
	"Brain drain"	Should health workers' migration be restricted?
	International disease threats	Who is responsible for monitoring and combating infectious diseases that move across national borders?
	Lifestyle exports	Do any obligations fall on countries or corporations who export unhealthy lifestyles?
Theory	Cultural variation	How should variation in cultures affect international research and health care provision?
	Priority setting	How should local and international priorities for research and health care be set?
	The right to health	What is the right to health and against whom is it held?
	Ideal and non-ideal theory	How should we move from the actual world to a world where there is justice in health?

example, some problems arise in more than one category, and answers to many questions have implications for other categories of questions.

Categorizing problems by subject area gives us some idea about the sheer breadth of the questions concerning global justice and bioethics. We can perhaps learn more, though, by examining the methods used to answer these questions. Looking at the contributions to this book, there

appear to be three strategies. First, some writers take a top-down approach to a problem. They first work out a general view about an aspect of global justice and then apply that view to the particular case at hand. In this collection Mathias Risse uses this strategy.[28] He starts with a discussion of how private property, in general, is justified. He then adapts his conclusions to private intellectual property, and finally applies his thinking to the particular case of pharmaceuticals.

A second strategy attempts to circumvent the controversies about more general questions of justice while still making use of the theoretical apparatus that political theory provides. This strategy looks for common ground between the different theories of global justice and then draws conclusions from that common ground. If, for example, there is good reason to think that any plausible theory of justice will require that trade rules be written so that they do not make the global poorest any worse off, then this premise can be used in discussion of trade agreements without having to defend any particular theory of justice. Ezekiel J. Emanuel uses a version of this strategy in his chapter on how researchers should design clinical trials in developing countries.[29]

The third strategy is to bracket the institutional questions and focus on individual interactions. Arguments that adopt this route take the nonideal nature of the world with its injustices as a given and consider what specific individuals ought to do under such circumstances. In his discussion of the obligations of medical researchers amid injustice or deprivation, Alan Wertheimer is not considering the question of how the institutions governing medical research should be structured, nor the question of how researchers should attempt to repair the social injustice in the societies in which they work; he is asking how the clinical research itself can be ethically carried out when the research participants and their communities are in such bad situations.

On a related note, it is worth mentioning the different actors whom writers may address. Sometimes they are addressing individual people, answering the question of how those particular moral agents ought to act. In his chapter, Nir Eyal develops the concept of global-health impact labels, which are certifications that individual, concerned citizens can set up themselves and that allow individual consumers to affect global health through their economic decisions.[30] He argues that individual consumers and investors ought to establish and make use of these labels. At other times, bioethicists' concerns lie more with institutional creation or reform. In discussing the basis of the global health duty, Jonathan Wolff is more concerned with the structure and actions of social institutions than with what any particular person does.[31] Exactly who one's target is may affect what argumentative strategies are available. For example, it is easier to set

aside more fundamental questions of global justice if you are primarily addressing individual doctors or clinical researchers rather than health systems as a whole. It may also make a difference to the appropriate level of idealization one adopts. Recommending to an individual what he or she alone should do right now is the most non-ideal of non-ideal theory; recommendations about institutional reform, with their requirements that multiple actors coordinate, tend to be "more ideal."

THIS BOOK

A single book could not cover all the possible issues that arise in global justice and bioethics, and this book makes no attempt to be comprehensive. Instead, our contributors provide their perspectives on a wide range of important topics. In doing so, they move discussion forward along a number of axes, methodological as well as subject-specific. They also demonstrate how rigorous academic work can cross from the most abstract concerns of political theorists to the most practical concerns of bioethicists. In doing so, they avoid two problematic extremes of this kind of academic work: that political theory may be too abstract to be of practical use, and that bioethics may be insufficiently grounded in theory, and so may lack rigor. We hope that this volume will introduce some of the ideas and methods of political theory to bioethicists, and likewise introduce bioethics to some political theorists.

NOTES

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20. See Millum J. "Global Bioethics and Political Theory," Chapter 2.
21. *Statist* may have slightly misleading connotations, but there does not seem to be a better alternative. See Millum, *ibid*., p20*n*.
22. See Risse M, "Is There a Human Right to Essential Pharmaceuticals?" Chapter 3.
23. Kymlicka W. *Multicultural Citizenship.* Oxford: Oxford University Press, 1995; Miller D. (1995). *On Nationality.* Oxford: Oxford University Press.
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