Just health: meeting health needs fairly

Author: Norman Daniels
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What does justice require with regard to population health? This is the question addressed by distinguished American philosopher Norman Daniels in his new book on justice and health. *Just health* is in many ways a successor to Daniels's seminal classic *Just health care* (New York: Cambridge University Press; 1985). It integrates his earlier account of the special moral importance of health and health care with his interim work on the social determinants of health, the fairness of health sector reform and limit-setting in health care. As indicated by the change of title, *just health* no longer focuses solely on the provision of health care, but spans all socially-controllable factors of health. The book's ambitious aim is to provide an integrated theory of justice and health.

In order to understand what justice requires for health, Daniels argues that we must address three focal questions. First, what is the special moral importance of health? Second, when are health inequalities unjust? And third, how can we meet health needs fairly when we can't meet them all? Daniels's answers to these questions are based on John Rawls's theory of justice as fairness. Rawls argues that a social contract among free and equal citizens would include three general principles of justice: a principle protecting equal basic liberties; a principle guaranteeing fair equality of opportunity; and a principle limiting inequalities to those that benefit the worst off. Health and health care were not topics for Rawls, as he assumed all members of society to be healthy.

Daniels extends Rawls's theory by arguing, first, that health is of special moral importance because it contributes to the range of opportunities open to us. If we have social obligations to protect individual opportunity, promoting and restoring health is one component of fulfilling these obligations. Second, health inequalities are unjust when access to health care is inequitable and/or when the social determinants of health – such as education and income – are not distributed according to Rawls's principles of justice. Third, although Rawls's principles can guide our general thinking about justice and health, they are too indeterminate to solve common limit-setting problems about which reasonable people disagree. Therefore, a fair process must ensure the legitimacy and fairness of limit-setting decisions.

Daniels claims that his theory provides comprehensive practical guidance that is applicable worldwide. The claims of practicality and global scope, in particular, raise a number of important questions for international health policy-makers.

First, will liberal principles of justice be accepted around the globe? Daniels argues that his theory is consistent with various competing accounts of justice, and even provides a reasonable justification for a human right to health. This suggests that the theory's worldwide acceptance is possible – although I believe more would have to be said to truly support the claim. The alleged consistency with multiple other theories also indicates how indeterminate Daniels's own theory is: reasonable people will disagree about almost any limit-setting problem, despite the stipulated common moral ground.

Second, how much practical guidance does Daniels's theory really provide? The wealth of fascinating normative questions raised in *just health* – for example, to what extent we should compromise on efficiency to reduce health inequities or to compensate people for previous medical errors – are, in the end, unanimously addressed by reliance on a fair process. However, despite Daniels's best efforts to elucidate them, the substantive constraints of this process remain largely unclear.

Third, policy-makers will want to know how much emphasis should be placed on fair process in situations of dire need. For example, the high prevalence of HIV/AIDS in some developing countries threatens social stability because young adults die prematurely. To the extent that engagement in a fair process risks delaying provision of treatment and consumes scarce resources, full-blown public accountability for reasonableness might not to be pivotal in all cases and under all circumstances. However, Daniels never addresses this question.

Fourth, Daniels himself acknowledges that his theory tells us when health inequalities within a society are unjust, not when inequalities between societies are unjust. Of course, international justice is not the topic of this book, and *just health* provides important ideas on how interdependent relationships and cooperative schemes might underpin justice, not charity, obligations towards members of other societies. But it remains unclear how Daniels can claim that his theory “can guide our practice with regard to health both here and abroad”.

There are no easy answers to these questions. *Just health* provides a remarkably broad and deeply engaging treatise of justice and health, which will influence both policy-makers and bioethicists for years to come. The rich empirical and conceptual analysis, along with first-hand policy insights from both national and international contexts covering more than 20 years, is truly impressive. But as Daniels sometimes states himself, his theory remains a work in progress.

Annette Rid*
Ethics and infectious disease

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In an oft-quoted statement, the Surgeon General of the United States of America, William Stewart, said in 1967: “The time has come to close the book on infectious diseases. We have basically wiped out infection in the United States.” This influential comment has, however, been contradicted by subsequent events. For example, Jones et al. recently reported that from 1940 to 2004 several hundred new infectious diseases emerged, many of which are zoonotic and bacterial. More than half of these new diseases have emerged since the 1970s, with the 1980s being the decade with the most new infections. Clearly, infectious diseases are still an open book.

Humans and pathogens share a long co-evolution, and infections have exerted a remarkable influence on the course of historical events and human societies. This has been abundantly well-documented by historians. Yet somehow, infectious diseases have not attracted a great deal of attention from bioethicists.

This volume of essays is a welcome attempt to remedy that deficit. It stems from a thematic issue of the journal *Bioethics* devoted to ethics and infectious disease, published in 2005. A point of departure for the book is the so-called 10:90 divide, whereby less than 10% of medical research is devoted to diseases that account for more than 90% of the global burden of disease. Driving this agenda is a concern for the most disadvantaged populations, which are disproportionately affected by infectious diseases. Selgelid, in the introductory essay, points out that a review of the bioethics literature demonstrates a paucity of serious ethical reflection on infectious diseases. He elucidates several reasons for this neglect. First, he argues that bioethicists have been overly concerned with the ethical issues associated with the use of high technology such as reproductive technologies and intensive care units. Second, he points out that optimism has given rise to the belief that infectious diseases are no longer the dominant threat to global health, a sentiment captured by the quotation in the first paragraph of this review. Third, infectious diseases entail “otherness”. Individuals with infectious diseases such as HIV/AIDS or tuberculosis are often stigmatized. The fourth, and perhaps the most important, point that he makes is the complex nature of infectious diseases. A true understanding of the implication of the impact of an infectious organism on individuals and communities requires the integration of microbiology, immunology, clinical medicine, epidemiology, psychology, geography, anthropology, zoology and many other disciplines. Unfortunately, there are few individuals who can achieve this with sufficient expertise.

The introductory essay superbly establishes the framework for those that follow. The book is extremely well laid out, the 22 chapters are pertinent, and the authors are first rate. It is divided into six parts. Part I explores the relationship between bioethics and infectious disease in three chapters that examine some of the special features of infectious diseases and the unique ethical issues pertaining to them. Part II covers ethics and infectious disease control, introducing the ethical challenges of drug-resistant tuberculosis, wildlife diseases, pandemic preparedness, and public health and the use of restrictive measures for disease control. Part III deals with the issues and dilemmas associated with the treatment of individuals with infectious disease. Part IV is a welcome contribution to the emerging and surprisingly limited literature on the ethical issues raised by mass vaccination programmes. Part V focuses attention on developing countries and global health, with stimulating essays by Paul Farmer, Nicole Gastineau-Campos, Thomas Pogge and Tim Anderson. Finally, part VI tackles the bioethical dimensions of security and bioterrorism.

Altogether this set of essays would make compelling reading for any public-health practitioner or clinician interested in infectious diseases. I can give it an unreserved recommendation. However, there is one small caveat. As timely as this book is, it already shows signs of needing updates. The emergence of extensively drug-resistant tuberculosis (XDR-TB) makes many of the book’s essays on tuberculosis control no longer completely relevant, since XDR-TB raises a whole host of ethical questions that are of the utmost importance for global health. Finally, there is little coverage of hospital-borne infections, such as methicillin-resistant *Staphylococcus aureus* (MRSA) and vancomycin-resistant enterococci (VRE), which raise significant ethical issues. The concept linking these last two topics is drug resistance, a largely human-made phenomenon that has had a catastrophic impact on hospital care and the health of communities.

In short, infectious diseases are still with us and they are likely to remain an eternal aspect of human existence. It is time that the bioethical issues relevant to the impact and control of infectious diseases on individuals, communities and populations receive the type of robust ethical reflection that other aspects of health care have received. The publication of this book is a welcome addition to the bioethics literature; it will be particularly suitable for use in postgraduate courses on infectious diseases, public-health ethics or clinical ethics. The authors are to be commended for their attention to this topic and for inviting some of the best minds in bioethics to address some of the most difficult, but neglected, ethical issues in public health and medicine.

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Cambridge textbook of bioethics
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This is a comprehensive and carefully designed textbook that will attract many users in the health professions. The chapters, written by a group of distinguished authors, are presented in a format that is well suited to interactive educational use. This is particularly important, given the enthusiasm of the modern medical profession for reducing everything to checklists – “tick 8 boxes out of 10 and you have made an ethical decision!” Bioethics, however, does not work in this way, although I sometimes think that part of the appeal of “principlist” approaches is that they seem capable of such a reduction. Ethics is a matter of reasoned judgement, a process that this book seeks to stimulate. Each chapter begins with a short case note describing a relevant situation. It would be easy for educators to use this as a basis for preliminary discussion and then to encourage students to work through the ethical analysis. They can review how the chapter author(s) would deal with the problem presented and compare this with their own responses. The book is divided into 10 sections and its 65 chapters present a wealth of material for “mix and match” adoption to support both generic courses on bioethics and those with particular emphases. The range of material that is covered also presents many opportunities to use the book as a practical resource to deal with presenting cases that parallel those described in the book. There is particular value in the section that deals with the religious and cultural perspective: bioethics in the northern hemisphere has often rightly been criticized for its neglect of the thoughtful consideration given to bioethical issues from sources outside a Judaeo-Christian heritage.

Given its strengths, the book also brings out some of the weaknesses of bioethics as an essentially normative discipline. The cases discussed point to ethically justifiable courses of action but do not communicate very well how these can be actually achieved. Empirical analyses of face-to-face interactions, for example, have found fundamental constraints on achieving the standards of informed consent stipulated by bioethicists. They have also shown that bad news is not necessarily best delivered in quite the direct way that bioethics tends to prefer. The chapter on torture urges doctors to report this to appropriate authorities, but presumes a state of law in which such reports will be welcomed: in many situations, doctors would simply be exposed to the same fate as the victims that they are trying to protect.

Despite the editors’ clear and commendable efforts, North American biases do creep in. The book is generally good at dealing with areas where the United States of America (USA) knows it does things differently from Europe, such as with stem cells. However, it is less good at explaining European differences to the USA, such as in the chapter on assisted conception, which does not discuss the European controversy over whether children born from donor gametes may have a right to know the identity of their genetic parents. Readers who are nurses will probably feel that the distinctive ethical voice of their profession is under-represented, although there are chapters on issues for pharmacists and for complementary healers. It is also slightly odd that there is no chapter that focuses on the extent that health professionals are ethically obliged to risk their own lives in order to treat sick people, an issue thrown into sharp relief by the experience with severe acute respiratory syndrome (SARS) in Toronto and a serious concern for those planning responses to potential health challenges such as pandemic influenza.

The book’s chapter by chapter approach leads to occasional contradictions. For example, “reproductive tourism” is seen as bad, but autonomy in seeking health care is taken as good. If, however, autonomy is generally favoured as a principle, why should there be anything wrong with free movement across international boundaries to choose a legal and regulatory regime under which to conceive and give birth? In fact, the contributors are almost all rather uncritically in favour of more regulation rather than less and they rarely acknowledge that there could be viable libertarian objections to their positions. These contradictions could, however, be valuable teaching points.

Finally, perhaps it is also time for bioethics to engage more with the historians’ work on their founding premises. It is far from clear, for example, that the Nuremberg Code deserves the importance that it is given, particularly in the light of the extensive regulation of biomedicine in Germany prior to the Second World War. The Nazi experiments on humans could equally well be seen as the result of a culture that emphasized compliance with regulation over professional deontology, which should give some pause to the contemporary enthusiasm for regulation. It is notable, too, that the recent revisionist work on the Tuskegee Syphilis Experiment is not acknowledged in the book. There is an argument that initially there was nothing wrong with the experiment, given the risk–benefit ratio for the syphilis treatments available in the early 1930s. If there was a scandal, this arose much later and today would be addressed by a clinical trial management committee that would consider whether to end a study early and make an emerging treatment generally available.

This book demonstrates the importance of bioethics to clinical practice in any reasonably developed health care system. It is respectful of cultural diversity and takes account of what may be realistically possible in resource-constrained environments. However, it is essential not to take the disciplinary project embedded within it wholly at its own valuation. The English writer Shelley once claimed that poets were the unacknowledged legislators of the world. I sometimes think that bioethicists would like to displace poets in this role but am not sure that I would really like to live in a world that was ruled by either. On the other hand, I can certainly see the point of regulative ideals that encourage reflection, but whose application is a matter of contextual judgements that place the contribution of ethics within a portfolio of relevant considerations. Singer, Viens and their team of authors have created a valuable resource to inform such judgements.

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