Michael Boylan
Editor

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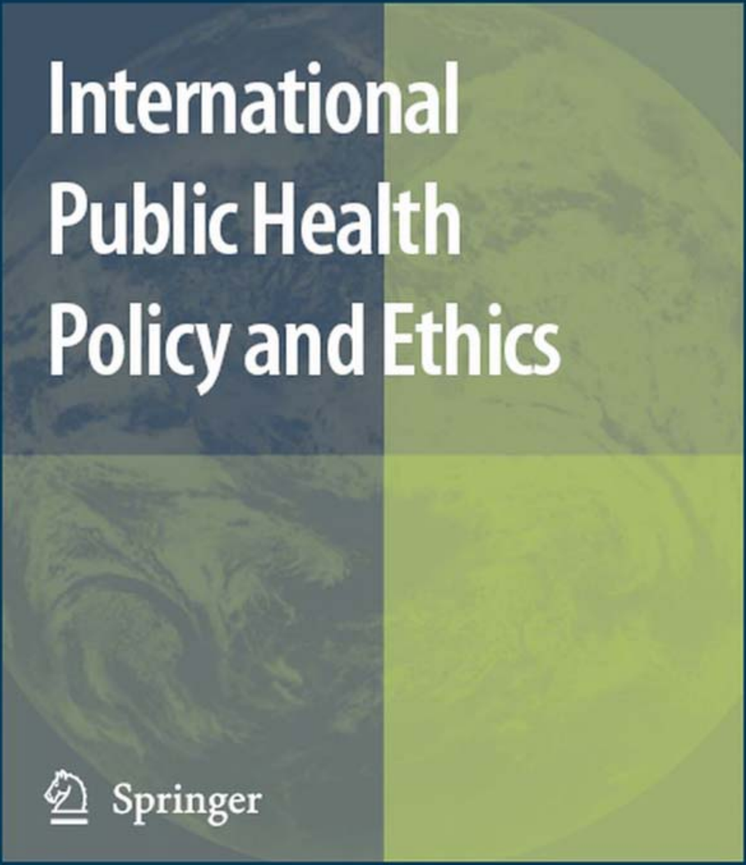

International Public Health Policy and Ethics

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Introduction: International Public Health: Morality, Politics, Poverty, War, Disease

Michael Boylan

This volume of original chapters follows on the well-regarded *Public Health Policy and Ethics* (Dordrecht: Kluwer/Springer 2004). What is similar about this volume to its predecessor is the general position that public health is more inclusive than just epidemiology concerning various vicious microbes and sanitation. There are many threats to public health and these include all the usual suspects: clean water, sanitation, and disease control (all included here). But this volume also includes other sorts of threats. These include human rights violations and unfairness in the allocation of the basic goods of human agency such as health care and the opportunity to protect one's self against threats against the same.[1] The time is the present. The place is the whole world. There is a conscious crafting of chapters and argumentation to the global stage. However, that said, each issue must be repeated within the context of individual countries. For purposes of clarity, I would suggest that readers think about two sorts of countries in the world: wealthy countries (those able to provide the basic goods necessary for action, including health care[2])

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[1] For a theoretical defense of this position see my book, *A Just Society* (Lanham, MD and Oxford: Rowman and Littlefield, 2004), chapter 3.

[2] **The Table of Embeddedness**

BASIC GOODS

Level One—*Most Deeply Embedded* (that which is absolutely necessary for human action): Food, clothing, shelter, protection from unwarranted bodily harm (including health care).

Level Two—*Deeply Embedded* (that which is necessary for effective basic action within any given society):

- Literacy in the language of the country
- Basic mathematical skills
- Other fundamental skills necessary to be an effective agent in that country, e.g., in the United States some computer literacy is necessary
- Some familiarity with the culture and history of the country in which one lives
- The assurance that those you interact with are not lying to promote their own interests
- The assurance that those you interact with will recognize your human dignity (as per above) and not exploit you as a means only
- Basic human rights such as those listed in the U.S. Bill of Rights and the United Nations Universal Declaration of Human Rights

M. Boylan (ed.) *International Public Health Policy and Ethics*,

and subsistent societies (those in which there are substantial portions of the population at risk for disease and starvation because the country simply does not have the resources to begin to help all its citizens). I have argued elsewhere that these two sorts of countries should be measured on a different scale of moral "ought"—because of the issue of "can." And that the wealthier countries should assist their more indigent neighbors in their quest for fair economic development.[3] The various chapters in this volume address financial feasibility along with the strength of human rights claims. But let us be clear about this: the claim is not simply that public health is *wider* than infectious disease and sanitation—but that in any issue that affects the general community, a plurality of considerations should be brought forth under the guiding principle of ethics. Pure science/medicine needs a supporting principle and that is the inclusive ethical/social/political considerations brought forth in this volume.

The structure of this volume basically follows a tripartite organization: *Morality and Politics, Money and Poverty, and Medical Need and Response*. I will briefly review the chapters in each part in order to provide the reader with a sense of what he/she might expect. First, however, I would like to describe the rationale behind each part of the book and how they are intended to relate to each other.

In Part I, *Morality and Politics*, there is recognition that public health policy is not considered in a vacuum. There are at least two sorts of contexts that frame international discussions on public health policy: morality and politics. In the realm of morality we are trying to ascertain what *ought* to transpire. Such policy is framed by individual (clinical) directions and group campaigns. By keeping the moral standpoint in view (for example human rights) various policy options such as torture, privacy invasion, and cultural imperialism might be avoided. In this way

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SECONDARY GOODS

Level One—*Life Enhancing*, medium to high-medium on embeddedness:

- Basic Societal Respect
- Equal Opportunity to Compete for the Prudential Goods of Society
- Ability to pursue a life plan according to the Personal Worldview Imperative
- Ability to participate equally as an agent in the Shared Community Worldview Imperative

Level Two—*Useful*, medium to low-medium embeddedness:

- Ability to utilize one's real and portable property in the manner she chooses
- Ability to gain from, and exploit, the consequences of one's labor regardless of starting point
- Ability to pursue goods that are generally owned by most citizens, e.g., in the United States today a telephone, television, and automobile would fit into this class

Level Three—*Luxurious*, low embeddedness:

- Ability to pursue goods that are pleasant even though they are far removed from action and from the expectations of most citizens within a given country, e.g., in the United States today a European vacation would fit into this class
- Ability to exert one's will so that she might extract a disproportionate share of society's resources for her own use

[3] Boylan 2004, chapter 7.

morality is a guiding force in the creation of policy within the political sphere. At the time of writing this chapter (2008) I have been a visiting fellow at the Center for American Progress, a policy think tank in Washington, DC. I have noticed the interplay of morality and politics first-hand as various initiatives are brought to Capitol Hill and lobbied by designated members of the Center. It is not always the case that members of Congress keep moral considerations in mind—especially when they think there may be a practical agenda involved. In these cases politics sets the terms of debate. This dynamic is not peculiar to the United States. In countries that are less open and democratic, the political influence is even higher. Thus, the first facet of understanding how and why international public health policy is formed requires an examination of the moral and political landscape.

The second topographical region to explore is how money and finance enter the picture and whether poverty is really affected. Economists have declaimed for a long time that everything depends upon money. One way this reality is expressed in public policy concerns is via distributive justice. The way allocation occurs is crucial to the projected outcome. There have been many ill-fated projects since World War II that have not adequately taken into account the distribution formula and its logical/moral justification; nor have they considered the way it might play out (politics again). Both foundational issues and policy realities play a role in the landscape architecture of this region.

The last area concerns actual public health problems. This final part of the book intends to bring the two pedagogical themes of the first two areas: morality/politics and money/politics. When we put it all together, what happens? The chapters of this part generally point to actual and emerging issues that require action—*now*. The mode of argumentation is twofold. First the urgency of the problem is set out, and second, the direction of policy solutions is suggested (consonant to the concerns outlined in the first two parts of the book).

In the end, we hope that this volume will prove as useful as its progenitor in stimulating discussion about public health that is strongly connected to moral theory.

Morality and Politics

This part begins with a chapter by Muireann Quigley and John Harris, "Personal or Public Health?" This is a wonderful launching of the book into a key principle of public health (and ethics in general). The authors set out one of the key issues in public health that (given limited resources) monies allocated to public health may come at the expense of monies for treating acute clinical care. This clearly sets out a dichotomy of the community versus the individual. If one moves too aggressively on either side, then bad results will follow. If the group is chosen in their cardiovascular medicine example, then particular individuals may not get the best care. If the group (particularly future groups), is given absolute priority, then there is the possibility of Broome's paradox setting in where present patients are abandoned for those of the future ad infinitum.

Within the categories of (a) prevention of disease (primary prevention); (b) treatment of disease once developed (rescue); and (c) the combination of treatment and prevention of reoccurrence (rescue and secondary prevention), the authors seek a dialectical tension of maximizing lives saved now without discounting future populations.

In Kristen Hessler's chapter, the discussion turns into a debate between the interest-based human rights approach of Jonathan Mann and an agency-based human rights approach advocated by James Griffin.[4] The lack of specificity that Hessler sees in the agency approach is rectified by the interest-based approach. One example of this is with HIV-positive husbands abusing their wives. Public health interventions that occur without regard for other, broader human rights concerns will be counterproductive. This is Hessler's point on "interest-based" rights. It is certainly possible that if one is so concentrated upon some abstract right or duty that someone may *fit the rule but not the intent*, then no real progress is possible. Hessler's call is for confronting individuals and populations, as they actually live—not according to some statistical ledger that may miss everything.

Deryck Beyleveld and Shaun Pattinson begin their chapter with a declaration that "Medical research on personal data involves a conflict between moral interests or values. On the one hand, research promises moral benefits that flow from the acquisition of generalisable knowledge related to human health or treatment. On the other hand, research participants have interests in being able to control the flow and use of private information about themselves." Their way to adjudicate this conflict is to evaluate the scope of the rights claim in privacy versus research and then to employ a singular normative ethical principle: Alan Gewirth's Principle of Generic Consistency ("Act in accord with the generic rights of you recipients as well as of yourself") to settle the relative strength of each claim right.

The strategy that Beyleveld and Pattinson employ is to create the theoretical framework for this analysis and then apply it to three sorts of cases: (a) infectious disease studies, (b) contraceptive studies on those with severe infertility problems, and (c) cancer studies. These sorts of cases provide empirical specification to the theoretical structure that Beyleveld and Pattinson set out. In the end, these authors argue vigorously that via their integrated approach of practice and theory, well-grounded privacy claims will trump the sort of research claims against patients privacy that are depicted in their examples.

In Wanda Teays' chapter, we are presented with a very uncomfortable issue: torture. Teays begins her chapter with how the issue of torture in the US *War on Terror* takes control of ordinary people and tries to take over on the principle that anything goes, *kraterism*.[5] What is harmed is the protection of democratic liberty. One cannot be inconsistent with her applications of moral principles of behavior. If it is all right for *us* to torture *you*, then it is all right for *you* to torture *us*—and by extension torture is fine all around. And if it is fine for quasi-war situations, then it may be fine whenever and wherever. But what does this leave us with?

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[4] For a possible compromise position between these two see: Boylan 2004, chapter 3.

[5] I use the term "kraterism" to refer to a principle of distributive justice—to each according to his ability to snatch it for himself, cf. Boylan 2004, chapter 7. The "might makes right" mentality is behind this standpoint.

Of course this reductio argument is present to all. One clear response is to pretend that we do not torture. Teays gives an interesting account of the noncognitivist linguistic factors involved. These include euphemisms that transform "torture" to "harsh interrogation techniques." The victims are also transformed from "prisoners" to "detainees" or "illegal combatants" or "unlawful combatants" or "foreign combatants." All of these new categories are not described under Geneva Conventions and so will circumvent some nominal legalisms of those who choose to be blind about what is actually happening.

And what is actually happening is that torture is going on under the supervision of medical personnel who have sworn an oath of doing no harm and promoting the health of the patient. In the United States, a physician has a duty to report a parent who he/she thinks has abused a child. This is not optional. It is part of the oath. But in this wartime situation, it seems that the political needs of the ruler breach not only the Hippocratic Oath and the Geneva Conventions, but also the safety of all our captured troops and the general country's concept of acceptable behavior. The consequences in all of these categories breach public health. New precedents of treating prisoners have abrogated public health guidelines. The result of this within the context of the United States and the Iraq conflict is still a work in progress.

Finally, ending this part is a chapter from Laura Purdy on exporting the culture of life. Purdy begins her chapter by highlighting two cases: (a) a 17-year-old girl with an anencephalic fetus; and (b) a woman with an ectopic pregnancy that will kill her. In both cases the countries in which the women live ban abortion. The result in the first case is a child who will die and in the second case a mother who will die.

Such results seem rather counterintuitive to most people—except the religious right. In Purdy's chapter, the religious right is depicted in American terms. But around the world there are many fundamental religious movements which base their assessment on public health policy upon their own private revelations from God. Now the problem with this is rather simple. If we assume that democracy is the fairest form of government (based upon its support of individual autonomy), and if democracy can only work based upon externalist epistemology—often called "transparency" in the social sphere—then the private internalist response, as such, is contradictory to the externalist approach and is inherently antidemocratic.

The internalist approach is also subject to inconsistent application. For example, Purdy notes that the so-called culture of life puts a high stake upon stopping abortion (no matter what the circumstances) but is often blind to other life-threatening situations—such as supporting the US war in Iraq which Pope John Paul II said violated just war theory and so was not justifiable. In the United States, many who support the "culture of life" oppose abortion, on the one hand, and support a war that violates just war theory (the result being that all consequent deaths are murders), on the other. This is a case of inconsistency.[6] Purdy's chapter calls for us to think about whether the principle of separation of church and state is also a principle of public health.

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[6] The first element of this author's Personal Worldview Imperative is that one must act consistently. This is necessary but not sufficient (the other points being: completeness, connection to a recognized theory of the good, and commitment to live out the principles that one believes in).

Money and Poverty

The next part of the book deals generally with issues of distributive justice and what might be done to rectify it. Norman Daniels begins his chapter by citing some stark inequalities in international public health: (a) life expectancy in Swaziland is one half that enjoyed in Japan, (b) a child born in Angola has 73 times the chance of dying before five than a similar child born in Norway, and (c) in sub-Saharan Africa a mother has 100 times the chance of dying in childbirth than a similar mother in the industrialized world. Since these distributions of health care are due to socially controllable factors, they may be termed "unjust."

There are three categories of these unjust inequalities:

1. *Domestic injustice* in the distribution of the socially controllable factors of population health such as caste, race, gender, religion, etc.
2. *International inequities* such as poor natural resources, the susceptibility to draught, flood, or disease vectors like mosquitoes carrying malaria or dengue
3. *International practices from rule-making bodies* such as those that permit a medical brain drain from poorer countries to richer ones or trade agreements that perpetuate poverty

How might these inequities be addressed? Two popular answers are *statist* solutions focusing upon the internal practices of individual countries (championed by Nagel) and cosmopolitan responses (such as Pogge's minimalist approach). Daniels discusses the drawbacks of each as he fashions his own post-Rawlsian relational approach that employs aspects of both statism and cosmopolitanism within the context of interdependent institutional and national relationships. In this way, he hopes that we may lessen these egregious international inequities in health care.

John-Stewart Gordon addresses the issue of poverty directly through an argument based upon the Aristotelian posit that all people strive for human flourishing. Since this is a primary assumption, impediments to human flourishing (that can be alleviated—similar to Daniel's claim about social causes) are prima facie wrong. Since the most concentrated areas of poverty in the world are in sub-Saharan Africa, East Asia, and South America, Gordon focuses his attention on these.

The biggest challenge to relief from poverty in these areas of the world is ethical relativism in which the brute fact of this poverty can often be explained away. Instead, Gordon offers an argument that centers on the access to primary health care as a global public good. Global public goods are: (a) public and nonexclusive, and (b) universal in scope.

Gordon's argument for the global public good of primary health care begins with the fact of extreme poverty in these designated areas of interest. The argument looks something like this: poverty ⇒ lack of access to primary health care ⇒ unwarranted bodily harm ⇒ loss of this basic human right ⇒ loss of human dignity ⇒ diminishing human flourishing (the basic posit to which all humans strive).

Gordon then examines various possible objections to his argument and concludes that if his argument holds, then it is incumbent upon the wealthy nations of the world to provide poverty relief to poorer nations—particularly in the area of access to primary health care.

Christian Illies begins his chapter by citing the staggering statistic that almost a billion people in the world today live on less than $1 a day. He then queries whether this empirical fact alone should exhort us all to action. Why philosophize when help is needed *now*?

The answer comes from the concurrent fact that though empirical experts can tell us a lot about the problem as it now exists, they cannot define the direction of our normative duty. This is the real and necessary job of philosophy. To this end Illies suggests three areas of inquiry: (a) the precise normative ends that we wish to achieve; (b) the rational justification of these ends; and (c) the way these ends relate to our basic human inclination toward free agency.

In the first category, one may derive guidance from the structure of human action. If the desire to act is fundamental to whom we are, then understanding this structure will do more to clarify the nature of the ends we wish to encourage and assist than mere broadly based imperatives such as “Help the poor.” Though we *should* help the poor, the rather vacuous nature of the imperative gives little action-guiding advice. Ethics can provide this greater specification so that we can transition from abstract directives to those that will be useful for productive action.

In the second category, Illies contends that we must go beyond emotional invocations, such as were advocated by Schopenhauer, to a rationally based foundation. This is because the emotionally based foundation is too dependent upon visual cues that are rather haphazard—such as seeing the picture of a starving child. Rather, what is preferable is something like the transcendental deduction of the categorical imperative that Kant put forth in part three of the *Grundlegung*.

As most commentators note, part three of the *Grundlegung* involves an interpretation of human freedom (the third category). Illies looks to contemporary philosopher Roger Brownsword to situate an account that can support a notion of human dignity. With the freedom-to-dignity composition in hand, Illies can return to the generating question by citing that this is the philosopher’s job: to situate our quest to alleviate poverty within the context of increasing the moral freedom of agency.

David Cummiskey challenges the common dilemma between a market approach and a government approach to delivering health care to its citizens. He sets out a third alternative that is a social insurance model. This social insurance model derives its origins from Germany that also created a hybrid model. The origins of this system, Cummiskey suggests, had these characteristics:

1. Multiple health insurance funds (often called “sickness funds”) that are quasi-public, independent (nongovernment), nonprofit organizations that collect revenues and pay health care providers.
2. Funds were originally occupation-based but now also include regional funds, including funds for small businesses and the self-employed. Membership in funds is based either on type of occupation or geographical region.
3. Social insurance systems may include choice in fund membership and it may include complete choice of health care providers.

4. Representatives of employees and employers are responsible for managing the funds within the constraints of general government mandates, which include basic coverage standards.
5. The health (sickness) funds are financed primarily by employer and employee contributions. Employee contributions are based on ability to pay through a percentage of wages or income, which is set by the funds and/or the government. The funds and/or the government set employer contribution levels.
6. Social insurance systems provide insurance to all eligible persons without regard to risk or previous health status. Social insurance systems include a system of risk-pooling, and/or general government contributions, to promote equity across funds.
7. Health insurance is usually compulsory for all either through the social insurance funds or through private insurance. Employment-based funds include all family members.
8. To achieve universal coverage, the employment-based social insurance systems must be complemented by a general government-financed fund (or funds) for the poor, unemployed, and retired.

Using this sort of model, Cummiskey advocates access to health care to be socially secured. But the way to this end involves a pluralistic approach.

In order to avoid the problems with solely provided government insurance or a government-run system as the one and final solution, Cummiskey encourages us to think outside the box and try to provide the best of the market-based solutions alongside basic minimums of patient care. This is an imaginative way to address one of the most important aspects of public health: how to deliver basic primary care to all citizens within a country.

The last selection in this part comes from Henrik Syse of Norway. In Henrik Syse's contribution we have the perspective of a unique individual who is both a philosopher and a person of practical action (having worked in a prominant position at the Central Bank of Norway). This sort of dual perspective is beneficial in offering suggestions on the role of money in public health efforts. Syse's chapter looks at the role that investors can play in modifying the behavior of the companies in which they hold stocks. In Syse's own role in the corporate-governance efforts of the Government Pension Fund (formally called the Petroleum Fund) he has shown that this theory really works.

At the beginning of his chapter, Syse asks where is the link between investors and public health? Isn't it the role of fund managers simply to maximize profits—whether they are in cigarette companies or arms fabricators? Syse says, no. Because of his concept of universal ownership (the large fund managers now have global perspectives), Syse believes that the owners—in this case large stock fund managers—should be concerned (out of rational self-interest) about social injustice and public health problems. This affirms John Donne's dictum that no man is an island unto himself and that every man is a piece of the continent and the part of the main, and Martin Luther King, Jr. who said from the Birmingham Jail that injustice anywhere is a threat to justice everywhere.

The investor tools to bring this about are: (a) company engagement and dialogue with the company standard setters, (b) an acceptance of the division of labor between the private and the public sector with a recognition that each can intelligently help the other meet their goals, and (c) investors using their universal owner insights for the benefit of all.

One of the very positive outcomes of reading Henrik Syse's chapter is to know that he, personally, has been positively involved in exactly what he is advocating. There are many ways to bring about change and one of them is via the stock-ownership system that is characteristic of modern economies.

Medical Need and Response

The third and final part of this book is devoted to specific individual public health problems. Each chapter intends to address a particular need in the context of a theoretical approach and then suggests directions that might be taken within the volume's broad understanding of public health.

In the first chapter, Margaret P. Battin, Charles B. Smith, Leslie P. Francis, and Jay A. Jacobson set out a model of how to think about infectious disease that is novel. They propose that we conceptualize the patient also as a vector. They call this the *patient-as-victim-and-vector* (PVV) view. The PVV is a model of the way to think about issues of policy and practice. They also conceive of five key steps to bring about the sort of radical changes that can reduce infectious disease. These five steps are: (a) national and international organizations and the development of the collective will, (b) epidemiologic and healthcare infrastructure, (c) scientific development, (d) religious, social, and cultural considerations (cf. Purdy), (e) legal and social protections for individuals and groups (cf. Hessler and Beyleveld/Pattinson). The practical suggestions always hearken back to the dual perspective of the PVV. On the practical side, the PVV suggests that "victim-hood" can have a dual sense: a person or group, or entire population, may be the victim of a disease—this is the primary sense of "victim" in the PVV view—but may also be the victim, so to speak, of policies, programs, prejudices, and other matters associated with disease, or both. By employing the PVV the authors create a dialectical dynamic not too dissimilar to my own use of dialectic in the "way we accept novel moral theories."[7] The result is a radical prescription of how we grab hold of the problem of infectious disease and really do something that works. Because of my own experience at the Center for American Progress (a Washington, DC think tank) beginning in 2007, I have become acutely aware of the necessity of blending "dreaming" and "practical policy solutions." This chapter introduces this part in a very creative/practical way.

In the second chapter, Rosemarie Tong relates her experience as cochair of the North Carolina Institute of Medicine/Department of Public Health Task Force

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[7] Boylan 2004, 10–14.

assigned to develop ethical guidelines for an influenza pandemic. Like Henrik Syse's earlier article, this is one that has been forged in the trenches of creating public policy. The potential threat of an influenza pandemic is real. Projections for US deaths alone range from 200,000 to almost 2 million. Some other accounts extend this by factors of up to 10×. One would assume that including international mortality figures, the result would increase significantly. Thus, for public health policy and ethics it is important to develop guidelines for action in the times of a crisis. In this case the national perspective is the focus. Tong's task force had this as its goal. They began with evaluating the response to the SARS crisis in Canada. In that case a report by Thompson's suggested procedural and substantive values:

> PROCEDURAL: (a) reasonability, (b) openness, (c) inclusiveness, (d) responsiveness, and (e) accountability; and SUBSTANTIVE: (a) individual liberty, (b) protection of the public from harm, (c) proportionality, (d) privacy, (e) equity, (f) duty to provide care, (g) reciprocity, (h) trust, (i) solidarity, and (j) stewardship

These key dispositions to action gave rise to five priorities for public health:

1. Priority should be given to assure the functioning of society.
2. Priority should be given to reduce the incidence or spread of disease.
3. Priority should be given to reduce illness, hospitalizations, and death due to the influenza.
4. Priority should be given to protect people with the most years of life ahead of them.
5. There should be no priority given for the distribution of limited health care resources to ensure that everyone has an equal chance of being protected (NC IOM/DPH Task Force 2007, 49–50).

The action outcomes of these priorities lead to: social distancing, isolation, and quarantine. These outcomes could effect many social events in society such as: church services, entertainment venues—movies, plays, concerts, and sports events. The social impact could be huge.

In addition the strategies of triage would also be in play. What supervening concept should rule this cascading series of events: deontology, utilitarianism, privilege? Each of these has proponents and critics. Instead of these usual suspects, Tong offers the *ethic of care* as the guiding principle in times of infectious crisis.

Michael J. Selgelid, Paul M. Kelly, and Adrian Sleigh contend in their chapter that tuberculosis (TB; a bacterial disease that kills many people—especially in the poor countries of the world rivaling or surpassing AIDS) should be upgraded to a front-line emphasis in the international concern for public health infectious diseases. This is partly because TB is a big killer. Another problem is that strategies for its control have often fallen prey to human rights and liberty abuses in the strategies of disease control. Finally, it is necessary to send out a clarion call for TB focus since the victims are primarily from subsistent societies. These souls have no automatic voice on the world stage. Thus, they need champions who will put forward their plight.

The authors assert that one third of the world's population (around 2 billion people) have at least latent-TB. This fact alone would prove the authors' case.

The poor suffer the most. Ninety-eight percent of the world's TB fatalities come from subsistent societies.

The suggested solution is moderate pluralism that identifies a panoply of values and issues and seeks to bypass the traditional conflicts between utility and liberty. TB reduction (done in the right way) can do this and rid the world of an insidious threat to international health.

This approach aims to identify the plurality of (intrinsic) values at stake in the context under study and strike a balance between potentially conflicting values without giving absolute priority to any one value in particular.

Simona Giorando's chapter confronts a lesser-known area of public health: atypical gender identity organization (AGIO). This condition occurs when one's gender identity is incongruous with his/her phenotype. For example, one's gender identity might be as a male but one's body has female genitalia (or vice versa). Though this appears to be a rare disorder (though how rare is difficult to ascertain because of its general social unacceptability leading to underreporting), it has clear public health consequences. For one thing, this terrible incongruence between body and mind often forces such individuals to emigrate to countries that offer operations to put the body in sync with the mind. However, such operations are expensive. To pay for them often requires one to become a prostitute and/or enter into the life of drugs and crime. This increases a public health problem. But what choice do many of these individuals really have? They are personally miserable to the point of life and death. They are discriminated against in society and subject to abuse and violence.

Giorando explores the tricky avenues of treatment before puberty with its medical effects and ethical snares. She suggests a general approach that may be effective for public health. We must assess the problem and cut through social prejudices in order to take general steps for the soundest medical treatment within an ethical context. This is a work in progress. Giorando's chapter points a way to the future.

Finally, to round out the book I present a chapter that takes up a traditional problem in public health: clean water and sanitation. These prescriptions have become engrained in public health aspirational practice in the developed world: the wealthiest 15 or so countries in the world. For these states, this chapter is preaching to the choir (though even among these countries there are problems—for example, in the United States clean water has recently been shown to be problem in our nation's capital, Washington, DC and in Milwaukee, Wisconsin (around the 22nd largest city in the USA)). Thus, even though the thrust of my chapter is addressed to the poor countries of the world, it is not limited to them. Some wealthy countries are often slack—especially when the victims of unclean water and improper sanitation are the invisible souls in society: the underclass. This is unacceptable on moral grounds.

The chapter attempts to describe the problem in a snapshot of the recent past and the foreseeable future with some realistic suggestions on what we can do *now*.

Conclusion

The volume as a whole can be accurately characterized as both *pluralistic* in its methodology and *proactive* in its exhortations for change: right now! The general tenor of the volume is to view public health and human rights as inextricably twined. The rationale of public health intervention cannot simply be convenience or personal advantage.[8] We are in this together. As Henrik Syse asserts, we have a universal ownership of the planet. This ownership entails responsibilities. We have to step up to these responsibilities. The time is now. Readers of this book take up the gauntlet and vigorously support public health initiatives—like those advocated in this book—so that we might make our planet more *habitable* and *just* for *everyone*!

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[8] For an extended discussion of this argument see the introduction to the predecessor volume to this volume: *Public Health Policy and Ethics*, edited by Michael Boylan (Dordrecht: Kluwer/Springer, 2004).

Part I
Morality and Politics

Personal or Public Health?

Muireann Quigley and John Harris

Abstract Intuitively we feel that we ought (to attempt) to save the lives, or ameliorate the suffering, of identifiable individuals where we can. But this comes at a price. It means that there may not be any resources to save the lives of others in similar situations in the future. Or worse, there may not be enough resources left to *prevent* others from ending up in similar situations in the future. This chapter asks whether this is justifiable or whether we would be better served focusing on public health in the form of preventative medicine. It looks briefly at the supposed difference between benefiting individuals and benefiting populations by considering the difference between interventions aimed at 'rescue' and those which are preventative. It then considers the rule of rescue in the health care setting, and looks at some of the reasons stemming from this that we might have for allocating resources to rescue interventions. If these reasons do not provide adequate justification for preferring these types of interventions, then the implication is that our current mode of resource allocation may need to be revised in favour of a more public health-oriented model.

Keywords Public health, individual health, rule of rescue, identifiable, non-identifiable, statistical victims, discounting the future

Introduction

Imagine the following scenario. The government is worried about their current spending on health care. There is not enough money to pay for all the staff, services, health care interventions, or medicines that seem to be required by the citizens. The minister for health feels that there might be a better, more efficient way to structure the health care budget. She thinks that there must be a way to make the citizens healthier and prevent major diseases (heart disease, diabetes, respiratory problems) from developing within the population. She believes that this would have the two-fold effect of decreasing morbidity and mortality and of cutting expenditure on acute medical services.

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To test this she brings together some leading experts in public health and preventative medicine, including epidemiologists, health educators, biostatisticians, nutritionists, and economists. She has even taken the recklessly extravagant step of including a couple of ethicists on the team. The team assure her that they can come up with a public health strategy that could raise the level of health of the population within a generation or two. There is, however, a significant problem with their plan: it would require a major redeployment in health care resources from the acute services to public health interventions. The ethicists are unsure if this would be a morally justifiable course of action since it would literally mean the sacrifice of the health and well-being (and perhaps lives) of some patients in the near future for those of some unidentifiable ones at some further point in time.

Intuitively we feel that we ought (to attempt) to save the lives, or ameliorate the suffering, of identifiable individuals where we can. But this comes at a price. It means that there may not be any resources to save the lives of others in similar situations in the future. Or worse, there may not be enough resources left to *prevent* others from ending up in similar situations in the future. This chapter asks whether this is justifiable or whether we would be better served focusing on public health in the form of preventative medicine. To do this we briefly look at the supposed difference between benefiting individuals and benefiting populations, considering the difference between interventions aimed at 'rescue' and those that are preventative. We then move on to consider the rule of rescue in the health care setting, and look at some of the reasons stemming from this that we might have for allocating resources to rescue interventions. If these reasons do not provide adequate justification for preferring these types of interventions, then the implication is that our current mode of resource allocation may need to be revised in favour of a more public health-oriented model.

Benefiting Individuals and Benefiting Populations

The Institute of Medicine in the United States has stated that public health medicine encompasses a range of interlinked fields including epidemiology, health promotion and education, public health administration, international health, maternal and child health, biostatistics, environmental health, and nutrition (Institute of Medicine 1988, 1). Whatever the multiple and varied subspecialties that feed into public health and its delivery, public health in its simplest form is just what it says on the tin: it is that aspect of health care which is concerned with the health of the public.

It has been noted by a number of commentators that public health medicine, and hence public health ethics, encompasses issues that are different from those in the normal clinical relationship (Bayer and Fairchild 2004; Boylan 2004; Charlton 1993; Childress et al. 2002). The typical clinical encounter involves a one-to-one consultation between the patient and health care professional. The focus is on the individual health care needs of that patient, and the best way to address and manage those. In the consultation the physician directs his attention only towards that particular patient and deploys health care resources with his patient in mind.

On the other hand, public health endeavours are aimed at the population as a whole, or specific populations such as children, the elderly, women, or those at risk of heart disease. The aim is not to treat any individual patient, but to put in place interventions that will show benefit at the population level. This does not necessarily mean that every person within the target population will benefit from the intervention, but that overall the target health outcome will be achieved. This approach requires that we treat sufficient numbers for the effect to be demonstrable at the population level. An example of this might be the current treatment regime for cardiovascular disease in the United Kingdom. The aim is to put everyone who has a certain level of cardiovascular risk on the same drug regime in order to treat sufficient numbers to decrease the country's overall cardiovascular burden. We may never know whether or not a particular individual has benefited from the regime, but we can demonstrate the effect on the population.

If we are interested in the health of the people, in the health of each and every person, then we are necessarily interested in health at the population level. Health care policies reflecting this would encompass strategies and interventions aimed at improving health for the population as a whole. Examples of these types of interventions would be national immunisation programmes, health education programmes, and screening programmes. The concept of patient autonomy, which derives from the individual patient model, can be seen to be in direct conflict with an 'ideal' model of public health. In this model individuals would not be able to opt out of the public health endeavours of their country. This is because optimal public health outcomes require maximal participation in order to get maximal health benefit for the population at large.

These two different approaches, individualised health and public health, are not completely independent of one another. They will in fact impact on each other. After all, any benefits seen at the population level are necessarily the sum of individual effects, and any benefit brought about through individual measures will contribute to the whole. However, the health care strategies in each approach are often in conflict. It can be seen as the difference between a bottom-up and a top-down approach to health care. This distinction arises because when we treat individuals we are looking at the specifics of their situation, responding to this, and treating accordingly. The individual outcomes and effects of this contribute to, and add up to give us, an aggregate population result. Conversely when practising public health medicine the broader picture is examined, looking at general measures that can be instituted across a broad range of the population, and working down to the minutiae. This has the end result that the benefits of the intervention trickle down to a proportion of the individuals in the population, although we may never know which ones exactly.

So far we have been talking about individual health and public health and have seen that they are in fact interconnected. If we look at the types of interventions which can be utilised to generate the required health outcomes, we can place them into three loosely defined categories: (1) those that are aimed at preventing a disease or illness (primary prevention), (2) those that treat an illness (or its symptoms) once it has developed (rescue), and (3) those that treat an illness or its symptoms, but also help to prevent recurrence in the future (rescue/secondary prevention). Of these the preventative health care measures seem to operate at a cost-effective level (for examples of this see Schwappach et al. 2007; Segal et al. 1998; and Lindgren et al. 2003). Taking the example of coronary artery disease we can see which interventions would fall into which category. Health education campaigns focusing on diet, exercise, and smoking can be seen as primary preventative measures, as can drugs such as statins, which decrease a person's overall cardiovascular risk. Interventions such as thrombolytic therapy to break down blood clots within the coronary arteries can be seen as 'rescue' medicines. Such interventions are administered when the patient presents in the acute setting and are aimed at the immediate relief of symptoms and are also often life-saving. Other interventions such as coronary artery bypass grafts (CABGs) can also be seen as a form of rescue medicine but they also play a role in the secondary prevention of the disease.

In a public health approach focusing *solely* on primary prevention, every individual would probably stand to gain certain health benefits; however, they would not be entitled to rescue interventions should they need one. Alternatively on the rescue model of health care each individual can expect specific large health benefits should they need such an intervention, but this might have the consequence that everyone else is left in a lesser state of health than they would be on the public health model. It is for these reasons that 'rescue' medicine can be portrayed as being in conflict with the common good. Any redirection of resources away from tertiary health care would necessarily have the effect that some people would not be able to access rescue interventions should they need them. While it is possible that the overall effect would be to increase the level of health of the population as a whole, and hence individuals within the population (Diehr et al. 2007; Pamuk et al. 2004), such a drastic move requires justification. In order to do this we want to look at the reasons we have to favour 'rescue' medicine and ask whether the arguments for this stand up to scrutiny.

Two of the strongest reasons why we might want to favour allocating resources to rescue interventions are (1) those individuals who benefit from rescue interventions are generally identifiable, whereas those who would benefit from interventions aimed at the population at large are statistical and non-identifiable; and (2) individuals benefit from rescue interventions now or in the near future, whereas those who would benefit from an input of resources into prevention measures are in the more distant future. We now briefly turn to look at the rules of rescue (RR) before examining each of these in turn.

Rule of Rescue

McKie and Richardson nicely explicate one of the prevailing views on rescue saying that the RR 'expresses the view that we cannot ignore certain situations because of cost or low QALY [quality-adjusted life years] benefit' (2003, 2409). While

Jonsen tells us that 'our moral response to the imminence of death demands that we rescue the doomed' (1986, 174) and that those 'doomed to death are certainly quite visible individuals' (1986, 173). However, he claims that the effect of this is that

> the rational effort to evaluate the efficacy and costs, the burdens and benefits, of the panoply of medical technologies – an effort essential to just and fair allocation – encounters the straitened confines of the rule of rescue. (Jonsen 1986, 174)

It is generally accepted that where we can save the life of an endangered person at little or no risk to ourselves, we are morally obliged to do so. Where there is little or marginal cost to ourselves, it is reasonable to posit that this also applies to cases where a person's life is not in danger but we could ameliorate their suffering.

The oft-quoted hypothetical example is of the child drowning in a pond. You can save the child's life at no risk to yourself and at no cost save some wet clothes. Are you morally obliged to save the child? We can think of no reason why this would not be the case. An analogous case in the health care setting might be that of the collapsed patient. You are walking along the hospital corridor and find a collapsed patient who is not breathing and you cannot find a pulse. You are on your way to lunch when you find the patient: Should you stay and administer cardiopulmonary resuscitation (CPR) until further help arrives? You will be delayed in getting your lunch but the dire need of the collapsed individual almost certainly creates a moral duty that you stop and help him or her.

However, such a case with its clear moral imperative is not analogous to all instances of rescue in the health care setting. This is because not all patients can be saved or have their suffering ameliorated at no risk to others or at no cost to the system. If resources are utilised performing a heart transplant, then, where there are limited resources, those same resources are no longer available to spend on others who might need them. This does not simply mean that another patient who might have needed a heart transplant cannot have one, but, perhaps, that 20 people who might have benefited from diabetes medication cannot be treated. Or it might mean that 100 people who might never have developed diabetes, maybe because of a health promotion campaign, do in fact go on to develop diabetes. Wherever health care resources are expended there will be an opportunity cost; some other person or persons will suffer a health risk or cost because of the decision to utilise those resources in a particular manner.

Of course, when it comes to rescue situations each individual could decide that they are willing to accept the associated risks and/or opportunity cost, even where they are significant, of the attempt. For example, some persons may still believe they should try and save the child in the pond from drowning when the weather is stormy and there is a good chance that they themselves might suffer an injury or even die in the attempt. Similarly an individual who freely decides to donate a kidney for transplantation willingly undergoes the associated risk of illness (and even death) involved in this act. What we cannot do is *force* people to take on those risks that would place their own lives or health in danger. As in the above examples it would be very nice of them to do so, but they cannot be seen as anything other than supererogatory acts.

If we go back to the pond analogy it is clear that if a rescue can be affected without personal risk, and with minimal inconvenience and cost, such a rescue would be morally obligatory (although not legally binding in the United Kingdom).[1] If we were to suggest that an individual was morally obliged to attempt the rescue even though they could be left with a serious injury, or might even die, this could or would be countered by pointing out the claim that the conduct almost certainly is beyond what could reasonably be understood as obligatory. If by attempting the rescue there would be no danger to you but 20 other people would suffer adverse health effects because of it (perhaps you need them to act as stepping stones in the water for you, thereby leading to some anoxic brain injury), and we were still to suggest that it was a moral obligation, we might well be accused of reckless endangerment. However, this is what happens when decisions are made to spend money on expensive rescue treatments. This is because the resources that could have been used to improve the health of, or save the lives of, others are used up. They are used up without asking each and every person if they are willing to put their chance at health or their chance to be saved at risk for others (Hope 2001, 184).

Having said that, it may be the case that there are factors which require us to allocate health care resources in this manner. We mentioned two possibilities regarding this earlier: the first is that in rescue situations the victim is generally identifiable, and the second is when they are likely to be in need.

Identifiable, Non-identifiable, and Statistical Victims

One of the reasons why we appear to be willing to spend a considerable portion of the health care budget on what can be seen as rescue interventions may be connected to what Jenni and Lowenstein (1997) have termed the ‘identifiable victim effect’. This is why the ‘society is willing to spend far more money to save the lives of identifiable victims than to save statistical victims’ (1997, 236). In the health care context this can be characterised as the conflict over whether to use some of the available resources to administer a rescue intervention that will benefit a particular patient (e.g. thrombolysis or emergency angioplasty for a myocardial infarction), or whether to use them for a preventative intervention that will benefit a ‘proportion of patients within a group but we cannot know who has been benefited’ (Hope 2001, 181) (e.g. health promotion campaigns or the use of statins).

This can be portrayed as competing claims between actual people and mere statistics. When characterised in this manner, the resource allocation problem appears simple: surely it would be morally remiss of us if we did not choose to save actual people. These are real identifiable individuals and we can clearly see their suffering and the risks that threaten them. On the other hand, what are they competing with? A bunch of numbers in the context of which we cannot be sure that anybody is actually at risk or of who would actually benefit were we to take action. While it might be easier for us to think of the rescue versus prevention problem in these terms, it is not the whole story.

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[1] It would be legally binding in France.

When talking about who might benefit (or not) from our resource allocation decisions there are actually three positions that the beneficiary might occupy. They might be (1) an identifiable individual; (2) a non-identifiable but real individual; or (3) a statistical possibility. Being non-identifiable could be equated with merely being a statistical possibility leading us to favour those individuals who we can identify in our considerations. However, as the following examples will show, the two categories are not synonymous and, therefore, ought not to be treated as such.

Scenario A: There is a sniper on the roof of a building. He has been contracted to kill a particular target. He knows the name and what the individual looks like. He spots his target and shoots. This person can be considered to be an identifiable individual to the sniper in this situation.

Scenario B: Again a sniper is on the roof of a building. He has not been hired to kill anybody; he simply has a murderous nature. He shoots randomly into the crowd below and kills one of them. This individual was not identifiable to the sniper but was *real*, thereby suffering the real consequences of the sniper's actions.

Scenario C: In Arthur Miller's play *All My Sons*[2] the Keller family and in particular Steve Keller, who does not appear in the play, were responsible for manufacturing and shipping defective cylinder heads for aircraft in the Second World War with the result that pilots were killed. Joe Keller admits his part in the killings: 'I was the beast; the guy who sold cracked cylinder heads to the Army Air Force; the guy who made twenty-one P-40's crash in Australia.' As he says of Steve Keller his 'partner in crime': 'I know he meant no harm'. Neither of them intended or planned the deaths of those pilots. But such excuses do not wash with the next generation of the family. As Ann Keller says of her father: 'He knowingly shipped out parts that would crash an airplane', and her brother Chris says bluntly: 'He murdered twenty one pilots' (Miller 1961, 117). The Kellers did not know for sure that anyone would die and they did not know how many or who precisely would be adversely affected by their actions. At the end of the play Joe Keller discovers that his own son, Larry, also a pilot in the war, had committed suicide when he learned of the family complicity in murder. Trying to make Joe and his mother take responsibility, Larry's brother Chris repeats his indictment of his father: 'Larry didn't kill himself to make you and Dad sorry', and his mother responds: 'What more can we be?' Chris's answer carries the message of the play: 'You can be better. Once and for all you can know that there is a universe of people outside and you're responsible to it, and unless you know that, you threw away your son, because that's why he died' (Miller 1961, 170).

This is an example of a statistical possibility because not only can we not identify those who might be affected, but it is uncertain that anyone will be affected at all. In addition, it is also extremely difficult to determine the probability that the event might happen at all or of the risk to those possible people who might be affected. It is clear from these examples that there is a distinction between identifiable,

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[2] For discussion of this point in a related context see Brazier and Harris (1996).

non-identifiable, and statistical victims. Such a distinction within the health care setting can be seen in the following examples.

Scenario D: A child presents to the emergency department with signs and symptoms suggestive of meningococcal meningitis. A lumbar puncture is performed and the meningococcal organism is confirmed on gram stain. The child is treated with intensive intervention including antibiotics. Here again there is an identifiable individual.

Scenario E: Under the United Kingdom's national immunisation programme the primary immunisations (diphtheria, tetanus, pertussis, polio, and *haemophilus influenzae* type B) are given at two, three, and four months of age.[3] The effects of these immunisations can be measured at a population level but we cannot know exactly who has benefited from them.[4] Such an intervention benefits non-identified but nonetheless real people.[5]

Scenario F: Tamiflu (oseltamivir) is an antiviral drug that has been used to treat influenza types A and B. It has also been used to treat patients who contracted the H5N1 strain of the avian flu virus. The UK government has ordered enough of the drug to treat 25% of the population in the event of an avian flu pandemic.

In this case there are three areas of great uncertainty. The first is uncertainty about the actual risk to the population from H5N1. This is because so far there have been no reported cases of human-to-human transmission; in all of these cases the virus was transmitted from bird to human. Additionally if human-to-human transmission occurs, we have no idea what the effect on the virulence of the strain might be. The second cause of uncertainty is that surrounding the efficacy of the drug itself. There is scant evidence that oseltamivir is effective in suppressing viral replication of H5N1 (De Jong et al. 2005) in the cases where it has been used. Given this it is even less evident what its efficacy might be on a mutated human-to-human strain. The third, and perhaps greatest, area of uncertainty is the fact that we cannot even begin to determine the population that might benefit from this intervention. We know that 25% of the population will stand to benefit but, as we do not know when (or even if) such a pandemic might occur, we cannot even know what the demographics of the population will be at that time. This all adds up to a situation where we are in effect treating a statistical possibility.

It is clear from the above examples that in the health care arena we are mostly talking about the competing claims, not of fictional persons versus actual persons but of real person's versus real persons, identifiable or not. Given this we need to ask whether there is anything in particular about being identifiable that might permit us to justifiably favour those who are identifiable in our resource allocation decisions.

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[3] See http://www.immunisation.nhs.uk/

[4] See http://www.immunisation.nhs.uk/article.php?id=400 for information on specific diseases and vaccines.

[5] Although in principle they could be identified.

The first factor might be knowledge of some personal attribute held by that person, such as their name, physical description, or age demographic. This seems an unlikely candidate for a justifiable reason to distinguish between people for treatment. Using criteria such as these would be tantamount to racism, sexism, and ageism and would simply be discrimination without a morally relevant basis.

The second possibility might be distance. It has been suggested that we owe greater moral obligations to those who are nearer to us than those who are far away (for a discussion of this see Kamm, 2000). However, while the criterion of 'nearness' might hold some moral sway when it comes to an individual person's obligation to help those in need (after all if you are near and can help then you should), it seems unlikely that it ought to be taken into account when making resource allocation decisions. The reason for this is that the institutions that make the allocation decisions, be they the government in the United Kingdom or the state legislatures elsewhere, cannot reasonably be said to owe greater obligations to those who live nearer their seat of power than to those who live further away. It would be odd indeed if the UK government gave priority in its decision making on health, security, or education to those living in or around London.[6] The government is an institution with no geographical locus to speak of when it comes to describing either its duties towards its citizens or its power over them. If we are to utilise the concept of nearness at all in this instance, then conceptually we would have to see it as being equally proximate to all its citizens. Moreover, distance is not simply a geographical concept. Those who are expensive to treat are also in a real sense more distant from us, not least because those geographically more distant from treatment centres are also more expensive to treat (Harris 1996).

Perhaps then the characteristic that inclines us towards rescue is not the fact that such individuals are identifiable but that their need is more pressing. In general, those identifiable individuals who are in need of rescue interventions are in need of them now (thus contributing to our ability to identify them), whereas those non-identifiable persons who might be helped will benefit not now but at some time in the future. We, therefore, need to ask whether it might be morally justifiable to favour rescue interventions that affect people now rather than preventative ones which will affect either people in the future or future people (people who as yet do not exist).

Discounting the Future

Many people believe that we have more powerful reasons to do things now rather than later, and that harms are less terrible the further into the future they occur and that the benefits are less beneficial. If the future should be discounted in favour of the present, we would have moral reasons (or economic/accounting reasons) for

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[6] Although it has been accused of doing exactly this while giving a lesser priority to more remote areas of the country.

rescuing individuals now rather than initiating public health measures which would protect people in the future or future people.

But why *should* the future come at a discount?[7] Let us start with the problem of duties to non-existent, future people.

We believe that this problem about duties to future, non-existent people is largely illusory. While future people have no rights and do not exist to make claims upon us now, it does not follow that we cannot harm them and therefore that they are not covered by all our person-affecting duties, including our duty not to harm others. Consider, if we put a slow-acting poison into the water supply, a poison that will not become active for 200 years, it will kill no one presently alive but everyone who drinks the water in 200 years' time. Such an action would not be harmless. While we cannot *identify* in the sense of *name* those who will die, we can identify them in another sense. They are all those who will derive their water supply from *x*, *y*, and *z* reservoirs in 200 years' time. Since our action will affect persons, future persons, it is part of person-affecting morality, and since it will cause a particularly harmful form of harm, namely death, it is covered by our duty not to harm and kill others. This sort of future harm cannot be discountable.

What is true of harms is also true of benefits; the two are the Janus faces of the duties we have to others.[8] Just as we have the same reason not to cause future harms as we have not to cause present harms, we have the same reason to confer future benefits as we have to confer present ones. John Broome has some interesting thoughts which are relevant here (1994).

Broome agrees with Derek Parfit's, surely unassailable, claim that equal harms to well-being count the same whenever they occur. There are, however, problems about what counts as a harm to well-being and how to quantify such harms:

> Some commodities represent a constant quantity of well-being whenever they occur; let us call them constant-well-being commodities. … Saving people's lives is plausibly another example of a constant-well-being commodity; on average, saving one person's life in one hundred years will presumably add just as much well-being to the world as saving one person's life now. Granted that well-being ought not to be discounted, constant-well-being commodities ought not to be discounted. … Lifesaving in the future will make the same contribution to well-being as lifesaving in the present. Certainly future lifesaving is cheaper than present lifesaving, but this is not a reason for valuing it less. (Broome 1994, 149)

So far so good. However, Broome points up a paradox:

> If we can convert a quantity of lifesaving now into a greater quantity next year, and if the lifesaving next year is just as valuable as lifesaving now, the conclusion we have to draw is that lifesaving should be deferred. We should withdraw resources from lifesaving today, and apply them to saving more lives next year. We should also defer lifesaving next year in order to save yet more lives the year after. … We will end up postponing all livesaving to the indefinite future, which never comes. So we will end up saving no lives at all. (Broome 1994, 150)

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[7] In this section we benefit from the work of our colleague Sarah Chan. Some of the ideas here presented are to be found in Chan and Harris (in press). See also Parfit (1984) and Broome (1994).

[8] As argued in Harris (1980).

Broome notes that this is ridiculous and concludes it is a paradox we must resolve and assays one possible solution:

> Lifesaving may not be a constant-well-being commodity. Undoubtedly, saving some people's lives adds more well-being to the world than saving other people's. Saving a twenty-year old with a long and happy future ahead of her adds more well-being than saving a ninety-year-old with little left to look forward to. (Broome 1994, 150)

Broome's big mistake is commodifying life, and his conception of what life-saving means commodifies life absolutely. He identifies the value of the life of a person as the quantum of well-being that life adds to the world. For Broome the reason to save a life is to maximise the amount of well-being such an action adds to the world. This is seeing the value of life exclusively as a commodity, as the amount of well-being it contains, and the value of saving a life as the quantum of well-being that life-saving adds to the world.

But well-being, or indeed welfare, is not an end in itself; it is an instrumental good, not a good that benefits the world in proportion to the amount of it there is floating about, but rather a good that benefits the individual person whose being is well (or otherwise). Well-being is the welfare of a being, not a quantum of abstract goodness. Concern for, or promotion of, well-being or welfare is then a state of being of a person, not a state of the world. It complements an individual's autonomy in that it provides the conditions in which autonomy can flourish and lives be given their own unique meaning. Well-being and welfare thus conceived has a point, as does concern for the welfare of others; it is not simply a good in itself. We need welfare, broadly conceived in terms of health, freedom from pain, mobility, shelter, nourishment, and so on, because these things create the conditions which not only maximise autonomy, but also give autonomy maximum scope for operation. In this way welfare is *liberating*; it is what we need to be able to pursue our lives not only to best advantage but also in our own way (Harris 2003). The value of a life is overwhelming to the individual whose life it is, and to that person, the loss of their life is the loss of everything, not simply of something or some things. This is why, as one of the authors of this chapter has argued on a number of occasions, including against other ideas of John Broome, the value of a life is not proportional to the amount of good or well-being or welfare it 'contains', nor to the amount of lifetime enjoyed or in prospect for the individual whose life it is. For that individual, however well (or ill) their being, or however long or short their life or lifetime in prospect, it is the loss of everything. That is why it is not simply wrong-headed but also wrongful to value lives differentially according to quality or quantity of life.

If the millionaire and the pauper both lose all they have in the stock-market crash, in one way of thinking about the loss, each has suffered the same degree of loss, each has lost everything. In another, each has suffered a different quantity of loss measured by the total sum lost. There is no straightforward way of reconciling these different approaches to the assessment of loss. If we are searching for an equitable approach to loss, it is not obvious that we should devote resources allocated to loss minimisation to ensuring that the millionaire is protected rather than the pauper. The same is true of health gain or indeed of well-being or welfare. Even if it is agreed that resources devoted to welfare or health care are resources devoted to minimising the loss of health or welfare or well-being, it could not be demonstrated that the person who stands to lose more well-being or more life years if they die prematurely stands to suffer a *greater loss* than the person who has less well-being or life expectancy.

If you and I are competitors for rescue or life-saving care and I have already, or will have after the rescue, more well-being or better welfare than you, it seems unfair to automatically prefer to satisfy my needs rather than yours. This is because both of us will receive something that is significant and important to us. Why should my life be judged more worth saving because I am more healthy or happy or have greater well-being, rather than because I am more intelligent or more useful? Arguments can be (and have been) made on both sides, but to define need, for example, in terms of capacity to benefit and then argue that the greater the well-being deliverable by rescue, the greater is the need for rescue (or the greater is the person's interest in receiving rescue) is just to beg the crucial question (Harris 1997).

The bearing of all of this on the question of the rival merits of rescue versus prevention is that regardless of age, life expectancy, or geographical or temporal proximity the value of a person's life remains constant and the moral reasons for rescue are equally strong. As Mill has reminded us, Jeremy Bentham memorably said 'each is to count for one and none for more than one'.[9] This should be the gold standard for rescue and for treatment now or in the future. It follows that prevention is not better than cure, but neither is cure better than prevention. While I would prefer a possible disease or accident to be prevented rather than wait for the necessity for cure, if I am already suffering I benefit as much from cure of this cause of suffering as I would by prevention of other comparable future suffering. There is nothing to choose between curing my present suffering and preventing the comparable future suffering of someone else.

If we now consider the case in which the future people do already exist but are different, we can see that there are now good reasons in principle to discount the future although some reasons connected with probability of outcome remain.

Intuitively it seems correct that a duty to rescue *X* today is more pressing than one to rescue *Y* in a year's time. But it seems likely that this is due to the probabilistic intuition that during the intervening year something else may occur to render our duty to rescue *Y* unnecessary or irrelevant. If we could say with 100% certainty that without our intervention *X* and *Y* would both suffer equal injury but at different times, it is hard to see why our obligation to *X* is greater than that to *Y*. The reasoning that one can distance oneself from future suffering only applies in the absence of forethought: future pain *will* hurt in the future, and choosing to avoid the present pain does not make the overall suffering any less. In fact one might argue that it would be better to undergo the pain now and hence avoid the mental torment caused by living in dread of the pain to come. In the case of saving lives, matters may be

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[9] The source for this famous remark of Bentham is his contemporary John Stuart Mill (1962, 319) in his *Utilitarianism*. See also Harris and Sulston (2004). For more on innumeracy in ethics see Taurek (1977) and Parfit (1978).

slightly different. It is clear that future-me will not exist if current-me is not rescued: the dereliction of one duty precludes the exercise of the other. This is not, however, the case when the present and future duties are owed to different parties.

However, the ethics of discounting the future where different people are to receive the benefits of rescue is complicated by two further considerations. The first is easily dealt with. While it is true that we are, in some ways, constantly changing, can we say that *Y* in one year's time exists now in the person of *Y*? If, and in so far as this is right, the problem of my trade-off between present and future rescue from harm may reduce to the problem of whether saving *X* now or *Y* in the future have different priorities. We do not believe so because even in the unlikely event that 'me' in one (or even 20) year's time is not really me, there will be enough psychological continuity between the two of us to make it rational for me now to have a strong interest in what happens to me modified in 20 years.[10] More significantly, if we opt to rescue *X* instead of *Y*, *Y* still gets an extra year of life. On a purely numbers basis, with no way of determining whose life is of greater 'benefit', this might make it better to rescue *X*. However, we would need theories about how the value of a life is varied by life expectancy or lifetime lived, not to mention cost of rescue and many other features, before this conundrum could be finally resolved.[11]

Other things being equal, if each counts for one and none for more than one, then more count for more. The contrary view is what Derek Parfit termed 'innumerate ethics'.[12] It follows that the life-saving of one person now cannot be more important than life-saving of more people later. But how does life-saving of one now count if the alternative is life-enhancing for a much greater number later? This cannot be finally resolved now. What can now be said is that these priorities are not affected by time or geography. Most people think that saving life has a higher priority than improving life but this is not always true.

Conclusion

We have seen that there can be no difference in principle between the ethics of saving one life or another whether now or later, whether by prevention of death, rescue, or treatment of disease. However, there is one important contraindication to this obviously rational and prudential conclusion. It is the undesirability of abandoning someone to death, illness, or injury without lifting a finger to help them.

It is inherently undesirable as well as psychologically difficult to say to someone who could be saved and who is at immediate risk that we have decided not to help him or her because we have committed resources elsewhere. This is particularly the

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[10] This is discussed by Harris (2007, chapter iv).

[11] These final sections borrow from Chan and Harris (2008). See also Harris (1994, 2002, 2005).

[12] Parfit (1978).

case where those resources have not been necessarily allocated to other such potential victims in circumstances where all cannot be saved but rather because the required resources have been allocated to a public health measure expected to reduce future risk.

In many cases the choice will be an artificial one, it being possible to make an extra effort or find extra resources to save lives immediately at risk. A transplant surgeon on her way to a full list at the hospital is unlikely to pass by on the other side of the street when she sees a child drowning in a puddle even though she is committed to an equally important alternative task – not least because these are unlikely to be real alternatives outside a philosophical discussion. Where it is not possible literally to have one's cake and eat it the choice must be to maximise lives saved and not to discount the future. But we might think that a decent person would not abandon the individual in front of them and trust time to save the future individuals some other way.

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Exploring the Philosophical Foundations of the Human Rights Approach to International Public Health Ethics

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Abstract This chapter has four main points. First, I argue that the human rights approach to public health ethics, championed by Jonathan Mann and others, needs to engage with philosophical accounts of moral human rights. Second, I argue that, while both interest-based and agency accounts of moral human rights are defensible as philosophical accounts of human rights, and both have advantages as the foundation for a human rights approach to public health ethics, the interest-based approach is a natural fit for this approach. Third, I illustrate how engagement with the philosophical accounts of the structure of moral rights can help respond to the criticism that certain rights underpinning the human rights approach to public health ethics, such as the right to health, cannot be justified. Finally, I argue that the human rights approach to public health ethics promises to contribute to our understanding of both health and human rights.

Keywords Human rights, Jonathan Mann, right to health, utilitarianism, well-being, agency

Introduction

The human rights approach to public health uses human rights as an ethical background for public health, drawing attention to the many ways in which health depends upon social justice, and vice versa. Currently, defenders of this approach shy away from engagement with the philosophical foundations of human rights. In this chapter, I argue that this is a mistake. First, I explain why the human rights approach to public health ethics needs to engage with philosophical accounts of moral human rights. Second, I argue that, while both interest-based and agency accounts of moral human rights are defensible as philosophical accounts of human rights, and both have advantages as the foundation for a human rights approach to public health ethics, the interest-based approach is a natural fit for this approach. Third, I illustrate how engagement with the philosophical accounts of the structure

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of moral rights can help address the criticism that certain rights underpinning the human rights approach to public health ethics, such as the right to health, cannot be justified. Finally, I argue that the human rights approach to public health ethics promises to contribute to our understanding of both health and human rights.

The Human Rights Approach to Public Health Ethics

Traditionally, utilitarianism has been considered the most natural ethical theory for public health ethics. This view is the product of the view of public health as concerned with the health of populations, not individuals, and the concomitant view that a concern with population health requires utilitarian reasoning.[1] By now, however, public health ethics has for the most part shed the simplistic conviction that public health measures necessarily conflict with individual rights. This view has been challenged in several respects. Several theorists have argued that, as Matthew Wynia put it, "public health is, frankly, much more consequentialist in theory than it is in reality" (Wynia 2005, 6). Part of Wynia's point is to suggest that both public health ethics and traditional bioethics, which emphasizes patient autonomy, are committed to a similar balancing between rights and utility, in which social goods like public health limit the extent to which individual practitioners may protect individual autonomy. According to Lawrence Gostin, for example:

> [P]ublic health does not simply aggregate benefits and burdens, choosing the policy that produces the most good and the least harm. Rather, the overwhelming majority of public health interventions are intended to benefit the whole population, without knowingly harming any individuals or groups. (Gostin 2001, 125)

However, this suggestion does not dispute the notion that public health is essentially about utility maximization; rather, the point is that ethical public health respects rights as "side-constraints" or limits on utility maximization. Such a characterization preserves the essential conflict between utilitarianism and rights, asserting that rights often "win" in public health ethics.

Another, more profound, challenge to the simplistic view stems from the work of Jonathan Mann and others who have argued for what Mann called the "underlying complementarity" of public health and human rights. According to Mann, "the human rights framework provides a more useful approach for analyzing and responding to modern public health challenges than any framework thus far available within the biomedical tradition" (Mann 1996, 924). Mann's central point was that if public health is truly about improving the health of populations, then it must be concerned not only with proximal causes of ill-health, but with the full range of "social determinants of health." For example, Mann noted that in the AIDS pandemic, "discrimination (and other human rights issues) were found not only to be tragic results of the pandemic but to be root societal causes of vulnerability to HIV" (Mann 1996, 925). While violations of human rights correlate with poor public health—such that those whose human rights are compromised generally have poor health—efforts to promote public health that also respect human rights have been shown in many cases to be more effective than policies that egregiously compromise human rights. According to Mann, "[W]hen people found to be infected were deprived of employment, education, or ability to marry and travel, participation in prevention programs diminished" (Mann 1997, 10).

The human rights approach to public health ethics has been criticized on a number of grounds. According to Mark Rothstein, this approach is "self-defeating," because in "annexing human rights into the public health domain," public health would be taking on social problems it is not prepared to address (Rothstein 2002, 45). Lawrence Gostin mentions three reasons why the human rights approach to public health ethics has been seen as "counterproductive": first, such a broad understanding of public health would deprive it of its focus; second, a broad understanding of public health deprives it of its "discrete expertise;" and third, "by espousing controversial issues of economic redistribution and social restructuring," public health would become "highly political" (Gostin 2001, 123).

Responding to these criticisms requires, I believe, two things. First, defenders of the human rights approach to public health ethics must continue to refine and articulate that approach. Surely public health should not "annex human rights into the public health domain," if that means that public health should become, or replace, the human rights activism of organizations like Amnesty International or Human Rights Watch. While much work has been done to articulate exactly how human rights and public health are interdependent, and how public health as a field should respond to this interdependence, continuing to articulate exactly what is entailed by the human rights approach to public health ethics is essential for responding to criticisms like these.

Second, those defending the human rights approach to public health ethics should be willing to engage with the philosophical foundations of human rights. Just as an adequate ethics for public health cannot get off the ground if it relies upon traditional misconceptions about public health—such as that it is relentlessly utility maximizing—the human rights approach cannot succeed without being willing to rely upon the philosophical foundations of human rights. As currently developed, the human rights approach to public health ethics does not engage with philosophical conceptions of human rights, relying instead on human rights as constructs of international human rights law. I argue that this is a mistake.

Human Rights: Moral and Legal

International human rights law provides an attractive starting point for those wishing to defend a human rights approach to public health ethics. The Universal Declaration of Human Rights (UDHR) of 1948 is the touchstone for international human rights law; despite the fact that it was a General Assembly declaration without binding legal force, it represents the first detailed statement by the world community on the content of human rights. Together with the UDHR, the International Covenant on Civil and Political Rights (ICCPR) and the International

Covenant on Economic, Social, and Cultural Rights (ICESCR) constitute the International Bill of Human Rights.

Many of those advocating a human rights approach to public health ethics have tended to rely on international human rights law, especially the International Bill of Human Rights, as defining the content of human rights. Insofar as these documents embody something of a consensus in the international community as to the content of human rights, this is a prudent approach. Moreover, the fact that these documents are part of international law gives the human rights approach to public health ethics some level of international commitment to the human rights norms as leverage, at least rhetorically, to use in making actual progress on improving health worldwide.

In an exchange about the legacy of Jonathan Mann, both Lawrence Gostin and Stephen Marks (2001) seem to assume that the concept of human rights is primarily, perhaps even essentially, a legal one, outside the purview of philosophy. For example, Gostin refers to "philosophers using human rights terminology" as an example of "language and ideas borrowed across disciplines," which "are often characterized by more passion than rigor" (Gostin 2001, 121). He also notes that

> [W]hen ethicists adopt the language of international human rights, there is bound to be a certain amount of confusion. For example, if an ethicist claims that health care is a "human right," does she mean that a definable and enforceable right under international law exists, or simply that philosophical principles such as justice support this claim? (Gostin 2001, 128)

The "simply" in this sentence is telling, and repeated: "The conceptualization of health as a human right, and not simply a moral claim, suggests that states possess binding obligations to respect, defend, and promote that entitlement" (Gostin 2001, 128).

There are two problems with this characterization of human rights. First, the contrast between claims of human rights that are "simply" (merely?) based on "philosophical principles such as justice," on one hand, and those that are binding and enforceable legal rights, on the other, is overdrawn. It is important not to overstate the extent to which international human rights law imposes either binding or enforceable norms on states. One commentator describes the system for "enforcing" the international Bill of Human Rights as one in which

> the procedures for securing compliance with major human rights treaties hinge upon a system that makes governments entirely responsible for reporting on themselves, once every five years, subject to soft questioning for a few hours by a cautious committee, elected by those very governments, and with almost no likelihood of serious censure or real sanctions. (Leckie 2000, 130).[2]

Mann et al. (1994, 11) note this as well: "While there are few legal sanctions to compel states to meet their human rights obligations, states are increasingly monitored for their compliance with human rights norms by other states, nongovernmental organizations, the media and private individuals." While the publicity and shaming mechanisms they refer to can be effective in moving states towards compliance, such measures fall far short of the imposition of binding and enforceable legal norms. International human rights law represents an enormous accomplishment and a tremendously promising vehicle for improving the human rights of people around the world, and is unquestionably one of the most hopeful and promising developments of the 20th century. However, it remains the case that it possesses very few and weak means for enforcing its norms. For this reason, the pragmatic appeal of basing the human rights approach to public health ethics on legal human rights alone should not be decisive in itself.

The more serious problem is that the UDHR and similar documents simply assert rights without explaining or justifying them. As James Griffin notes, leaving out philosophical justifications makes sense in legal declarations:

> It is common in law not to dwell on justification; different groups, particularly different cultures, might agree that there is such a thing as the dignity of the person, and largely agree on the rights that follow from it, but differ in their understanding of quite what that dignity is. So silence on the subject is often simple wisdom. (Griffin 2001, 6)

However, in seeking to make sense of international human rights law, the silence of the law itself on matters of justification means that we have to look elsewhere for standards by which to assess the rights claims that the law asserts. Criticisms of international human rights law as unjustifiably extravagant abound. If the human rights approach to public health ethics relies only on a reference to international human rights law for its claims about human rights, that approach will be vulnerable to the same objections. (I return to this issue in section on "Human Rights and Duties.")

There are two directions to choose from in replying to this criticism. One is a positivist direction: to assert that human rights as legal rights simply are whatever the international legal documents say they are, and as such they ought to be complied with and enforced if necessary. The trouble for this answer is that, without an understanding of the moral basis of legal human rights claims, it is difficult to understand why international human rights law has the moral urgency we generally associate with it. There is no widespread global movement demanding conformity with other branches of international law, such as the one governing territorial waters, for example. Moreover, when we focus on other branches of international law, such as trade or patent law, one of the most frequently discussed questions is whether the law as it stands is morally defensible. As these examples show, the bare fact that a norm is part of international law does not imply that it has a privileged moral status. Thus, grounding the human rights approach to public health ethics in international human rights law and shunning a philosophical account of human rights sells short the potential moral significance of this approach.

It is possible to take the positivist line and still imbue legal human rights with moral urgency. The strongest case to be made in this vein is to defend on moral grounds the political legitimacy of the institutions that generate international human rights law, and then to assert that because those institutions declared the list of human rights that they did, these rights ought to be implemented. Two points are important here, however. First, this strategy does not avoid philosophical discussion about the moral significance of human rights, but rather shifts the locus of philosophical discussion from the justification of moral human rights to the criteria of political legitimacy for the institutions that generate international human rights law. Second, if we take this route, then we have no way to distinguish between the moral urgency of different rights declared in the International Bill of Human Rights. Without some further means to distinguish them, then, on this approach the right to periodic holidays with pay stands on equal footing with the right to health. Thus it is only when we are willing to engage in the debate, necessarily philosophical, about the deeper moral significance of rights claims that we can avail ourselves of the moral urgency of human rights claims generally, and the special moral urgency of some human rights claims, such as those especially relevant to health, as compared to others.

Therefore, the advisable direction to take in responding to the request for an account of why we care about international human rights law is to engage with the philosophical theory of moral human rights.

Interest-Based and Agency Accounts of Human Rights

James Griffin critiques international human rights law, especially the ICCPR and the ICESCR, for its divergence from the list of human rights justifiable on what he calls "the best philosophical account of human rights." According to Griffin, the best philosophical account of human rights sees them as protecting human agency, understood as the capacity to choose and pursue goals. He writes:

> The first stage of agency is our taking our own decisions for ourselves, not being dominated or controlled by someone else (autonomy). To be more than empty tokens, our decisions must be informed; we must have basic education, access to information and to other people's views. And then, having formed a conception of a good life, we must be able to pursue it. So we need enough in the way of material provisions to support ourselves. And if we have all that, then we need others not to stop us (liberty). (Griffin 2001, 7)

For Griffin, this understanding of human rights provides a basis for critiquing the rights asserted in international human rights law.[3] For example, he takes issue with the UDHR's assertion of a right to free movement and residence within one's country on the grounds that one's agency is not threatened if one is not free to live precisely where one wants to live. He also disputes the ICESCR's assertion of a right to "the highest attainable standard of physical and mental health," on grounds that such a standard is not necessary to protect human agency. He writes, "On my account, we have a right to life, because life is a necessary condition of agency, and to the health care necessary for our functioning effectively as agents" (Griffin 2001, 25). But asserting a right to the highest attainable standard of health is entirely unwarranted on Griffin's preferred account of human rights, because we can function meaningfully as agents at a level of health well short of the highest attainable standard.

Griffin's account depends on defending the value of agency as having the special importance required of the justification for human rights. As he says, "We value our status as agents especially highly, often more highly even than our happiness" (Griffin 2001, 4). It also depends on an understanding of human rights as minimalist or especially urgent moral claims, rather than more broadly as a full description of the good life for human beings. On a minimalist view, human rights are not coextensive with all of justice, nor all of fairness, nor all of human well-being. Rather, they have the special urgency of a moral minimum. The strength of this account is its parsimony—that it is supposed to rule out dubious claims of human rights. Thus the agency account can claim the strategic benefit of grounding important human rights in a relatively minimalist moral view, thereby resisting skepticism about human rights and providing a powerful appeal to a wider audience.

Jonathan Mann, by contrast, saw human rights as protecting a different and much broader good: human well-being. According to Mann: "The implicit question behind the modern human rights movement is: 'what are the societal (and particularly governmental) roles and responsibilities to help promote individual and collective well-being?' " (Mann 1996, 924).

In describing human rights as fundamentally concerned with human well-being, the human rights approach to public health ethics (unintentionally) takes sides in the debate about the best philosophical account of human rights, endorsing a version of "interest-based" rights. For example, one prominent account of interest-based rights is Joseph Raz's: " 'X has a right' if and only if X can have rights, and, other things being equal, an aspect of X's well-being (his interest) is a sufficient reason for holding some other person(s) to be under a duty" (Raz 1986, 166). Extending this account of rights to an account of human rights requires starting from the basic idea that human rights accrue to individuals simply because they are human.[4] For an interest-based account of human rights, then, there must be some common human interests that ground human rights. Adequately defending the claim that there are universal (or nearly universal) human interests is beyond the scope of this chapter. But at least some claims to this effect seem intuitively plausible. It seems clear, for example, that it is universally true of human beings that a well-ordered political community, a society that meets its members' basic needs, and health are important components of individual well-being.

Indeed, it would seem that the problem for an interest-based account of human rights is that it permits very many rights, rather than too few. But to be fair to the account, it does not imply that people have a human right to anything that would make them better off. Just as Griffin's agency account limits rights to only those things necessary for agency, Raz's account places limits on those interests that ground rights. Raz writes:

> Only where one's interest is a reason for another to behave in a way which protects or promotes it, and only when this reason has the peremptory character of a duty, and, finally, only when the duty is for conduct which makes a significant difference for the promotion of protection of that interest does the interest give rise to a right. (Raz 1986, 183)

As Raz notes, a complete account of a right will depend "on political, legal or moral arguments" (Raz 1986, 267). These points show that one cannot simply derive human rights directly from the notion of well-being in any simple fashion. This fact might be daunting to advocates of the human rights approach to public health ethics; if the account of human rights does not solve the problem of what rights count as human rights, what is the point of engaging it? Two further points are relevant. First, the interest-based account of human rights focuses discussion on human well-being and the duties that can be justified on the basis of that value. The fact that open questions on this topic need to be addressed simply indicates that we have work to do in articulating both our moral theory of human rights and our conception of human well-being. This is a point, it would seem, that the human rights approach to public health ethics can embrace. The more general statement of this point is that the adoption of a philosophical account of human rights does not answer all fundamental questions, but rather provides a conceptual framework within which they can be productively asked and addressed. Second, the agency account leads leaves similarly foundational questions open, since on that view human rights cannot be straightforwardly derived from the notion of agency. Rather, careful thought must be given to the valuable aspects of human agency and what kinds of social circumstances contribute to or hinder its development.

On an interest-based account of human rights, it is no accident that public health and human rights are interdependent. If human well-being is the core value of both human rights and public health, then it will not be surprising when we find that human rights are closely correlated with public health. However, taking this perspective requires rethinking our understandings of both public health and human rights. Regarding the former, the World Health Organization's constitution defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." This is a much-quoted and often-criticized definition, which has been pressed into service on behalf of the human rights approach to public health ethics. Such a definition risks being attacked as impossibly broad and ambitious. But this criticism could be turned into an asset to the human rights approach to public health ethics, which asks us to at least consider whether, as many of the criticisms of this definition assume, health can be neatly sliced away from other aspects of human well-being.

Though this has been a necessarily sketchy discussion, I suggest, as a starting point for further research, that the interest-based account of moral rights is a natural fit for the human rights approach to public health ethics, and has the benefit of meshing nicely with the rhetoric already used in that approach. However, the strategic value of endorsing a minimalist account of human rights should not be underestimated. The interest-based account needs to be deployed with an awareness of its expansiveness and a readiness to justify it.

Human Rights and Duties

Onora O'Neill has argued against a human rights approach to public health ethics for a variety of reasons. Instead, she claims, "if we want to establish intellectually robust norms for health policies it would be preferable to start from a systematic account of obligations rather than of rights" (O'Neill 2002, 42). One important difference between a systematic account of public health obligations as opposed to a systematic account of public health human rights is, as Joel Feinberg notes, that a right specifies conduct that is "morally mandatory … in the older sense of actions that are due others and can be claimed by others as their right," as opposed to a duty understood as “any action we feel we must (for whatever reason) do” (Feinberg 1970, 244). Raz emphasizes the same feature of rights:

> [R]ights discourse indicates a kind of ground for a requirement of action. To say that a person ought to behave in a certain way is to assert a requirement for action without indicating its ground. To assert that an individual has a right is to indicate a ground for a requirement for action of a certain kind, i.e. that an aspect of his well-being is a ground for a duty on another person. The specific role of rights in practical thinking is, therefore, the grounding of duties in the interests of other beings. (Raz 1986, 180)

On this view, then, the feature of “rights-talk” that is missing from “duty-talk” is the grounding of the duty in some feature of another person—their interests or their agency.

One reason that O’Neill prefers an account of obligations is that, on such an account, “it is clearer who holds the obligations than it is when obligations are derived from accounts of the good or of rights. … The need for an internally coherent allocation of obligations, including trans-border obligations, is more explicit, hence more readily addressed, than it is in rights-based account of justice” (O’Neill 2002, 42–43). O’Neill believes that if an account of obligations could be given instead of an account of rights, this would minimize the assertions of rights that really are not rights:

> “[A] focus on required action, rather than on entitlements to receive, makes it easier to spot incoherence. For example, it is easy and rather fetching (and regrettably common) to talk about a universal ‘right to health,’ but plain enough when one considers who has to do what for whom that universal health cannot be provided, so that there can be no such right. (O’Neill 2002, 42)

Let us briefly consider this argument. O’Neill assumes that a right to health entitles one to be provided with health itself. If the content of the right, in this case universal health, “cannot be provided,” then the assertion of a right to health was clearly mistaken. But this is not the only view about how to read rights claims. Relying on Raz once again, for example, we see that he holds that “[a]ssertions of rights are typically intermediate conclusions in arguments from ultimate values to duties” (Raz 1986, 181). One implication of this, as Raz argues, is that “one may know of the existence of a right and of the reasons for it without knowing who is bound by duties based on it or what precisely are these duties” (Raz 1986, 184). On this view, then, statements of rights are not meant to be specifications of duties, but rather are meant as part of a continuing discussion leading towards the assignment of particular duties to particular agents. To quote Raz once more:

> Which duties a right gives rise to depends partly on the basis of that right, on the considerations justifying its existence. It also depends on the absence of conflicting considerations. If conflicting considerations show that the basis of the would-be right is not enough to justify subjecting anyone to any duty, then the right does not exist. But often such conflicting considerations, while sufficient to show that some action cannot be required as a duty on the basis of the would-be right, do not affect the case for requiring other actions as a matter of duty. In such cases, the right exists, but it successfully grounds duties only for some of the actions which could promote the interest on which it is based. (Raz 1986, 183)

O’Neill’s argument concludes that there cannot be a right to health, because universal health cannot be provided, and therefore the provision of it cannot be a duty on any agent. There are two senses in which "universal health cannot be provided." The first, which O'Neill emphasizes, is that *universal* health cannot be achieved: "A demand that we be totally dedicated to others' health is not achievable; even a demand that we always give priority to health improvements over other action is unachievable" (O'Neill 2002, 43). For these reasons, achieving universal health is impossibly demanding, even if it is understood as a coherent aim. The second sense in which universal health cannot be provided is that *health* itself cannot be provided, since health is not a commodity that can be distributed among a population.

O'Neill thinks that these points suffice to defeat the claim of a right to health. On Raz's view of the relation to rights and duties, however, O'Neill's argument against the right to health does not go through. Rather, while her argument shows that we cannot have a duty literally to provide health, or a duty to achieve universal health at the expense of all other goods, it is still open to us to argue that the right to health grounds other important duties. Moreover, there is no reason to confine the duties grounded in this right to states (as O'Neill fears will be the result of a rights-based approach), since different considerations can coherently and powerfully serve to ground duties on the part of citizens of wealthy democracies, intergovernmental organizations, recipients of health-related aid, physicians, nurses, public health workers, and other agents.

It is important to note that international human rights lawyers can answer objections like O'Neill's on their own terms. Through a series of commentaries on the primary treaties of international human rights law, various groups and committees under the auspices of the United Nations have worked to clarify the content of human rights law. For example, the Committee on Economic, Social and Cultural Rights in 2000 issued a "General Comment" on the right to health, which responds to some of the concerns that O'Neill mentions. For example, the Comment states:

> There are a number of aspects which cannot be addressed solely within the relationship between States and individuals; in particular, good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health. … Consequently, the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health. (para. 9)

The same General Comment also recognizes that states are not the only agents who bear duties regarding international health (para. 42). However, recall that the point of O'Neill's criticism (as well as Griffin's) was that there is no right to health. Without alternative ways to read claims about moral rights, the explication provided by the General Comments could reasonably be dismissed as embellishments on a legal fiction. Thus, alternative ways of understanding how moral rights ground moral duties helps provide a context to explain why the legal rights should not be dismissed. This, then, is another reason for the defender of the human rights approach to public health ethics to engage with the philosophical foundations of human rights.

Conclusion

It seems clear that the human rights approach to public health ethics would turn the main criticism of that approach, that it is counterproductive, on its head, asserting that it is really the narrow view of public health that is counterproductive, since it is ignoring the complex determinants of health that renders some public health policies utterly fruitless. Gostin offers an example:

> Think about HIV prevention among vulnerable women in resource-poor countries in Africa or South America. Public health practitioners may educate them about the risks of sex and drug use. They may even distribute the means for behavior changes (e.g., condoms and sterile injection equipment). Yet, if women are culturally and economically dependent on, or physically and emotionally abused by, their husbands, they remain powerless to reduce their risk of HIV. (Gostin 2001, 126)

One reason for the futility of efforts to protect health that deal only with proximal causes is that health, as it turns out, is a more complex good than any of us had reason to believe. The realization that there is a correlation of health with seemingly meaningless increases in rank in the British civil service is one indication of this (Mann 1997). The observations of Mann, Paul Farmer, and other pioneers in delivering public health services to the world's poor and oppressed are others. What all these show is that health cannot be neatly sliced away from other aspects of human well-being—respect for human dignity, social standing, healthy communities, and political justice. It is for this reason that the human rights approach to public health ethics insists that, to be effective, public health must work alongside other disciplines to ensure the background conditions for health.

Criticizing the human rights approach to public health ethics on the grounds that it is self-defeating, because it takes on problems public health cannot address, seems in this light misguided, or at least far too quick. Rothstein comments that "just because war, crime, hunger, poverty, illiteracy, homelessness, and human rights abuses interfere with the health of individuals and populations does not mean that eliminating these conditions is part of the mission of public health" (Rothstein 2002, 144). This is true enough as stated. And yet it is also true that public health in many circumstances can ignore such issues only at the cost of what everyone agrees to be its mission. So the best response has to be a more precise articulation of how public health should engage with such issues. In particular, it need not take utopian abolitionist aims as its mission, but instead devote traditional public health methods to study the connections between these social conditions and health and well-being more generally. Developing programs to do this will contribute enormously to our understanding of health and human well-being, as well as human rights themselves. If we understand "human rights" to mean legal human rights alone, then what we can learn from public health about the complex good of human well-being will be truncated, for on this approach to understand what human rights are we only need to look at the documents of international law. If we understand human rights in the moral sense, however, we need to think more deeply about the value and functions of rights, as well as whether international human rights law actually got the lists of recognized legal rights correct. One great benefit of the human rights approach to public health ethics, therefore, is that the engagement of public health with human rights promises to deepen our understanding of human rights: their content, the boundaries and interactions between them, and how social circumstances contribute to or hinder their realization. This benefit can only occur if public health does not simply adopt the lists of human rights in international law, but rather engages with the philosophical foundations of moral human rights.

Notes

1 See Goodin (1989): "Presumably it is in straightforward utilitarian terms that public health measures of all sorts are standardly justified. We do not leave it to the discretion of customers, however well-informed, whether or not to drink grossly polluted water, ingest grossly contaminated foods, or inject grossly dangerous drugs. We simply prohibit such things on grounds of public health. That appeal is justified, in turn, most standardly by recourse to utilitarian calculations of one sort or another." (Goodin 1989, p. 123)

2 I have argued that the "softness" of the treaty bodies' enforcement of the international covenants is not necessarily the strong objection to this system that some might make out. In order to adopt this view, however, it is necessary to see the point of human rights law not as enforcing binding commitments, but rather something more like initiating discussion between the international community and particular states (or within states) about the requirements of human rights norms in those states (Hessler 2005). However, this view requires abandoning the model of international human rights law as effectively binding and enforceable.

3 Griffin recognizes different approaches for rights in international law that are "unacceptable" on his account than for ones that are merely "debatable." At least some of the former, he recommends, should be given "the legal cold shoulder," while at least some of the latter should stand. I critique Griffin's arguments to this effect elsewhere (Hessler 2005).

4 This is a commonly mentioned feature of human rights. See Griffin: "A human right is one that a person has, not in virtue of any special status or relation to others, but simply in virtue of being human" (Griffin 2001, 2). Also see Mann et al.: "Several fundamental characteristics of modern human rights include: they are rights of individuals; these rights inhere in individuals because they are human; they apply to all people around the world; and they principally involve the relationship between the state and the individual" (Mann et al. 1994, 10).

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Moral Interests, Privacy, and Medical Research

Deryck Beyleveld and Shaun D. Pattinson

Abstract This chapter examines the relationship between the values of research and privacy in the context of medical research on patient data. An analytical framework is developed by interpreting the conception of privacy advanced in the jurisprudence of the European Court of Human Rights by reference to the Principle of Generic Consistency, seminally argued to be the supreme principle of morality by Alan Gewirth. This framework is used to uncloak the inequity of positions uncompromisingly prioritising research values over privacy values or vice versa—research worship and consent worship, respectively. We then apply this framework to three hypothetical studies to show how apparent conflicts between research and privacy values can be resolved.

Keywords Consent, interests, rights, research, Principle of Generic Consistency, privacy

Introduction

Medical research on personal data involves a conflict between moral interests or values. On the one hand, research promises moral benefits that flow from the acquisition of generalisable knowledge related to human health or treatment. On the other hand, research participants have interests in being able to control the flow and use of private information about themselves. However, precisely how these values relate to each other, and how conflicts between them are to be resolved, stands in need of analysis.

To focus our discussion we will examine three hypothetical studies. The first, the *infectious disease study*, involves the use the data of recipients of blood transfusions for the purpose of investigating the spread of a specific infectious disease by transfusions. The second, the *cancer study*, uses data from patients diagnosed with cancer for the purpose of investigating cancer. The third, the *contraceptive study*, involves the use of data from patients diagnosed with severe fertility problems and associated conditions for the purpose of investigating future avenues for research into chemical contraceptives.

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The identification and relative weight of the moral factors evoked by these studies will differ from one moral theory to another. We will, therefore, say no more about these hypothetical studies until we will have outlined the features of the moral theory that we intend to apply. In the section on ‘The PGC and its Derivation’, we will outline our reasons for applying the Principle of Generic Consistency (PGC), which Alan Gewirth (1978) has argued—to our minds successfully—to be the supreme principle of morality. In the section on ‘Research, Privacy, and Consent’ we will outline a *framework* for viewing the relationship between privacy and medical research values with reference to the jurisprudence of the European Convention on Human Rights (ECHR)—that we contend is broadly in line with the requirements set by the PGC, and its conception of privacy. We will argue that privacy and research values, while capable of conflicting are also capable of supporting each other and that to an important extent research values are privacy values and vice versa. Not to see this distorts the nature of the relationship. Nevertheless, conflicts can exist between these values and, in the section on ‘The Hypothetical Studies Considered’ we analyse the three hypothetical studies by reference to the PGC, in order to illustrate how the PGC may be used to balance the conflicting values involved therein.

The PGC and Its Derivation

The PGC grants all agents[1] rights to the generic conditions of agency, so-called generic rights. The generic conditions of agency consist of what agents need, *irrespective of what their purposes might be*, in order to be able to act at all or in order to be able to act with general chances of success. The former category comprises ‘basic’ generic needs, termed ‘basic goods’ by Gewirth. The latter category is divided into non-subtractive and additive generic needs. Whereas lack of, or interference with, a basic generic need precludes action altogether (or at least diminishes an agent’s chances of being able to act at all), lack of a non-subtractive generic need adversely affects the agent’s ability to maintain his or her capacity to act, and interference with an additive generic good affects the agent’s capacity to increase its capacity to act—in all three cases, *regardless of the purposes involved.*

The generic conditions of agency (and consequently the generic rights) are hierarchically ordered according to a criterion of needfulness for agency (see Gewirth 1978, ch. 2; 1996, 45–46). According to this criterion, basic rights override non-subtractive rights, which, in turn, trump additive rights in cases of conflict.[2]

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[1] Beings that take voluntary steps in pursuit of their freely chosen purposes, which they treat as reasons for their actions.

[2] Gewirth (1978, 53–55) identifies, e.g. life and physical well-being (including such means to these as health, food, clothing, and shelter) as basic needs, accurate information as a non-subtractive need, and further information as an additive need. However, as the generic conditions of agency figure in Gewirth’s argument for the PGC (as against in application of the PGC), such concrete specification is not necessary.

For reasons that will become clear when we present Gewirth's argument, the generic rights granted by the PGC are rights under the 'will' or 'choice' theory or conception of rights. According to this conception, agents may always waive the benefits they are granted by the rights they have (though not the generic rights themselves, which Gewirth's argument renders inalienable).

The generic rights are essentially Hohfeldian claim-rights (Hohfeld 1964). They are also, in principle, positive as well as negative. That the rights are positive means that agents have rights to be assisted (by those able to do so without *comparable cost* to themselves) to secure/protect their having the generic conditions of agency when they are unable to do so by their *own unaided efforts*. That they are negative means that agents have rights to non-interference by other agents with their having the generic conditions of agency. That the generic rights are claim-rights under the will conception, however, means that duties imposed on other agents by the positive rights are subject to the rights-holder wishing assistance, while duties imposed by negative rights are subject to interference, being against the rights-holder's will.

According to Gewirth, agents who do not accept and act according to the PGC contradict that they are agents (i.e. he argues that the PGC is 'dialectically necessary' for any agent: Gewirth 1978, 42–47). His argument has three main stages. First, he argues that it is dialectically necessary for an agent A to accept that A ought to defend and pursue A's having the generic conditions of agency on the grounds that A needs these conditions in order to be able to pursue the purposes A wishes to pursue, either at all or with any general chances of success, regardless of what these purposes might be. This 'ought' is not a moral 'ought', but a categorically (or unconditionally) instrumental one. Secondly, from this, he claims that it is dialectically necessary for A to accept that all other agents B ought not to interfere with A's possession of the generic conditions against A's will and ought to assist A to pursue or defend having these conditions when A is unable to do so by A's unaided efforts if A wishes this assistance (the instrumental nature of the 'ought' in the premise being responsible for the 'will' provisos). This 'ought' is, again, not a moral one. It is propounded by A on the basis that, because the generic conditions are unconditionally needed by A, A unconditionally needs the generic conditions in order to pursue/defend A's having these conditions. Correlative to this, Gewirth claims that it is dialectically necessary for A to hold that A has both a positive and a negative 'prudential' right to the generic conditions. Thirdly, he argues by 'The Argument from the Sufficiency of Agency' (see Gewirth 1978, 110) that it follows purely logically from the dialectical necessity of A's claim to have the generic rights that A must not only claim the generic rights on pain of contradicting that A is an agent, but must hold that A has the generic rights just because A is an agent on pain of contradicting that A is an agent. On this basis, it follows purely logically that A must grant that all agents have the generic rights (just because they are agents). By virtue of this recognition the correlative 'ought' that A must accept not to interfere with B's generic conditions etc. is a moral 'ought' as only at this point is A shown to be required to have positive regard for B's (generic) interests.

While we consider Gewirth's argument to be sound (see, in particular, Beyleveld 1991), it has not received widespread acceptance. However, there are alternative arguments for the PGC that, if valid, would be rationally compelling for those who are prepared to accept certain dialectically contingent premises. These include arguments directed at agents who accept the idea that:

1. There are morally binding requirements on action, defined as categorically binding *impartial* ones (i.e. categorically binding requirements that require the agents to take equal account of the interests of all agents in determining what they themselves may do) or
2. There are categorically binding requirements on action or
3. I (any agent) have a human right to do X or
4. Practical rationality is impartial.

The first three of these arguments have been explored in depth elsewhere (see Beyleveld and Brownsword 2001, 72–86, 91–94). The argument from the third claim is worth emphasising because of its obvious implications for legal systems that recognise human rights. This argument proceeds on the basis that acceptance of a right to do X requires acceptance of a right to the necessary means to do X, and hence to the generic conditions of agency *whatever X might be*. Consequently, anyone who recognises that there are human rights to do anything, must also recognise that there are human rights to the generic conditions of agency. Hence, human rights (to do things) must be structured in line with the generic conditions of agency.

Human rights must be thought of as having a number of features if the mere acceptance of human rights is to require these rights to be interpreted in accordance with the PGC. Firstly, they must be thought of as overriding all competing considerations in case of conflict. Secondly, being human must be regarded, at least centrally, as being an agent. Thirdly, human rights must be held to be rights under the will conception. Fourthly, human rights must impose duties not only on the State and its arms, but on all individuals who are capable of acting so as to affect rights-holders abilities to enjoy the benefits of their human rights. Finally, human rights must be considered (where agents are capable of obeying the correlative duties) to be positive as well as negative. While we consider that a good case can be made for holding these to be features of the European Convention of Human Rights (ECHR) space prevents our detailing this case here (see further Beyleveld and Brownsword 2001, 79–86). However, on the assumption that we are correct about this, *interpretation* of the ECHR must be in accordance with the PGC so that the PGC can be used to assist with interpretation of the ECHR and not merely as an external resource for ethical critique.

Finally, the fourth argument simply combines the first stage of Gewirth's dialectically necessary argument with the assumption that practical rationality is impartial in requiring agents to take equal account of the interests of all agents, from which acceptance of the PGC follows immediately as a requirement of practical rationality. Should we be wrong that the ECHR jurisprudence supports the will-conception of rights, this consideration may be used to argue that any coherent application of human rights to agents requires the European Court of Human Rights to adopt the will-conception.

Research, Privacy, and Consent

Any discussion of the right to privacy needs to specify what this right covers. For our purposes, the right to privacy will be identified as the right that is granted by Article 8 of the ECHR. Consequently, our first concern is whether the protections granted under this Article are in line with the PGC (or, alternatively, what interpretation of Article 8 must be given to render it consistent with the PGC's requirements). What then is the right to privacy under the ECHR?

The Concept of Privacy in the ECHR

For some time the UK courts have supported a narrow conception of the right to privacy. This is exemplified in the *Source Informatics* case,[3] which concerned the use of non-identifying (i.e. anonymised) patient data. In addition to dealing with the matter before them on the law of confidentiality, the Court of Appeal of England and Wales made a number of *obiter* comments (i.e. non-binding asides) about Directive 95/46/EC (the European Union's Data Protection Directive), which aims in its Article 1(1) to protect fundamental rights and freedoms, in particular privacy, in the processing of personal data. In particular, the Court claimed that anonymisation of data needs to be brought to the attention of patients only if it would be contrary to their interests in relation to treatment they are receiving (where, e.g. it would prevent them being informed of a diagnosis of a serious treatable condition). In giving this opinion, the Court adopted a *narrow conception of privacy*, according to which, except in circumstances covered by the example just given, the only privacy interests that patients have in use made of their data is in concealment of their identities.

However, such a conception of privacy is inconsistent with the broader conception utilised in the jurisprudence of the ECHR (as well as with the decision of the House of Lords in *Campbell*,[4] in which their Lordships considered the matter of disclosure by the Mirror Newspaper Group of pictures taken of the supermodel Naomi Campbell leaving a drug addiction clinic). According to Jacques Velu (1973, 92), the right to respect for private life under Article 8(1) of the European Convention on Human Rights protects the individual against:

1. Attacks on his physical or mental integrity or his moral or intellectual freedom
2. Attacks on his honour and reputation and similar torts
3. The use of his name, identity or likeness
4. Being spied upon, watched, or harassed
5. The disclosure of information protected by the duty of professional secrecy.

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[3] *R v Department of Health ex p. Source Informatics* [2001] Q.B. 424, reversing [1999] 4 All ER 185.

[4] *Campbell v. MGN* [2004] UKHL 22.

More specifically, according to the Commission of the Council of Europe, while

> [F]or numerous Anglo-Saxon and French authors the right to respect for 'private life' is … the right to live as far as one wishes, protected from publicity … the right to respect for private life does not end there [but includes also the right to] … the development and fulfilment of one's own personality. (Application No. 6825/74 DR5, 87)

This was recognised in the *Campbell* case, with Lord Nicholls declaring that the right is wider than protection of private information ([2004] UKHL 22, para 15) and Lord Hoffmann holding that the right is an aspect of human autonomy and dignity (para 50) in accordance with which Lord Hope declared that breaches are to be measured by what is offensive in the eyes of the individual rights-holder not in the eyes of the reasonable person (para 99).

So wide, indeed, is the right recognised under Article 8 that it has become commonplace to say that Article 8(1) covers all rights that the European Court of Human Rights is prepared to recognise that are not expressly provided for in the other articles of the Convention (see Loucaides 1990, 196).

Is such a broad conception of privacy consistent with the PGC? Since 'privacy' is just a label for a cluster of rights, the answer depends on what rights the European Court of Human Rights is prepared to recognise. Quite simply, under the PGC a right is to be granted to any generic condition of action. Undoubtedly there are generic conditions of action that do not find expression in the other rights of the ECHR. Similarly it is not to be doubted that the activities listed earlier by Velu are capable of affecting the generic conditions of agency at one or other level. Indeed, at this level, the PGC can assist the Court. This is because the Court surely needs a rationale for identifying the rights captured by Article 8 beyond those expressly recognised in the other articles of the ECHR, and the PGC, in conceptualising a fundamental right and freedom as a generic one, does the job.

There is at least one other feature of ECHR jurisprudence that we need to consider. This is that under the jurisprudence of the European Court of Human Rights, any use of sensitive personal data without the explicit consent of the individual concerned engages Article 8(1),[5] which means that the use will constitute a violation of Article 8 unless it is justified under Article 8(2), according to which

> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

In principle, the idea that explicit consent is required accords fully with the idea that the generic rights are rights under the will-conception. Under this conception free and informed consent to an activity that impinges on the individual's right will negate any wrong done; but, without such consent a wrong will be done to the individual unless it can be justified as required to defend the more important conflicting

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[5] See, e.g., *Z v Finland* (1998) 25 E.H.R.R. 371; and *M.S. v Sweden* (1999) 28 E.H.R.R. 313.

rights of others. However, it does follow from this that exempting conditions mentioned under Article 8(2) must all be conceived of as serving generic rights of others. This is because only generic rights can override generic rights under the PGC (and then only in a distributive, not an aggregative way). However, there is no conflict here with the jurisprudence of the ECHR, for a fundamental right and freedom can only be overridden by a conflicting fundamental right and freedom.[6] Consequently, things like public safety and economic well-being must, under ECHR jurisprudence, be viewed as things that, in a standing way, are necessary to protect fundamental rights, and the explicit reference to the rights and freedoms of others in Article 8(2) must be viewed as to rights and freedoms not implicated in a standing way. Consistency with the PGC then requires that protection of public safety etc. must involve protection of generic rights of others in a standing way. This is surely the case. Unsafe public conditions, economic collapse, public disorder and crime, disease, and immorality are all things with negative effects in a generic way.

The Relationship Between Privacy and Medical Research Values: A Framework

Some medical researchers consider privacy and recognition of the rights of the participant to be a hindrance to the much more important concerns of medical research. Consider, for example, the rhetoric of epidemiological researchers, at least as reported by the press, to the effect that the UK Data Protection Act 1998 and the UK law on confidentiality are killing patients, and should, therefore be rendered inapplicable to medical research.[7]

Such *research worship* assumes that research is indubitably of overriding value. However, some research objectives are trivial or even ignoble and the likelihood that research projects will successfully achieve their objectives can be speculative or even fanciful. The historical abuses associated with Nazi Germany are in no way representative, but it should not be forgotten that the resolution of uncertainty is the driving force of research and even the best-designed projects hold few guarantees.

Those inclined towards research worship are prone to point to the practical difficulties raised by obtaining consent as a reason for dispensing with consent altogether. Obtaining consent can, in particular, have a negative impact on the practicality or usefulness of conducting the research. The usefulness of the research will, for example, be severely impeded where the sample is reduced to one that is unrepresentative or statistically below optimal. Such dangers must, however, be

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[6] This follows directly from the idea that human rights in instruments like the ECHR that have their roots in the American Declaration of Independence of 1776 and in the French Declaration of the Rights of Man and the Citizen of 1789 are conceived of as ‘by nature inherent, universal and inalienable’ (Davidson 1993, 5).

[7] See, for example, the so-called Peto campaign (reported on in, e.g. Dix 2000).

kept in their proper place. The potential effects of requesting consent and complying with refusals do not render research projects statistically insufficient or unrepresentative *merely because* the sample will be below 100%. Research into conditions that are not isolated to a small, easily identifiable group or geographical cluster will inevitably involve an incomplete sample of those with the condition because of international borders and other practical restrictions. Moreover, the non-aggregative nature of the PGC means that practical difficulties in obtaining consent from a large number cannot justify dispensing with the need for consent where to do so will seriously endanger even a single hierarchically more important right of one of the participants. Thus, contrary to the research worship position, practical difficulties in distinguishing those from whom consent is required from those from whom it is not will sometimes justify a more stringent consent mechanism than would be required to protect the rights of the majority of participants.

There are also those who take a position diametrically opposed to research worship and consider the consent of the research participant to be sacrosanct and never capable of being overridden by anything. Such *consent worship* is equally inimical to the proper application of the PGC. Obtaining consent is supererogatory and sometimes even contrary to the PGC where no relevant right is otherwise infringed (i.e. there is no threat of generic harm to an agent) or where the relevant right is validly overridden by a more important (negative or positive) right. This is because there is no right to consent as such under the PGC. The requirement for consent is essentially a function of the will-conception of rights supported by the PGC. Hence ignoring consent only engages a right when the activity requiring consent impinges negatively on the generic conditions of agency (i.e. it constitutes a generic harm).

Consent worship is a danger suggested by paragraph 5 of the 2000 version of the World Medical Association's Helsinki Declaration, which proclaims that 'the well-being of the human subject *should take precedence* over the interests of science and society',[8] and perhaps even more so by the 1996 version, which states that 'the interests of the subject *must always prevail* over the interests of science and society' (our emphasis). Read literally, these provisions elevate the interests of potential participants over all other interests, irrespective of their relative hierarchical importance. This reading is bolstered by the fact that the 2000 version of the Declaration goes on to state that the participant's 'free-given informed consent' must be obtained (para 22) and ostensibly makes only one exception, namely, 'research on individuals from whom it is not possible to obtain consent' (and then only 'if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population') (para 26). A close reading, however, reveals that the Helsinki Declaration does not offer wholesale support for consent worship with regard to *research on patient data*, because paragraph 1 defines medical research to include research on 'identifiable data', rather than research on patient data *as such*. Thus, the Helsinki Declaration treats consent as having absolute value where the participant is capable of giving consent and the data

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[8] The text of the 2000 version is available at: http://www.wma.net/e/policy/b3.htm

remains identifiable, but places no limitations on the research use of data rendered non-identifiable. The result is a position that, paradoxically, seems to both overvalue and undervalue the rights of the participant.

Consent worship rides roughshod over positive rights. Subject to the own unaided effort and comparable cost provisos, the PGC-derived duty to assist in the achievement of appropriate research objectives implies a *duty to participate* in suitably designed research projects. Where such a duty exists, to insist upon consent is to deny the positive right underpinning the duty. In principle, an agent has a positive duty to participate in a research trial that is properly designed for the purpose of preventing generic harm or providing generic needs where the burden of participation carries no realistic prospect of the same or higher generic harm. A *prima facie* duty to participate will, for example, exist where the research project is well-designed, non-interventional, and aimed at preventing basic generic harm to others. Research on patient data is non-interventional, unlike many related medical activities directed at protecting or advancing the generic needs of others—including morally important activities such as participation in pharmaceutical trials, vaccination programmes, and blood donation programmes. It would, nonetheless, be a mistake to assume that non-consensual participation in data research programmes cannot cause generic harm to participants (see below) and this will clearly limit any positive obligations. Constraints on the enforcement of the participant's positive obligations will also need to take account of those situations where individual duty-bearers cannot be proportionately identified or distinguished from others. It is important that any mechanism seeking to encourage or enforce positive obligations is itself consistent with the requirements of the PGC, taking into account the danger of abuse and misuse. In particular, procedures need to be in place to address the fact that researchers will often have considerable self-interests in conducting and publishing research, and, if given opportunity, commercial entities are likely to seek to profit from the moral commitments of others.

It is arguable that the tendency of research and consent worshippers to ignore relevant considerations is a function of treating the values of research and the values of privacy as necessarily in conflict and seeking to side with one set of values over the other (see further Beyleveld 2006). However, once we use the shorthand of privacy to capture the participant's rights to control the use of that person's data (which is a function of the broad conception of privacy in ECHR jurisprudence), we need to recognise that many research values, particularly those concerned with increasing life choices and improved quality of life, are also privacy values. Conversely, it follows that protecting the participant's privacy by obtaining consent to the use of personal data for research permits more accurate research data to be obtained, and contributes to better cooperation from research participants, both of which enhance or facilitate research. The latter is the case because respect for privacy facilitates public trust, which is positively necessary for research, not merely facilitative of better quality research. Indeed, public trust is necessary for society to be governed by the rule of law/human rights. This, in turn, is necessary for effective democracy. So, viewed through the lens of a broad concept of privacy, a picture emerges that while conflicts between values protected by privacy and research values can still arise, when they do, the conflict might better be viewed as a conflict between different privacy values or as a conflict between different research values. So, how are such conflicts to be adjudicated?

The Hypothetical Studies Considered

In the 'Introduction', we outlined three hypothetical studies: the infectious disease study, the cancer study, and the contraceptive study. These studies involve use of data from specific categories of patients for research. While these studies share many features, there are evident differences in the expected benefits of the research, and each study potentially raises different objections and counter-considerations to participation. These differences are relevant to whether dispensing with consent is consistent with a proper attempt to apply the PGC or amounts to research worship.

The Infectious Disease Study

The infectious disease study seeks to use the data of recipients of blood transfusions to investigate the spread of a specific serious disease through transfusions, where there is suggestive but inconclusive evidence of a link. This study is one for which the results could be of immediate benefit to other patients, especially if the spread of the disease in question is preventable. As envisaged, such a study would track basic generic rights by seeking to protect future recipients of blood transfusions and those potentially exposed to secondary infection or dangers caused by damage to public confidence in blood transfusions. In contrast, with appropriate safeguards, this study should not threaten basic harm to the data subjects. Thus, to insist on consent for a well-designed data infectious disease study is *prima facie* tantamount to consent worship. Yet, if the dangers of research worship are to be kept at bay, procedural safeguards will be needed to ensure that the rights are properly weighed (e.g. scrutiny procedures for individual research projects); interference with the rights of participants is minimised (e.g. anonymisation of data, particularly where the disease is one attracting social stigma); and the benefits of the research are achieved without avoidable study duplication or endangerment of public confidence (e.g. procedures to ensure that the research results are appropriately disseminated and participants are not deceived).

The Contraceptive Study

The contraceptive study seeks to use data from patients diagnosed with severe fertility problems and associated conditions to investigate future avenues for research into chemical contraceptives. It is thereby not designed to obtain life-saving information but to facilitate future research that could enhance the lifestyle options of those wishing to use chemical contraceptives. The generic needs tracked by this study are, therefore, less weighty (under the criterion of degrees of needfulness for action) than those protected by attempts to prevent others suffering the effects of a serious infectious disease or cancer. This is not to suggest that research into chemical contraceptives lacks moral value under the PGC. On the contrary, pregnancy can cause serious social inconvenience and can be life threatening (though rarely in countries such as the UK and the USA), and the ability to control fertility is at least an additive good. There are, however, already many methods of contraception available, ranging from abstinence to barrier contraception, including many existing forms of chemical contraception. Thus, the interests potentially protected by this study are less significant than those protected by the infectious disease study or many instances of the cancer study.

The contraceptive study is also likely to provoke vociferous objection from some individuals and groups. A committed Catholic woman opposed to chemical contraceptives could, for example, be expected to be conscientiously opposed to the use of data associated with her irregular periods in such a study (see Beyleveld and Histed 1999, 73–74). If participation in the contraceptive study were to take place without consent, such a conscientious objector would be exposed to a very real risk of disabling anxiety or might even be placed in the invidious position of choosing between her health and her conscience. For some these harms will be basic. The Catholic woman's rights to prevent exposure to such generic harm, by preventing the use of her data in research into chemical contraception, are at least as potent as the rights tracked by the study.

The study envisaged here is, therefore, one for which dispensing with consent would be tantamount to research worship. Dispensing with consent is not required by the possibility that the contraceptive study could yield a 'consent bias', whereby refusals will undermine the adequacy of the sample. Whatever the plausibility of a consent bias—refusals might be disproportionately tied to groups that attach significant social stigma to sub-fertility or contraceptive research—we have seen that at least some objectors will have significant generic rights supporting non-participation.

Cancer Study

The cancer study seeks to use data from patients diagnosed with cancer to investigate cancer. This is the most problematic of the three hypothetical studies under consideration because it is the least specified. Cancer is potentially life threatening; some forms more so than others. Yet, general opportunistic information gathering in the name of cancer research is so far removed from the goal of preventing and curing cancer that it cannot provide a justification for dispensing with consent without one thereby adhering to research worship. This study has particular resonance in the UK, where legislation has been enacted to allow the relevant government minister to make regulations permitting the use of confidential patient information without consent for research and wider purposes in the National Health Service and the first set of regulations passed under that provision were concerned with cancer studies.

Section 60 of the Health and Social Care Act 2001 was ostensibly intended as a temporary measure, but, some six years later, replacement provisions have yet to be enacted. It empowers the Secretary of State to pass regulations to allow the use of confidential patient information without consent, despite any obligation of confidence (s.60(2)(c)). The information must be used for 'medical purposes' in the interests of improving patient care or in the public interest, where it is not 'reasonably practicable' to achieve that purpose by other means. The first set of regulations made under this provision was the Health Service (Control of Patient Information) Regulations 2002. These provide for the creation of databases for medical purposes related to the diagnosis and treatment of, in effect, tumours (Reg. 2). The intention was to allow cancer patients' information to be entered on to cancer registries without consent or anonymisation. Significantly, these regulations do not distinguish between patient information relating to cancer and patient information relating to patients with, or referred for, cancer. Read literally this would appear to allow any research without consent using the medical information of patients who happen to have cancer, *irrespective of the weight of the respective rights*. A very restricted interpretation is required to prevent descent into research worship. The issue is not that a cancer study could never justify dispensing with consent, but that the UK legislation is too broadly drafted to capture only those instances where a plausible case for doing so can be made out.

If we were to suggest a type of cancer study that might justify dispensing with consent, a plausible candidate would be one well designed to test suggestive evidence—perhaps obtained from smaller, consensual data studies—of a link between a specific life-threatening cancer and a specific causal factor. Additional procedural safeguards of the type already suggested would be needed to ensure that the specifics of the study are adequately evaluated.

Concluding Remarks

Our analysis of the way in which the PGC can assist in the adjudication of conflicts of interests and rights has been confined to the conflict between medical research values and privacy. It should, however, be clear that, schematically, the analysis is equally applicable to adjudicating conflicts between privacy and other values. A structure for the adjudication is provided by the form of Article 8 of ECHR; this form being that a right granted by the first part of the Article may be overridden to the extent that this is necessary to protect more weighty rights of others (as specified by the second part of the Article). What the PGC essentially does is to provide a means of determining what rights are more important than others in case of conflict. This applies when the rights to be weighed against privacy are explicitly recognised by, e.g. the ECHR. But it also applies when these rights are not explicitly recognised. Of course, the significance of this depends on the justification for deploying the PGC in the first place. It is worth noting that while all the arguments for the PGC that we mentioned are contestable, to deploy the PGC in the way in which we have done within the ECHR requires no more to be accepted than that to grant a right to something rationally requires a right to be granted to the necessary means for that right to be exercised. For, as we pointed out, from this it follows that the rights to the generic conditions of action must be granted. While, as we noted, this does not automatically require the PGC itself to be accepted (because of special features that the PGC itself requires of the generic rights) our analysis of adjudication of conflicts of rights is to a large extent independent of those features. If nothing else, this indicates the significance and usefulness of the Gewirthian concept of a generic condition of action even if arguments for the PGC itself are not considered to be watertight.

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Torture and Public Health

Wanda Teays

Abstract In this chapter, I examine the ways in which "harsh interrogation" methods, such as indefinite detention, hooding, use of vicious brutality (such as the use of dogs), and force-feeding, function as acts of torture. Although singularly they may only be "abusive," when used together or in tandem ("clustering"), they cross the line into torture.

Torture is an issue of public morality. My focus is on the role of medical professionals who have enabled torture by standing by, keeping silent, or actively participating in the abuse of detainees. To understand how this occurs, we need to look at the context and the ways the language as well as the practice have an effect. For example, there is widespread use of euphemisms; e.g., "stress positions," "sleep adjustment," "takeout," and "waterboarding" to create a climate of acceptance. Key medical associations such as the American Medical Association (AMA) and the World Medical Association have issued declarations prohibiting doctors from participating and calling for them to step forward. However, we must go beyond whistle-blowers taking personal risks, however commendable, and, thus, put in place scaffolding to make it easier to report and investigate suspected abuse or torture. I set out guidelines for doing so in my essay.

Keywords Doctors, torture, interrogation, prisoners, detainees, force-feeding, waterboarding, Geneva Conventions

> *There were some awful scenes. It felt like you were descending into one of the rings of hell, and sadly it was our own creation.*
> *Sen. Richard J. Durbin (D-Ill.) on the photos from Abu Ghraib*
>
> *Sometimes you have to work with the devil.*
> *Michael Scheuer, CIA, Osama bin Laden unit, noted by Stephen Grey*

Introduction

Torture is an issue of public morality. As events since 11 September 2001 demonstrate, we are locked in a battle testing our social conscience, remorse, and moral grip. Official reports, watchdog agencies, photographs and testimony from victims

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and perpetrators provide sufficient evidence that abuse and torture are systemic. The net of responsibility ranges from guards and interrogators to their peers and supervisors, from an indifferent and misinformed public to misguided politicians, from abusers to those who stand by and keep silent. Unfortunately, this includes doctors, nurses, psychologists, and other medical personnel who have witnessed or enabled torture.

The public health system cannot abdicate its duty to the victims and to the medical personnel conflicted over torture and unsure where their loyalties should lie. Health caregivers need to keep before them the moral building blocks of non-maleficence (“do no harm”), beneficence (“act for the good of the patient”), and justice (“strive for fairness”). These are fundamental aspects of human decency.

For the victims of torture, the harms are both mental and physical. Whether we condone it or are merely complicit, torture etches its mark on our psyches. We should examine the worldview that treats torture as a useful tool or an inevitable consequence of war. Unfortunately, humiliating, even abusive, practices are common in the “war on terror.” Just look at the “takeout” of suspects by the Central Intelligence Agency (CIA):

> A former member of a C.I.A. transport team has described the “takeout” of prisoners as a carefully choreographed twenty-minute routine, during which a suspect was hog-tied, stripped naked, photographed, hooded, sedated with anal suppositories, placed in diapers, and transported by plane to a secret location. A member of the Council of Europe inquiry spoke of the cavity searches and use of suppositories during the takeout of detainees, as being like “sodomy.” “It was used to absolutely strip the detainee of any dignity,” he stated. Similarly, a former C.I.A. officer said that one reason the agency photographed the prisoners naked “because it’s demoralizing.” (Mayer 2007)

As we will see in this chapter, there are a number of issues here—both in terms of practices and techniques, as well as the combination of abusive treatment that, together if not singly, effectively becomes torture. The role played by medical personnel is a foremost concern.

According to Article 3 of the Geneva Conventions, torture is unacceptable: Prisoners of war are to be treated humanely, with personal dignity, and not be subject to undue hardship. Article 2 of the 1984 UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment states that there are no exceptional circumstances justifying the use of torture (ur Rashid 2004). Such international ethical guidelines serve as a common ground for addressing global conflict. We cast them aside at our peril.

Torture treats others as a means to an end and is an affront to human dignity. Victims of torture confess to virtually anything to get it to stop.[1] Movies and television shows perpetuate the myth that torture is effective. However, in a public letter, eight high-ranking members of the US Armed Forces asserted that: “Information gathered through physical torture or dehumanizing humiliation is notoriously unreliable.

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[1] See, e.g., *Rasul v. Bush*, 542 U.S. 466 (2004).

It has a demoralizing effect not only on those subject to violations, but also on our own troops." It also jeopardizes the USA's moral and practical authority to promote democracy and human rights abroad (Brahms et al. 2004). On 10 May 2007 General David H. Petraeus echoed this sentiment:

> Some may argue that we would be more effective if we sanctioned torture or other expedient methods to obtain information from the enemy. They would be wrong. Beyond the basic fact that such actions are illegal, … the techniques in the [Army Field Manual] work effectively and humanely in eliciting information from detainees. What sets us apart from our enemies in this fight, however, is how we behave. In everything we do, we must observe the standards and values that dictate that we treat noncombatants and detainees with dignity and respect. While we are warriors, we are also all human beings. (Petraeus 2007)

In December 2007, Frank Gibney, an interrogator of Japanese prisoners in World War II, contrasted his work with the corruption of the rule of law today. "We had the sense that we were on the side of the good guys," he seethed. "People would get decent treatment" (Liptak 2007). Gibney is not the only World War II interrogator to express concern. In World War II, they debated the morality of bugging prisoners' cells and censoring letters. "We got more information out of a German general with a game of chess or Ping-Pong than they do today, with their torture," noted 90-year old MIT physicist, Henry Kolm, who had been assigned to play chess in Germany with Rudolf Hess, Hitler's deputy (Dvorak 2007). Things have changed.

The congressional compromise on the treatment of detainees of September 2006 "expands legal protection for CIA agents, military personnel and U.S. government employees by prohibiting detainees from invoking the Geneva Conventions in court."[2] The operating assumption is that Geneva Conventions do not cover those who are not part of a state-sponsored military, such as al-Qaeda (Mayer 2005). Furthermore, the guideline requiring the prompt registration of detainees is not seen as binding, because our soldiers are "lawful combatants" while the terrorists-insurgents are "*unlawful* combatants." For Professor of Medicine, Steven Miles, such bifurcation has been shown unwise: "Before the [Abu Ghraib] photos became public, every POW returned alive, but not afterward. [Television carried the Abu Ghraib photographs on April 29, 2004. The first of 11 beheadings in Iraq occurred 12 days later.] … By behaving in these ways, we undermine our legitimacy as a world leader" (Thieme 2006).

Torture should be viewed as a social institution, Miles asserts, not a set of techniques. Torturing societies create laws and policies authorizing the practices. As a result, moral responsibility must be broadly shared, rather than fall on the shoulders of a few "bad apples" (Miles 2006, 5–6). We need to realize, as well, that acts of torture harm abusers as well as victims. Perpetrators cross a threshold of malice that erodes inhibitions against further acts of cruelty. Moral scars heal slowly, if at all.

As history shows, a society that sanctions or tolerates torture bears tremendous moral costs. Some believe that the utilitarian concern for society's well-being

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[2] CNN. *Deal on Detainee Treatment Quells GOP Revolt*, 22 September 2006, at *www.cnn.com/2006/POLITICS/09/21/terror.bill/*

overrides any prohibition against torture, as we see in "ticking bomb" scenarios. Time is running out and disaster will ensue if we do not resort to torture. This argument has acted as a trump card: Surely we would sacrifice a suspected terrorist to save innocent civilians. That the argument is flawed does not negate its power.

Most acts of torture are not in response to an imminent attack. And subjecting detainees to abusive interrogation practices rests on a *presumption* of terrorism, since no charges have been placed. But it seems that detainees have at best a tangential relationship to a terrorist cell or organization. According to Mark Denbeaux and Joshua Denbeaux, government data indicates that 8% of detainees are "fighters for," 30% "members of," and 60% merely "associated with" a group or groups deemed terrorist organizations.[3] Detainee lawyer P. Sabin Willett estimates only 8% of the Guantánamo detainees are al-Qaeda, leaving 92% who are not (Willett 2006). And labeling an "enemy combatant" rests on such "evidence" as the "possession of rifles, use of a guest house, possession of Casio watches, and wearing of olive drab clothing."[4] Critics question the lax standards here.

Once torture is an option in the extreme case (e.g., the ticking bomb), it is hard to draw lines when the stakes are lower. We certainly have no Institutional Review Board (IRB) for adjudicating torture—and the slippery slope has become evident as the war on terror grinds along. Brigadier General Janis Karpinski testified to Major General Geoffrey Miller advising her that: "You have to have full control. … You have to treat these detainees like dogs. If you treat them any differently … you've lost control of the situation" (Miles 2006, 48). The Congressional "compromise" of September 2006 reins in the military but not the CIA. In January 2007, the Pentagon set rules for detainee trials that would "allow terrorism suspects to be convicted and perhaps executed using hearsay evidence and some coerced testimony" (Flaherty 2007).

Some think ratcheting up the torture will get the job done. In an interview with news anchor Wolf Blitzer, Law professor Alan Dershowitz observed that: "a sterilized needle underneath the nail, … would violate the Geneva Accords, but you know, countries all over the world violate the Geneva Accord." (Dershowitz 2003).

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[3] Mark Denbaux and Joshua Denbeaux, *Report on Guantánamo Detainees: A Profile of 517 Detainees Through Analysis of Department of Defense Data*, Seton Hall Law Center For Policy And Research at *www.law.shu.edu/aaafinal.pdf*. Note also that large sums of money (bounty) were offered for the capture of persons identified as enemy combatants in Afghanistan and Pakistan. One flyer states: "Get wealth and power beyond your dreams. … You can receive millions of dollars helping the anti-Taliban forces catch al-Qaida and Taliban murders. This is enough money to take care of your family, your village, your tribe for the rest of your life." (See Josh White and Robin Wright, "Detainee Cleared for Release Is in Limbo at Guantánamo," *Washington Post*, 15 December 2005.

[4] Mark Denbeaux and Joshua Denbeaux, *Report on Guantánamo Detainees: A Profile of 517 Detainees Through Analysis of Department of Defense Data*, Seton Hall Law Center For Policy And Research, *www.law.shu.edu/aaafinal.pdf*, p. 17. They state that evidence against 39% of the detainees at Guantánamo rests on the possession of a Kalashnikov rifle, even though Kalashnikov culture permeates both Afghanistan and Pakistan—and Afghanistan is the world's center for unaccounted weapons. There are at least ten million small arms in the country (p. 19).

He calls himself a "realist"—torture happens—thus, we should deal with it more openly. Consequently, we need more transparency and accountability, as with the approval of a judge.

Certainly, history shows that a myriad of methods have been used—all with the view that torture works. Evidence suggest otherwise. Some people willingly die for a cause. We must never underestimate ideological crusades or personal vendettas. Surely suicide ("martyr") bombers make that apparent. To think torture leads to an outpouring of the truth, however comforting, is no certainty.

We need to examine the acceptability of torture. We need also to look at the moral hurdles facing the public health system and try to formulate some guidelines for medical caregivers and the institutions of which they are a part. As I will set out, there needs to be scaffolding in place to provide channels and support for public health officials and personnel who do not want to enable abusive practices that border or cross the line of torture.

Part One: Moral Quandaries Facing Caregivers

Doctors and other medical personnel face moral quandaries around the abuse and torture of detainees and prisoners. As seen in a May 2006 report, the Pentagon did not initially release its updated *Army Field Manual* on interrogation. This was due to congressional opposition to such provisions as one allowing tougher techniques for unlawful combatants ("detainees") than for traditional prisoners of war (Barnes 2006).

This issue is compounded by "black sites;" usually in other countries where suspects are taken under a process called "extraordinary rendition." "CIA interrogators in the overseas sites are permitted to use the CIA's approved 'Enhanced Interrogation Techniques;' some of which are prohibited by the U.N. convention and by US military law," such as simulated drowning ("waterboarding"; Priest 2005b). These facilities are far from the eyes of watchdog agencies like the Red Cross. The fact that 14 detainees were moved in September 2006 from secret CIA prisons to Guantánamo Bay[5] does not mean that rendition will not continue.

Techniques such as mock executions, ferocious dogs,[6] and near drowning undermine the very humanity of the subject. And weapons like white phosphorous (aka "shake and bake") that can burn for hours inside a human body are downright

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[5] See BBC News, *Bush Admits to CIA Secret Prisons*, 7 September 2006 at news.bbc.co.uk/2/hi/americas/5321606.stm.

[6] The "military working dogs" (MWDs) were unauthorized prior to 12 November 2002. At that point a "Category II technique" permits the use of dog "to exploit 'individual phobias' during interrogations." (See *Finding #11B, Army Regulation 15–6: Final Report. Investigation into FBI Allegations of Detainee Abuse at Guantánamo Bay, Cuba Detention Facility*. Unclassified 1 April 2005.)

macabre (“Shake and Bake,” *New York Times* editorial 2005). Such practices should concern all medical personnel.

In 1999, the AMA set forth the following guidelines:

- Physicians must oppose and must not participate in torture for any reason. Participation in torture includes, but is not limited to, providing or withholding any services, substances, or knowledge to facilitate the practice of torture. Physicians must not be present when torture is used or threatened.
- Physicians may treat prisoners or detainees if doing so is in their best interest, but physicians should not treat individuals to verify their health so that torture can begin or continue (American Medical Association 1999).

World Medical Association president James Appleyard calls on physicians to report torture: “Doctors cannot turn a blind eye to what is going on. Torturers rely on the cloak of secrecy. The ability to expose acts of torture is crucial to its prevention” (*Medical News Today* 2004). And yet not all doctors report abuse, as Bioethicist M. Gregg Bloche points out:

> According to press reports, military doctors and nurses who examined prisoners at Abu Ghraib treated swollen genitals, prescribed painkillers, stitched wounds, and recorded evidence of the abuses going on around them. Under international law—as well as the standards of common decency—these medical professionals had a duty to tell those in power what they saw. Instead, too often, they returned the victims of torture to the custody of their victimizers. Rather than putting a stop to torture, they tacitly abetted it, by patching up victims and staying silent. (Bloche 2004)

Doctors dignify torture by falsifying records or signing death certificates misrepresenting the cause of death. Steven Miles cites cases where medical assistance was denied and medical professionals failed to report injuries and deaths caused by torture (Tinkelman 2005). He accuses the medical system of collaborating with the design and implementation of coercive interrogations, e.g., by providing the detainees’ medical histories for interrogators.

Further evidence supports Miles’ accusations. For example, *The Guardian* reports on an Abu Ghraib detainee who died after an abusive interrogation: “The US military later issued a death certificate, … citing the cause of death as ‘cardiac arrest of unknown etiology.’ The American doctor who signed the certificate did not print his name, and his signature is illegible” (Harding 2004).

Professor of Psychiatry and Social Medicine Leo Eisenberg observed of Abu Ghraib that: “Clearly doctors went along with misrepresentations to keep things under cover” (Brown 2005). For instance, a surgeon covered up the asphyxia death of an Iraqi Major General by saying he had died of natural causes, and a medic covered up the death of a detainee under interrogation by sticking an intravenous catheter into the corpse (www.englishialjaseera.net 2004)[7].

At times medical personnel failed to show even minimal standards of professional conduct: “We heard rumors of PUCs [detainees in Iraq] dying so we were

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[7] US Doctors “Aided” Abu Ghraib Abuses. 20 August 2004. *Al Jazeera, english. aljazeera.net/ English/archive/archive? ArchiveID=5917.*

careful. We kept it to broken arms and legs and shit. If a leg was broken you call the PA—the physician's assistant—and told him the PUC got hurt when he was taken. He would get Motrin [a pain reliever] and maybe a sling, but no cast or medical treatment."[8] The U.S. Army's 82nd Airborne sergeant adds: "Broken bones didn't happen too often, maybe every other week. The PA would overlook it."[9]

Expert witness S.G. Mestrovic asserts that the doctors, nurses, and medics turned "a blind eye and a deaf ear to abuse." He sees the medical dimension as "one of the most neglected aspects of the Abu Ghraib saga" (Mestrovic 2007, 111). Others agree. The journal *Lancet* condemned the behavior of the doctors, saying that they are doctors first and soldiers second (Associated Press 2004). As Bloche asserts: "The duty of doctors in such circumstances is clear. They must provide needed treatment then do all they can to keep perpetrators from committing further abuse" (Bloche 2004). Being a whistle-blower is one such duty. Eisenberg thinks it ironic that: "Prisoner abuses were reported not by medical staff, but by an infantry captain [Joseph Darby]. This reached Sen. John McCain, who then brought it to light" (Brown 2005).

Health professionals may, nevertheless, be stuck on the horns of a dilemma. As citizens, they may condone brutal interrogation methods or abusive treatment as a tool for fighting terrorism. But, as health caregivers, the emphasis shifts. The subjects are not just "detainees," they are *patients*. That changes everything. Political tensions have ratcheted up the fear factor and opened the door for widespread abuse. It is crucial that those representatives of our public health system steer a clear moral course.

Part Two: From Terrorism to Terror and into "The Dark Side"

Terror is a form of dread. Unlike fear, dread has no object and no clear endpoint—and it can lock us in a stranglehold. The war on terror is a war to loosen that grip and, presumably, the gloves are off. Look at Zacarias Moussaoui, the only individual brought to trial for the 9/11 attacks. Though his links to the hijackers appeared limited at best, he was sentenced to life in solitary confinement without the possibility of parole (Lewis 2006).

In her ruling in *Rasul v. Bush* on 31 January 2005, Federal Judge Joyce Hens Green observed that: "the government cannot even articulate at this moment how it will determine when the war on terrorism has ended" (Stout 2005). Joseph Margulies, lead counsel for Shafiq Rasul, contended that: "the war on terror makes hope impossible. Even today, the Administration cannot say when the war will end. In fact, it cannot even say how it will know that the end has come" (Margulies 2006, 138).

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[8] Human Rights Watch (2005a). Account of "Sergeant A," in *Firsthand Accounts of Torture of Iraqi Detainees by the U.S. Army's 82nd Airborne Division*, September 2005, at *www.hrw.org*. In the Summary, the term "PUC" is explained. It is a replacement for "POW," since the Geneva Conventions were said not to apply since they are not prisoners.

[9] Ibid.

Americans show little regard for the detainees in the war on terror. This attitude extends beyond interrogators and guards; the indifference is widespread. The disclosure of “extraordinary renditions,” with the USA shipping suspects to countries known to practice torture, provoked little public outcry.[10] The dramatic win by Democrats in the midterm 2006 elections was linked opposition to the Iraq War, not the treatment of detainees. The 2008 race has been similar, perhaps because of the mixed response of the public.

Except for Senator John McCain, the Republican presidential candidates in 2008 favored looser limits to “harsh” interrogation practices. Rudolph W. Giuliani condoned the use of “every method they could think of,” including waterboarding. Mitt Romney recommended doubling the Guantánamo detention facility, presumably to permit many more detainees (Wallsten 2007). The pre-2005 “enhanced interrogation techniques” (before the Congress set down restrictions) seems only to bother McCain. He contends that the USA would lose far more from torturing prisoners than it would gain.[11]

Even then, McCain elicited criticism by his February 2008 vote against a congressional ban on coercive techniques such as waterboarding. The bill would have required the CIA to abide by the Army’s field manual for interrogations. Although the bill passed, it was vetoed by President Bush on 8 March 2008. He argued: “The bill Congress sent me would take away one of the most valuable tools in the war on terror—the CIA program to detain and question key terrorist leaders and operatives” (Bush 2008).

There is a reason ex-Army officer Philip Carter calls Guantánamo: “the perfect legal black hole in which to house detainees and practice the dark arts of interrogation” (Carter 2004)—rules such as those of the Geneva Convention which the then Attorney General Alberto Gonzales found “obsolete” and “quaint” (Barry et al. 2004). And Vice President Cheney argued for spending time “in the shadows in the intelligence world.” For him: “A lot of what needs to be done here will have to be done quietly, without any discussion” (Cheney 2001). With this, the old restrictions and civilities were cast aside, as was an open discussion about what was going on.

This is the social context in which medical personnel find themselves. Of paramount importance is their fiduciary duty to patients—even suspected terrorists. They must not lose sight of the ethical codes and values of the public health system. When facing abusive practices, doctors and other caregivers need to be clearly supported—e.g., by the armed forces, government agencies, medical associations, and professional groups.

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[10] Stephen Grey claims there are three kinds of rendition: (1) those high-profile detainees taken to “black sites” were they remain entirely in American (CIA) hands; (2) those held by the US military as “unlawful combatants”—either shipped to Kabul (Afghanistan) or rendered to Guantánamo Bay; and (3) those rendered to Egypt, Jordan, Morocco, Syria, Uzbekistan, and Libya. See Stephen Grey, *The Ghost Plane: The True Story of the CIA Torture Program* (2006), p. 239.

[11] See “A Question of Torture,” *Washington Post* editorial, 17 May 2007. See also Ken Rudin, “Republican Presidential Contenders Meet on Stage,” *National Public Radio* at *www.npr.org*, 16 May 2007.

Clarifying the use of language may help reach that goal. The linguistic ambiguity falls into two categories: The *subjects* we refuse to consider "prisoners" and the *action* we hesitate to call "torture." The policies and regulations that inform medical personnel rest, to a great degree, on definitions, categories, connotations, and concepts. For example, the set of criteria characterizing "adult" versus "child" determines who is competent to make decisions and who is not.

What we consider vital to "informed" consent makes all the difference in the parameters around human experimentation. Indeed, what we consider "legal" factors in as well. In November 2007, the top US law enforcement official, Attorney General Michael Mukasey, refused to tell the Senate whether he believed waterboarding was legal or not (CBS 2007).

Words have power. Just note the energy spent in preventing use of the term "prisoner" to apply to a "detainee"—to ensure that the protections afforded the former would be inapplicable to the latter. Make no mistake about the weight of the words we use.

Part Three: Parameters of Language—The Subjects

Who constitutes the "patients" a health professional faces in a situation of abuse or torture? Who is the subject? The term "insurgents" is also commonly used. "Detainee" is used for those who have been caught. *Al Jazeera*, the leading news source for the Arab world, uses the term "captives."[12] The terms "enemy combatants," "illegal combatants," "unlawful combatants," "foreign combatants," "unprivileged enemy combatants," and (God forbid) "unlawful enemy combatants" are often used for those yet to become detainees. Value-laden adjectives like "enemy," "illegal," "unlawful," and "foreign" have linguistic power.

Mario Mancuso, Special Assistant to U.S. Department of Defense Council explained why he would not use the term prisoner of war (POW): "We want to shield civilians from these *unlawful enemy combatants* because, in fact, they target civilians and we want to protect our troops" (Rhem 2005, *my emphasis*). A great deal follows from what terms are permitted in—or out.

Fourth Circuit Judge Diana Motz observes that the *Hamdi* decision allows the president to detain an enemy combatant. "But what I don't understand is," she says, "How do you make that determination? When I call someone an ostrich, I look in the dictionary for a definition. But what did the president look to in determining whether he [Yasser Hamdi] was an enemy combatant?" (Lithwick 2007). Let us look at the descriptions.

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[12] See for example, *Ex-Captives Push Guantánamo Film, Al-Jazeera*, 14 February 2006, *at english.aljazeera.net/English/archive/archive?ArchiveId=18623*. In this article, two former Guantánamo Bay *captives* have joined Michael Winterbottom, a British director, to promote his semi-documentary film about their experience, an appearance that they coupled with a call for the prison's closure (*my emphasis*).

CATEGORY #1: “Prisoners” are people charged with a crime, awaiting trial. Their numbers are small. Only a few high-profile examples, like “the American Taliban” John Walker Lindh, remind us that there has been a prisoner or two. However, then Secretary of Defense Donald Rumsfeld and others made it clear that the word “prisoner” is a misnomer. They cannot be prisoners, since they have not been charged with a crime! So long as we imprison someone without charging them of an offense, the traditional rules about humane treatment set out by the Geneva Convention must be irrelevant. But if you think about it, this is a strange war with no *prisoners of war*. This leaves many who are placed in the next category.

CATEGORY #2: “Detainees” have neither been charged nor convicted of a crime. They are held at detention centers under the theoretical scrutiny of the Red Cross. Steven Miles rejected the term “detainee,” opting for “prisoner” to stress the importance of the long-established policies around their treatment (Miles 2006, iii–iv). He certainly has a point. However, the very term “detainee” is more sinister, because it lacks any specific legal meaning. Consequently, it underscores the vulnerability of the captives to actions deemed out of bounds in dealing with “prisoners.”

Confirming the power of language, the judge in the Abu Ghraib trials involving Graner and others would not permit the use of the word “victim.” When Special Agent Nora from the CID testified, he stated that his job was to locate the “victims” abused at Abu Ghraib. “The judge corrected him immediately. Call them detainees, not victims” (Mestrovic 2007, 133).

It is vital to understand how many detainees we are talking about. The *Associated Press* reported that, as of 15 November 2005: “The United States has detained more than 83,000 foreigners in the four years of the war on terror, enough to nearly fill the NFL’s largest stadium. … Roughly 14,500 detainees remain in U.S. custody, primarily in Iraq” (Shrader 2005). An April 2006 estimate for detainees in Iraq, Afghanistan, and Guantánamo Bay was in the 15,000 range (Scarborough 2006). As of 18 February 2007, the American detention camps in Iraq alone “now hold 15,500 prisoners, more than at any time since the war begin” (Moss and Mekhennet 2007).

CATEGORY #3: This category includes detainees undergoing “rendition.” “Rendition” is a euphemism for “transport to a country known to allow torture.” Those who have undergone rendition are called “rendered.” Rendition is supposed to be for those likely to resist customary interrogation methods. International law expert Scott Horton estimates 150 people have been “rendered” since 2001 (Mayer 2005).

According to former British ambassador to Uzbekistan, Craig Murray: “A handful have emerged from what has been labeled a secret gulag, and have given deeply disturbing accounts of horrific mistreatment” (Murray 2005). Consider the case of Canadian citizen Maher Arar, who was sent to Syria in 2002 under “extraordinary rendition” and later released:

> The underground cell was tiny, about the size of a grave … [that was] damp and cold, contained very little light and was infested with rats … Mr. Arar’s captors beat him savagely with an electrical cable. He was allowed to bathe in cold water once a week. He lost 40 pounds while in captivity. (Herbert 2006)

Such treatment brought results—of a sort. "After months in a windowless room and regular beatings with thick electric cables, he said, he confessed to anything they wanted just to stop the torment" (*Los Angeles Times* editorial 2005). We see such false confessions with the three British detainees (the "Tipton Three"), who said they met with Osama bin Laden when they were actually employed in England (*The Guardian* (UK) 2004).

Few things compare to rendition. "You just give up. You become like an animal," asserted ex-detainee Arar (Mayer 2005). And who could be caught in the rendition net? Only the guilty ones? "The horror story of the post-9/11 world is that any foreign national anywhere in the world can be plucked from the streets of anywhere, whisked off to another country, never be heard from again and be utterly beyond the reach of the law" (Wilkinson and Drogin 2005). Journalist Bob Herbert opined that: "In terms of vile behavior, rendition stands shoulder to shoulder with contract killing" (Herbert 2006).

CATEGORY #4: The last group is "ghost detainees" or "ghost soldiers;" those held without charge at secret detention centers around the globe, far from the accessibility of the Red Cross. Some of those centers are said to be mobile: "There are very, very serious accusations that the United States is maintaining secret camps, notably on ships," says Manfred Nowak, UN Special Rapporteur on Torture. He thought the evidence was sufficient to merit an official inquiry (*Agence France-Presse* 2005).

In 2004, General Paul J. Kern estimated that the number of CIA ghost detainees was in the dozens, perhaps up to 100 (Priest 2004). James Risen says a CIA prison code named "Bright Light" is used for those who will probably never be released (Risen 2006, 21). The euphemism does not obscure the horror of the situation. A 15 March 2008 report tells on the case of Majid Khan, who was held under "extraordinary rendition" for three years. His lawyer found this program to be "operating criminally, shamefully, and dangerously." (Mazzetti, 2008).

Journalist Dana Priest reports that the facilities—called "black sites"—"are known to only a handful of officials in the United States and, usually, only to the president and a few top intelligence officers in each host country" (Priest 2005b). This may change in time: An 15 August 2006 press release from Amnesty International details their requests for records on ghost detainees under the Freedom of Information Act.

The term "ghost detainee" attempts to make invisible the individual subject who can be incarcerated for an indefinite period of time outside of the reach of peering eyes, or digital cameras. They are dead to the outside world and to their families. As McCain told the congressional hearing: "the situation with the CIA and ghost soldiers is beginning to look like a bad movie" (Burkeman 2004). Indeed, this "bad movie" may end up with a CIA-maintained "secret prison system" of aging terrorists, asserts journalist Douglas Jehl. He adds: "No one has a plan for what to do with these guys" (Jehl 2005).

And what of the health caregivers who attend to those "ghost detainees" ("ghost soldiers") inhabiting the "secret prison system," those "black sites"? Presumably, they are expected to act in the shadows, bound by vows of secrecy as they care for their "patients." What this must do to their sense of themselves as medical professionals stretches comprehension. Such secrecy seems to conflict with the Patient's Bill of Rights: "If you have severe pain, an injury, or sudden illness that convinces you that your health is in serious jeopardy, you have the right to receive screening and stabilization emergency services whenever and wherever needed, without prior authorization or financial penalty" (Emergency Services section, *Patient Bill of Rights*).

Part Four: The Parameters of Language

The next twist of language is with the word "torture." Said to be excluded from "torture" are mock executions, threatened electrocutions, 24-hour strobe lights, shackles, deafeningly loud music, months-long solitary confinement: "stress positions" like forced standing,[13] the threat of live burial, and "waterboarding," whereby the detainee is strapped to a board, forcibly pushed under water wrapped in a wet towel and made to believe he might drown.[14] The euphemisms trivialize the actions; e.g., "To 'smoke' someone is to put them in stress positions until they get muscle fatigue and pass out. That happened every day."[15] Another example is "fear up harsh," which requires instilling fear and provoking disorientation (White and Allen 2004).

American citizen Jose Padilla was held for 21 months in near solitary. His windows were blacked out; there was no clock or calendar and only a steel platform to sleep on (he had no mattress) before he had access to legal counsel (Sontag 2006). Joseph Margulies observes that there is no upper bound on holding a detainee in solitary confinement or being subjected to interrogations (Margulies 2006, 107). The lack of restrictions may relate to the utter secrecy—those shadows of the intelligence world that Cheney advocates. In the name of "security," there is little transparency or accountability.

Torture expert Darius Rejali speaks of "stealth torture" that is accomplished leaving few, if any, physical marks or scars (Rejali 2004).[16] He says the hooded prisoner appearing to be electrocuted in the infamous photo is in a torture pose called "The

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[13] See, for example, R. Jeffrey Smith and Dan Eggen, "Gonzales Helped Set the Course for Detainees," *Washington Post*, 1 May 2005.

[14] Senate Confirmation Hearings, Kennedy quoting *The Washington Post*. Also, Joseph Margulies points out that prisoners may still be kept indefinitely in solitary confinement and/or subjected to interrogations of indefinite duration. See *Guantánamo and the Abuse of Presidential Power* (New York: Simon & Schuster, 2006), p. 107.

[15] Account of "Sergeant A," in *Firsthand Accounts of Torture of Iraqi Detainees by the U.S. Army's 82nd Airborne Division,* September 2005, *Human Rights Watch*, 17(3G), *www.hrw.org/reports/2005/us0905/*

[16] In the same commentary, Rejali states that: "In 1956, the CIA commissioned two experts, Wolf and Hinkle, who described the effects of forced standing. The ankles and feet swell to twice their size within 24 hours. Moving becomes agony. Large blisters develop. The heart rate increases, and some faint. The kidneys eventually shut down." In addition, U.S. Army Criminal Investigation Command (CID) has released sworn statements that detail the effects on detainees forced to stand for hours on end. See also his book, *Torture and Democracy* (2007) for a more extensive discussion.

Vietnam." This is one evidently well known in torture circles for its painful effects, as is forced standing, referred to by British soldiers as "The Crucifixion" (Rejali 2007, 298) As Rejali points out, these techniques are known in intelligence agencies worldwide and were not "dreamed up" at Abu Ghraib (Rejali 2004).

Ex-British ambassador Craig Murray spoke of two cases in Uzbekistan, one of the countries of rendition, in which prisoners had been boiled to death. Evidently in Uzbekistan, "partial boiling of a hand or an arm is quite common" (Mayer 2005). Tales from Egyptian renditions are similarly horrific. And Maher Arar's case suggests that Syrian renditions also leave a lot to be desired.

On 5 October 2007 President Bush insisted: "This government does not torture people" (Bush 2007). Nevertheless, an FBI memo of 22 May 2004 disclosing abuses at Guantánamo Bay refers to an Executive Order where President Bush sets out the parameters of allowable torture. It included the use of military working dogs (MWD), sleep deprivation ("sleep adjustment"),[17] stress positions, isolation,[18] water abuse,[19] environmental manipulation such as the use of loud music and sensory deprivation through the use of hoods.

The cumulative effects of abusive ("enhanced") interrogation techniques need to be examined more closely. Whereas a single action may be abusive, but tolerable, layers of abuse can act as forms of torture. Rejali refers to this as "clustering" (Rejali 2007, 4). We need to recognize how often they are done in combination—not as a solitary technique of interrogation.

Consider also how interrogation is tailored for maximum effect. M. Gregg Bloche and Jonathan H. Marks contend that: "interrogators tapped clinical data to craft interrogation strategies," thus violating patient confidentiality. Apparently, since late 2002 psychologists and psychiatrists "have been part of a strategy that employs extreme stress, combined with behavior-shaping rewards, to extract

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[17] According to Finding #14 of the *Army 15-6 Final Report* investigating FBI allegations of abuse at Guantánamo from 23 November 2002 to 16 January 2003: The subject of the first "Special Interrogation Plan" was interrogated 18–20 hours per day for 48 days, with "the opportunity for a minimum of four hours rest per day." This technique was "officially permitted under 2 December 2002 SECDEF Memorandum—The use of 20-hour interrogations." Later in 2 June 2003, CDR USSOUTHCOM formalized the definition of sleep deprivation "as keeping a detainee awake for more than 17 hours, or allowing a detainee to rest briefly and then repeatedly awakening him, not to exceed four days in succession." The Army recommended that this policy be "clarified."

[18] For example, "Finding #16K" of the *Army 15-6 Final Report* stated that: "Particularly troubling is the combined impact of the 160 days of segregation from other detainees, 48 of 54 consecutive days of 18 to 20-hour interrogations and the creative application of authorized interrogation techniques." Requiring the subject of the first Special Interrogation Plan to be led around by a leash tied to his chains, placing a thong on his head, wearing a bra, insulting his mother and sister, being forced to stand naked in front of a female interrogator for five minutes, and using strip searches as an interrogation technique were found to be abusive and degrading by the AR 15-6, particularly when done in the context of the 48 days of intense and long interrogations. However, "this treatment did not rise to the level of prohibited inhumane treatment."

[19] The very subject of the first Special Interrogation Plan noted in the above footnote was also subjected to forced standing and he "regularly had water poured on his head." However, "interrogation logs indicate that this was done as a control measure only."

actionable intelligence from resistant captives" (Bloche and Marks 2005). Such revelations prompted the American Psychological Association to issue a condemnation in 2006, reaffirmed 19 August 2007:

> An absolute prohibition against psychologists' knowingly planning, designing, and assisting in the use of torture and any form of cruel, inhuman or degrading treatment or punishment [and this] includes exploitation of phobias or psychopathology, the use of psychotropic drugs or mind-altering substances used for the purpose of eliciting information. (APA 2007)

The phrase "define your terms" takes on new meaning in the lower circles of Hades. If we restrict the definition of "torture" to include *only* actions that either result in death or cause an intensity of pain comparable to organ failure and exclude any mental suffering whatsoever, then the meaning of torture has shrunk to miniscule dimensions. And who is talking about having a conscience these days? That term was swept under Gregor Samsa's rug right after we linked Saddam Hussein to 9/11, or earlier, when we tolerated the abuse of John Walker Lindh, an American citizen.

For Antonin Scalia, Supreme Court Justice, it was "extraordinary" to assume that the Eighth Amendment of the Constitution's ban on "cruel and unusual punishment" also applied to "so-called" torture (BBC 2008). Donald Rumsfeld argued that the "harsh interrogation methods" he sanctioned should be contrasted with the actions of terrorists. He said: "Does it rank up there with chopping someone's head off on television? It doesn't" (Lumpkin 2004).

Putting a positive spin on torture or "harsh interrogation methods," by comparing it to televised beheadings, sounds like a "straw man" fallacy. If it is not as bad as being beheaded, then it must not warrant our concern. By that reasoning, pulling out fingernails, chopping off hands or boiling arms do not sound so bad. To consider beheadings the benchmark for torture takes us to new levels of moral evasion. There is a reason the Geneva Conventions do not restrict torture to actions that leaves scars or pain associated with organ failure. And there is a reason the American Psychological Association condemned practices "used in a manner that represents significant pain or suffering or in a manner that a reasonable person would judge to cause lasting harm; or the threatened use of any of the above techniques to the individual or to members of the individual's family" (APA 2007).

Part Five: The Boundaries of Torture

There are four practices we will examine: (1) indefinite detentions; (2) use of ferocious violence; (3) hooding; and (4) forced feeding. Each issue raises concerns of morality for medical personnel.

Indefinite Detentions

People are being incarcerated without facing criminal charges. They are often in solitary confinement and at the mercy of guards and interrogators. The picture is one of gradual dehumanization without recourse—and seemingly without end. For these detainees, security detainees and ghost detainees, Kafka is our man. No more can the protagonist, “K” from Kafka’s novel *The Trial* finds his way, can detainees navigate the labyrinthine system shaping their daily reality.

That K’s case was a sham from beginning to end resonates with the thousands of detainees hauled off, moved from place to place, hooded, bound, often in solitary confinement in dark, even underground, cubicles—and never charged with a crime. As Khalid Al-Odah said in a plea that his son, imprisoned for over four years in Guantánamo, be brought to trial: “Our demand has been to charge and try them, or to release them. Give the prisoners due process so their guilt or innocence can be determined fairly. In a country that presumes innocence, it is categorically unjust to imprison so many who are probably innocent to punish so few who may be guilty” (Al-Odah 2006).

Being locked up with neither recourse nor hope of release explains the suicide attempts. Twenty-three detainees at Guantánamo Bay tried to hang themselves during a mass protest in August 2003 (Northam 2005). Three detainees did commit suicide at Guantánamo in 2006 and on 30 May 2007, a Saudi detainee killed himself (Reuters 2007). As one detainee attorney stated: “Under these circumstances, it’s hardly surprising that people become desperate and hopeless enough to attempt suicide.”[20]

Christopher Girod of the American Red Cross said that when he visited Guantánamo, the number one question the inmates asked was: “What’s happening? How long will this last?” Girod believes this uncertainty has led to widespread clinical depression. One-in-five inmates is on an antidepressant (Lewis 2003). James Yee, former Muslim Army Chaplain at the camp, said the indefinite detentions severely traumatized some inmates. He said many sang “childish songs, repeating the song over and over” and spent their days lying on the floor or bed of their cells drawing pictures with paper and crayons (Yee 2006, 139). This accords with the view that: “people generally have a much higher tolerance for physical discomfort than they do for psychological stress” (Margulies 2006, 118).

Concerns about Guantánamo Bay led the Attorney General of Britain on 10 May 2006 to call for its closure: The camp had become a symbol of injustice and its existence was “unacceptable” (BBC 2006). Similarly, a 19 May 2006 United Nations’(UN) report concluded that detention of suspects without facing charges runs counter to established human rights law and that the war on terrorism does not constitute an armed conflict under international law.[21]

And let us not ignore other potential detention sites—such as within the USA itself. As 4th Circuit Judge Motz noted: “I fear that [this court] may also have opened the door to the indefinite detention, without access to a lawyer or the courts, of any American citizen, even one captured on American soil, who the Executive designates an ‘enemy combatant,’ as long as the Executive asserts that the area in

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[20] CNN, Gitmo inmates attack guards stopping suicide attempt, 19 May 2006 at *www.cnn.com/2006/WORLD/americas/05/19/gitmo.clash.ap/index.html*

[21] CNN, *U.N.: Gitmo Violates World Torture Ban*. 19 May 2006 at *www.cnn.com/2006/US/05/19/un.torture/index.html*.

which the citizen was detained was an ‘active combat zone,’ and the detainee, deprived of access to the courts and counsel, cannot dispute this fact.”[22]

Brutality

Contrary to Major General Geoffrey D. Miller’s testimony under oath that dogs were never used to intimidate prisoners at Guantánamo, FBI memos of May 2004 indicate otherwise (*Washington Post* editorial 2004). Indeed, Rumsfeld authorized the use of dogs back in December 2002,[23] opening the door for using the dogs to threaten and frighten detainees.

Photographs indicate that dogs were used in Iraq and in Guantánamo as well, and evidence points to their use in Afghanistan.[24] Dogs were used to terrorize the “20th hijacker,” Mohammed al-Qahtani and Australian Mamdouh Habib. Habib was apprehended in October 2001 and released without charges in January 2005. He spoke of threats of being sexually abused by specially trained dogs. His lawyer did not know if it went beyond threats (Mayer 2005). This was seen as a factor in the coerced confessions during his rendition to Egypt.

Sergeant Santos Cardona was convicted of using dogs to abuse inmates at Abu Ghraib in 2003 and 2004. In at least one documented case, a *psychologist was present* when a dog was used in an interrogation at Guantánamo.[25] Fortunately, the use of dogs came under scrutiny and standard operating procedures now expressly prohibit the use of dogs (MWDs) in the *interrogation room* (*my emphasis*).

Vicious dogs are but one form of brutality used on detainees. FBI agents observed detainees being subject to strangulation and having lit cigarettes placed in their ears (American Civil Liberties Union 2004)[26]. Some reported electrical burns on their extremities.[27] Then there are shackles and chains that bind detainees to the

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[22] Dissent in *Hamdi v. Rumsfeld*, as noted by Dahlia Lithwick, *The Third Man: The 4th Circuit Does One More Round on Enemy Combatants*, Slate.Com, 1 February 2007 at *www.slate.com/id/2158861/*

[23] See *Rasul v. Bush*, 542 U.S. 466 (2004).

[24] See, for example, Physicians for Human Rights (2005), *Break Them Down: Systematic Use of Psychological Torture by US Forces* at *physiciansforhumanrights.org/library/report-2005-may.html*. This report notes that: “Detainees held at Bagram Air Force Base and Kandahar, Afghanistan in 2002 report being threatened with dogs.”

[25] See discussion in “Finding #11” of the *Army Report 15-6*: “[A] MWD was brought into the doorway of the interrogation room and ordered by the dog handler to growl, show teeth and bark at the detainee. In addition, a psychologist assigned to the Behavior Science Consultation Team (BSCT) for JTF-170/JTF-GTMO witnessed the use of a MWD named ‘Zeus’ during a military interrogation … during the November 2002 time period.”

[26] American Civil Liberties Union. 20 Dec 2004. FBI E-Mail Refers to Presidential Order Authorizing Inhumane Interrogation Techniques. *American Civil Liberties Union. Torture Documents Released Under FOIA www.aclu.org/safefree/general/18769prs20041220.html*

[27] See, for example, Department of Defense (DOD) document #052172, dated 10 November 2004, along with DOD #052167 report on a detainee arrested on 27 April 2004 who was later abused and tortured by American forces.

floor in twisted, painful positions (one descriptively called "the scorpion"). They are then left for hours or days in their own urine and excrement, or submerged in water,[28] barely able to breathe.

Short shackling consists of chaining the ankles and wrists closely together to force the detainee into a contorted and painful position.[29] That these are euphemistically called "stress positions" does not negate their brutality. For example, the Army Criminal Investigation Command (CID) cites the case of a detainee arrested on 27 April 2004 and hung from a hook about a meter (about 3 feet) off the ground. He testified that: "My hands and my legs were tied behind my back together they put a hook on my cuffs. It was tied with a rope to the ceiling and there was a machine on the wall they use it to pull me up."[30] That was at Abu Ghraib—but it does not stop there. A Guantánamo detainee reported having to stand for five days straight and answer questions.[31] Similar techniques were reportedly used in Afghanistan.

Medical caregivers play their part when it comes to brutality. Steven Miles points out that: "Among other things, the regulations required detainees to be declared physically fit for interrogation and gave interrogation leaders power over detainees' medical treatment" (Tinkelman 2005). An 20 October 2003 incident led to the conviction of U.S. Army Reservist Jeremy C. Sivits for abuse at Abu Ghraib. Sivits testified that: "Detainees are piled in a pyramid and Graner and Davis jump on them, stomp on their feet and hands, later punch them and make them strip and masturbate." He testified that a medic was present, but "did not report this up the chain of command because Graner asked him not to, saying 'You did not see shit' "[32] Such intimidation of medical personnel merits our concern and may be a factor in doctors failing to report abuse and torture.

The case of Guantánamo detainee Muhammad bin Gimeshan al-Qahtani reveals that doctors were directly involved. After a variety of "harsh" interrogation techniques such as the use of dogs, al-Qahtani refused food and water. Medical personnel treated al-Quhtani and returned him to further interrogation, as the report demonstrates:

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[28] See, for example, incident of 31 July 2003 noted in the Army Criminal Investigation Command Report of Investigation Number 0050-2004-CID369-69273, Document #: DOD053707-DOD054242.

[29] See for example, the FBI memos obtained by the ACLU. See also Carol D. Leonnig, "Further Detainee Abuse Alleged," *Washington Post*, 26 December 2004, Shafiq Rasul and Asif Iqbal''s Open Letter to the US Senate, 13 May 2004, *www.cageprisoners.com*.

[30] DOD Document #052167, posted on the ACLU website materials obtained through the Freedom of Information Act.

[31] Summary of FBI Interview of Detainee at Guantánamo, Document #: DOJFBI003333-DOJFBI003335, Date of Record: 2003-03-27.

[32] See *Court Martial Record of Ivan L. Frederick II, SSG*, Document #: DOD042400-DOD042696, Date of Record, 2004-08-01.

> Dec. 7: a **medical corpsman** reports that al-Qahtani is becoming seriously dehydrated, the result of his refusal to take water regularly. He is given an IV drip, and a **doctor** is summoned. An unprecedented 24-hour time out is called, but even as al-Qahtani is put under a doctor's care, music is played to "prevent detainee from sleeping."
>
> Nine hours later, a **medical corpsman** checks al-Qahtani's pulse and finds it "unusually slow." An electrocardiogram10 is administered by a **doctor**, and after al-Qahtani is transferred to a hospital, a CT scan is performed. A **second doctor** is consulted. Al-Qahtani's heartbeat is regular but slow: 35 beats a minute. He is placed in isolation and hooked up to a heart monitor. The next day, a **radiologist** is flown in from Roosevelt Roads Naval Air Station in Puerto Rico, 600 miles away, to read the CT scan. The log reports, "No anomalies were found." The next evening, … al-Qahtani is "hooded, shackled and restrained in a litter" and transported back to Camp X-Ray in an ambulance. Over the next month, the interrogators experiment with other tactics. (Zagorin and Duffy 2005, *my emphasis*)

Detainees have alleged forced injections of an unknown substance—which has led to speculation about interrogation methods and/or medical experimentation. The September 2006 Congressional compromise on torture bars biological experiments[33] presumably because of actual or planned experiments. Bioethicist Jonathan Moreno has criticized such human experiments at Guantánamo, saying: "[H]istory tends to be less forgiving when governments ride roughshod over those values that are supposed to be among their most cherished" (Moreno 2003).

We know there have been detainees killed by guards or interrogators. As a *Washington Post* editorial notes: "For now the appalling truth is that there has been no remedy for the documented torture and killing of foreign prisoners by this American government" (*Washington Post* editorial 2004). The 2007 Academy-award winning documentary *Taxi to the Dark Side* addresses this by interviewing interrogators linked to the beating-death of an Afghani detainee.

Evidence is overwhelming that torture has been systemic and across all the armed forces[34] (Lobe 2004). There is the Navy SEAL photographed in May 2003 pointing a gun at the head of a bloodied prisoner; the June 2003 case of four Iraqi juveniles forced to kneel while a Marine discharged a gun in a mock execution; and the Iraqis classified as enemy prisoners of war (EPWs) taken by Marines to an empty swim pool, shackled, hooded, and forced to remain in a kneeling position for up to 24 hours awaiting interrogation (Lobe 2004). Refuting the "bad apples" theory, Senator McCain insisted that it was not plausible that soldiers would abuse prisoners without being instructed to do so (White and Allen 2004).

The Abu Ghraib photographs frequently combine aggression and sexuality—and sadistic pleasure on the part of smiling guards. We see this with the mock or real

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[33] See CNN, *Deal on Detainee Treatment Quells GOP Revolt*, 22 September 2006 at *www.cnn.com/2006/POLITICS/09/21/terror.bill/*

[34] See, for example, the collection of documents in Amnesty International, *Torture in Iraq*, at *www.amnesty.ie;* such as October 2001, "Systematic Torture of Political Prisoners in Iraq." See also, "Torture in Iraq," Human Rights Watch (2005b), New York Review of Books, 52(17), 3 November 2005.

sodomy,[35] forced nudity,[36] forced masturbation,[37] dunking or pouring water (or urine) on heads,[38] setting dogs at the legs of naked detainees,[39] the use of electrical wires and threatened electrocution (which the ironic photo of the hooded detainee so vividly illustrates)[40] and the like.

Although it violates the Geneva Conventions, forced nudity was common at Abu Ghraib and is widely reported by government documents. There is more at stake here than humiliating the enemy. Although the judge at the Abu Ghraib trials "ruled that the 'nudity thing' was irrelevant," some consider it a serious concern (Mestrovic 2007, 32). According to The Fay Report of 2004, forced nudity "contributed to an escalating 'de-humanization' of the detainees and set the stage for additional and more severe abuses to occur" (Fay 2004, 44). Thus, "What started as nakedness and

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[35] Numerous examples can be found in the sworn testimony taken by the CID at Abu Ghraib. See also "Sworn Statements of Abu Ghraib Detainees," *Washington Post*, 16–20 January 2004. These include detainees being sodomized with brooms and phosphorescent light sticks.

[36] For example, Hiadar Sabir Abed Miktub al-Abudi said under oath that he was stripped, hooded, ordered to stroke his penis in front of a female soldier and then get on his hands and knees on the floor. Then they took off their hoods and "they placed three others on our backs naked … they [American guards] were laughing, taking pictures, and they were stepping on our hands with their feet … then after that they forced us to walk like dogs on our hands and knees. And we had to bark like a dog and if we didn't do that they started to beat us on our face and chest." Al-Abudi also reported soldiers pointing a gun to his head and threatening to kill him and being hung on the cell door "allowing the dogs to try to bite me." ("Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 20 January 2004.)

[37] For example, Nori Samir Gunda al-Yasseri said under oath that after they were detained (in Abu Ghraib), sandbags were put over their heads, they were beaten, stripped naked and "they ordered us to hold our penises and stroke it. … They started to take photographs as if it was a porn movie. … Then they started to write words on our buttocks … they left us for the next two days naked with no clothes, with no mattresses, as if we were dogs. … The first night when they stripped us naked they made us get on our hands and knees and they started to pile us on top of the other. They started to take pictures from the front and the back." (See, "Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 17 January 2004.)

[38] See, for example, sworn statement of Abd Alwhab Youss, who relates being handcuffed to the cell door for two hours and then taken into a closed room where "more than five guards poured cold water on me and forced me to put my head in someone's urine that was already in that room. After that they beat me with a broom and stepped on my head with their feet while it was still in the urine. They pressed my ass with a broom and spit on it. Also a female soldier whom I don't know the name was standing on my legs." See also the sworn statement of Mohassein Mata al-Zayiadi, who said: "After the end of the beating, they took us to our separate cells and they opened the water in the cell and told us to lay face down in the water and we stayed like that until the morning, in the water, naked, without clothes. Then one of the other shift gave us clothes, but the second shift took the clothes away at night and handcuffed us to the beds." ("Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 17 January 2004.)

[39] See the *Abu Ghraib files* on Salon.Com at *www.salon.com*. The photographs of a naked detainee with dog bites on both legs include in at least one photo the smiling face of a female American soldier looking up at the camera.

[40] For more photographic evidence, see "Electrical wires," in the Abu Ghraib files at Salon.Com, *www.salon.com/news/abu_ghraib/2006/03/14/chapter_4/*

humiliation … carried over into sexual and physical assaults" (Fay 2004, 44). Photographs and videos make that apparent as well.

Major General Fay reports that forced nudity and sexual assaults were brought into Iraq from Afghanistan and Guantánamo. Rapes and sodomy of detainees have been widely reported. See also the FBI memo on the president's authorization of torture and the sworn statements taken by the U.S. Army CID unit.

Detainees have also been subjected to threats (both veiled/implied and direct ones). These included death threats and threats to be sent to Guantánamo. Ameen Sa'eed al-Sheikh testifies: "The guard put a pistol to my head. He said, 'I wish I can kill you right now.' … Every hour or two, soldiers came, threatening … to kill me and torture me and I'm going to be in prison forever and they might transfer me to Guantánamo Bay."[41]

The complicity of doctors is demonstrated in both sworn testimony and photographs. For example, Marine Corporal Charles Graner (later convicted of abuse) asked a doctor stitching the nose of a tortured detainee to show him how this was done. Evidently he complied and Graner took over stitching up the wound.[42] Moreover, the Abu Ghraib photo archive reveals medics/doctors giving medical treatment to tortured detainees. One of these shows a doctor standing with her foot on the detainee's arm and hand while administering a shot in the patient's side.[43] It is hard to see this as medical *care*.

That members of Congress agreed to censor the videos of Abu Ghraib speaks volumes. They refused to share what they found so morally repugnant in the photos and videos. Photos released to the public showed only adult male victims of abuse; evidently those of women and children being abused, raped, and humiliated were thought to elicit even more outrage and repulsion by the public. Rumsfeld said they included acts that were "blatantly sadistic" (Mitchell 2005). It seems likely, nevertheless, that the censored photos will eventually surface.

The historical record is, nevertheless, a work in progress. Such abuse is devoid of morality, like the random violence of a mob spun out of control. Just look at the photos that *were* made public—the ghoulish grins of pleasure, the viciousness that was unleashed, and the gleefulness in treating the "enemy" with such brutality.[44]

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[41] From "Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 16 January 2004. There were more than threats, as seen by the deaths of detainees. Some take time to come to light. See also Dana Priest, "CIA Avoids Scrutiny of Detainee Treatment," *Washington Post*, 3 March 2005, regarding the hypothermia-death of an Afghan man at the secret CIA-run prison north of Kabul.

[42] See sworn statement of Shalan Said al-Sharoni who relates the beating of nude detainees stacked on top of one another and then photographed. One who was badly beaten about the testicles and then handcuffed to the cell door and had water poured over him was eventually treated by a doctor. "The Doctor came to stitch the nose and the Graner asked the doctor to learn how to stitch and it's true, the guard learned how to stitch. He took the needle and he sat down to finish the stitching." ("Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 17 January 2004, at *www.washingtonpost.com/wp-srv/world/iraq/abughraib/swornstatements042104.html*.).

[43] See photographs in "Lacerations," in "The Abu Ghraib Files," Salon.Com, at *www.salon.com/news/abu_ghraib/2006/03/14/chapter_7/*.

[44] There are any number of websites posting photos of torture; see for example, *www.salon.com, www. harpers.org, www.cageprisoners.com,* and *www.washingtonpost.com*.

As "Sergeant A" of the 82nd Airborne revealed: "Some days we would just get bored so we would … make them get in a pyramid." He adds: "We did that for amusement."[45]

The Department of Defense CID report reveals others who found abuse and torture a source of entertainment. It is hard not to label this "sadistic." For example, in Section 1A of Abu Ghraib there are tack marks on the wooden wall to indicate how many stitches detainees have received after being abused, particularly by dog bites.[46] And let us note the grinning faces in the photos from Abu Ghraib that were first released in 2003. Susan Sontag observes of the grinning guards:

> Looking at these photographs, you ask yourself, How can someone grin at the sufferings and humiliation of another human being? … Rape and pain inflicted on the genitals are among the most common forms of torture. Not just in Nazi concentration camps and in Abu Ghraib when it was run by Saddam Hussein. Americans, too, have done and do them when they are told, or made to feel, that those over whom they have absolute power deserve to be humiliated, tormented. They do them when they are led to believe that the people they are torturing belong to an inferior race or religion. (Sontag 2004)

The violence is sexualized—the stuff of photographs. The fact that so many of the victims are faceless, with heads in bags erasing their identity, makes the aggression even more atrocious.

The Use of Hoods

Hoods function as a form of suffocation. Such sensory deprivation (blindfolds, ear muffs, duct tape, etc.) can terrify, disorient, and breakdown even the most recalcitrant subject. This practice is inhumane. I see it also as a form of torture.

Consider the 25 April 2006 decision of the Movie Picture Association of America to censor the poster advertising a documentary, *The Road to Guantánamo*. The poster shows a man hanging by his handcuffed wrists, with a burlap sack over his head and a blindfold tied around the hood. The reason given for the censorship "was that the burlap bag over the guy's head was depicting torture, which wasn't appropriate for children to see," said Howard Cohen, co-president of Roadside Attractions, distributor of the film in North America (Kennicott 2006).

At the congressional hearing over interrogation practices, Deputy Defense Secretary Paul Wolfowitz and Marine General Peter Pace admitted that practices in dozens of Iraqi jails violated the Geneva Convention by keeping bags over prisoners' heads for 72 hours (Sisk 2004). The FBI inquiry also details use of duct tape, as with:

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[45] See Human Rights Watch, "Account of Sergeant A, 82nd Airborne Division," in Leadership Failure: Firsthand Accounts of Torture of Iraqi Detainees by the U.S. Army's 82nd Airborne, September 2005, at *www.hrw.org/reports/2005/us0905/.*

[46] Sworn statement, CID Interview, regarding abuse at Abu Ghraib, 2 February 2004, DOD #052851.

"Investigators wrapped a detainee's head in duct tape because he would not stop quoting the Koran."[47] A March 2008, Pentagon review of videotaping interrogations did not condemn such tactics: Lieutenant General Michael D. Maples, director of the Defense Intelligence Agency found the forcible use of duct tape to silence Qatar detainee Ali al-Marri from chanting to be "acceptable." (Mazzetti and Shane 2008).

"American Taliban" John Walker Lindh also got the duct-tape treatment after his capture in fall 2001. Shot in the leg prior to his capture and badly dehydrated, Lindh was hooded and left with an untreated wound festering for days, despite doctors being readily available. He was repeatedly threatened with death, kept in an enclosed, unheated and unlit metal shipping container (with holes drilled in for air) and removed only during interrogations (Lindorff 2004). Journalist Richard Serrano points out: "An untold number of U.S. military service members took 'souvenir photographs' with Lindh." Aboard the ship, he was kept in irons, blindfolded and strapped to a gurney with duct tape —"all of which made him stand out as a prize captive for the U.S." (Serrano 2002). Lindh became "a prized deer instead of a defendant." (Cohen 2002).

In *Being and Nothingness*, Jean Paul Sartre asserts that sadism entails the objectification of the other. We see this with hooding. Besides the sensory deprivation, hoods strip away the identity, uniqueness, and subjectivity of the individual. Hoods and isolation are destabilizing, tearing at the person's sense of place and time. No doubt this was true for Lindh—and countless others. For instance, American Jose Padilla was detained for over three years as an "enemy combatant." A December 2006 "trip" to the dentist for a root canal conveys the extent such sensory deprivation can go: His legs were shackled, his hands manacled, and he wore noise-blocking headphones over his ears and blacked-out goggles over his eyes. "Then the guards, whose faces were hidden behind plastic visors, marched their prisoner down the hall to his root canal" (Sontag 2006).

This is not the only time guards sought anonymity. Both detainees and the Army Unit investigating alleged abuse mention Department of Defense (DOD)'s masked interrogators relaying veiled death threats; some relayed as "dreams."[48] One such "dream" told to a detainee was: "There are worse things than physical pain," and

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[47] American Civil Liberties Union, *FBI Inquiry Details Abuses Reported by Agents at Guantánamo*, 3 January 2007 at *www.aclu.org/safefree/torture/27816prs20070103.html*. This technique was deemed "unauthorized" by the *Army Report 15-6* (see "Finding #7") and the ICE Chief received a "verbal admonishment," but did not receive any formal discipline action. The Army Report concluded that he ought to have been formally admonished.

[48] See "Sworn Statements by Abu Ghraib Detainees," *Washington Post*, 16–20 January 2004. See also, "Finding #22," *Army Regulation 15-6: Final Report. Investigation into FBI Allegations of Detainee Abuse at Guantánamo Bay, Cuba Detention Facility*, *www.defenselink.mil/news*, July 2005. One relayed a "dream" that he "saw four detainees that were chained together at the feet. They dug a hole that was six-feet long, six-feet deep, and four-feet wide" and that the dream "meant that he was never going to leave GTMO unless he started to talk." The Army deemed the "dream" not at the level of a threat, but that it was a prelude to a direct threat made by the Special Team Chief who followed the first interrogator.

that the detainee "will very soon disappear down a very dark hole. His very existence will become erased. His electronic files will be deleted from the computer, his paper files will be packed up and filed away, … No one will know what happened to him and, eventually no one will care."[49]

Masked interrogators—and doctors—are mentioned elsewhere. Khaled el-Masri is a German citizen and victim of mistaken identity who was seized by the CIA as part of "extraordinary rendition." He told of an English-speaking *doctor who was masked* when he was inspected on his arrival at the "Dark Prison" in Afghanistan, where he was detained and tortured for five months before being released (Grey 2006, 88, *my emphasis*). Such incidents conjure up images of hooded executioners or Klan members seeking to hide their identity.

The hoods may protect the guards' anonymity, but they dehumanize the subjects and become targets for the displacement of rage and racist fury. With hoods in place and the other's gaze shielded, it is easier to stand on the necks and bodies of the detainees, stack them up like pieces of wood, yank their genitals, or put them in humiliating positions, rape or sodomize them, pour ice water on them, threaten to drown or electrocute them and so on. There is a reason the hooded prisoner standing on the box with electrodes attached became an icon of horror.

Darius Rejali asserts that hoods were used in Brazilian and South African torture—infamous for human rights violations (Rejali 2004). Reverend George Wauchope, a torture victim under South African apartheid, argues that: "The use of a suffocating bag or hood around one's head, of dawn to dusk interrogation for days without a break, and of physical and psychological abuse are all forms of torture" (Wauchope 2004).

That the hooding may open the door for further abuse has not been given the attention it deserves. Some trivialize it—as with Guy Womack, attorney for M.P. reservist Charles Graner, who was convicted of a number of charges, including assault and battery. It boggles the mind that Womack could look at the piling up of hooded, naked detainees by laughing perpetrators and compare it to college sports. In his opening statement at Graner's trial, Womack said: "Don't cheerleaders all over America form pyramids six to eight times a year. Is that torture?" (Booth 2005). And it is certainly not as bad as being beheaded! The barbaric nature of hoods being used today—in our names—should trouble us all. And they must cause medical personnel to feel like they are trapped in some horror movie.

Force-Feeding

Omar Deghayes, a Libyan held at Guantánamo, explained why he went on a hunger strike: "Look, I'm dying a slow death in this place as it is. I don't have any hope of fair treatment, so what have I got to lose?" He was not alone. It was September

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[49] Ibid. The interrogator also relayed a threat to the detainee's mother.

2005 and as many as 200 prisoners—more than a third of the camp—refused food to protest conditions and prolonged confinement without trial. Military officials acknowledged that 20 of them were kept at the camp's hospital, fed through nasal tubes, and sometimes given fluids intravenously (Lewis 2005).

Detainee lawyer David Remes argues that: "Tube feeding is itself a form of torture. You have no conception of the brutality that is inflicted on these men. And anybody who tells you otherwise from within the camp, from the military, is lying" (Pessin 2006). Force-feeding is a "disgrace," says another detainee lawyer, Thomas B. Wilner. He adds: "It is clear that the government has ended the hunger strike through the use of force and through the most brutal and inhumane types of treatment" (Golden 2006).

To prevent hunger strikers from vomiting, specially designed restraint chairs that immobilize the legs, arms, shoulders and head are being used with long periods of isolation. Some strikers quit protesting after being strapped in the chairs and feeding tubes inserted and removed so violently that they bled or fainted. Some claimed that too much food was given deliberately, causing diarrhea, resulting in detainees defecating on themselves (Golden 2006).

Reports suggest adversarial relationships between the striking detainee-patients and the medical staff, e.g., Abdul Rahman complained that a Navy doctor put in the feeding tube and moved it up and down, causing him to throw up blood. Others say feeding tubes were forcibly shoved into detainees' noses and stomachs with no anesthesia or sedative—and reused without being sanitized. "The detainees could see the blood and stomach bile from other detainees remaining on the tubes" (Lobe 2005).

Evidently force-feeding has been standard policy at Guantánamo since early 2002 and those who resist may face harsh consequences. Journalist Adam Zagorin cites the case of 20-year old Yusuf al-Shehri, detained since he was 16. He was regularly strapped into a restraint chair and force-fed through a plastic tube 50% larger than those commonly used. His *medical records* include a note that al-Shehri was informed that "dying is not permitted" (Zagorin 2006).

The "do no harm" prohibition in the Hippocratic Oath seems to have slipped under the radar. Or it was trumped by draconian policies for handling detainees. Al Qaeda expert Saad Al-Faqih, opined: "The Americans tend to deal with things in a quantifiable manner and they do not appreciate the full strategic significance of Islamic ideology and spirituality" (Abedin 2004).

After the three suicides of hunger-striking detainees in June 2006, Rear Admiral Harry B. Harris, Jr. made a public statement. He insisted that the suicides were "not an act of desperation, but an act of *asymmetric warfare* against us" (White 2006). Rumsfeld dismissed the hunger strike as a publicity stunt (Pessin 2005). In contrast, many medical professionals deplored the situation. Over 260 doctors from seven countries issued this call: "We urge the US government to ensure that detainees are assessed by independent physicians and that techniques such as force-feeding and restraint chairs are abandoned."[50]

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[50] See, "Doctors Demand End to Guantanamo Force-Feeding," *Guardian* (UK), 10 March 2006.

The World Medical Association (WMA) and the AMA prohibit force-feeding (Khamsi 2006). The WMA Declaration of Malta on hunger strikers asserts that: "Where a prisoner refuses nourishment and is considered by the doctor as capable of forming an unimpaired and rational judgment concerning the consequences of such voluntary refusal of nourishment, he or she shall not be fed artificially. Those who are mentally competent normally have the right to refuse force feeding—even if they are prisoners."

According to the Physicians for Human Rights (PHR), the USA admits that military physicians have force-fed hunger strikers at Guantánamo. These physicians may have been pressured into intervening in ways that contradict their ethical obligations (Physicians for Human Rights 2005b). PHR called for an independent group of physicians to investigate and verify that no health personnel are compelled to engage in force-feeding—and that the AMA should sanction those who violate their ethical duties (Atkinson et al. 2006).

Bioethicists Michael A. Grodin and George J. Annas contend that the hunger-striking detainees do not want to die: "Their goal is not suicide but to change the inhumane conditions of the prison." They recommend that: "The United States should focus on bringing procedures at Guantánamo into conformance with international human rights law, not on developing novel coercive techniques to break the hunger strikes" (Grodin and Annas 2006). The lawyers for striking detainees at Guantánamo say the tube feeding is a violation of medical ethics—and the AMA says physicians should respect the decision not to take nourishment, as long as the person is competent and understands the potential consequences.

Conclusion

Joseph Margulies writes about the fake interrogations staged at Guantánamo for the public (journalists and members of Congress who visited the base). He says: "According to Erik Saar, a linguist and former interpreter at Camp Delta, the military routinely staged bogus interrogations to dupe congressional delegations" (Margulies 2006, 171). Margulies contends: "Like the decision to create a bogus set of financial records to conceal an elaborate accounting fraud, one does not stage phony interrogations except to conceal wrongdoing" (Margulies 2006, 174).

And what of medical personnel who stay silent or enable torture? Bloche is right to tell them: "turn yourselves in." Standing up against abuse must take precedent over any allegiance to the military or to the nation. We can resolve these two loyalties by clarifying the frame of reference of medical caregivers. If we hold the duty owed to *patients* as paramount, the moral qualms about the *detainees* are more readily addressed. As Steven Miles says: "health professionals are accountable for the health of their patients, regardless of the fact of imprisonment" (Miles 2006, 65).

Journalist Seymour Hersh reports on a senior intelligence official who is being asked: "When do we start blowing the whistle?" and "When does it cross the line from abuse of prisoners to war crimes?" In the heat of it he observed, people "do strange things that in retrospect they can't explain or condone. Guys are having pangs of conscience now—and they're scared shitless of a future investigation. In time somebody is going to start blowing the whistle" (Hersh 2004, 53). That is not the only worry. Such abuse is a two-way street: both victim and victimizer suffer. A former CIA officer reportedly told Jane Mayer that:

> The C.I.A. kept a doctor standing by during interrogations. He insisted that the method was safe and effective, but said that it could cause lasting psychic damage to the interrogators. During interrogations, the former agency official said, officers worked in teams, watching each other behind two-way mirrors. Even with this group support … "When you cross over that line of darkness, it's hard to come back. You lose your soul. You can do your best to justify it, but it's well outside the norm. You can't go to that dark a place without it changing you. … You are inflicting something really evil and horrible on somebody." (Mayer 2007)

An important first step is to cast a brighter light on protocols and practices tied to the war on terror. Too much has been done in secrecy, outside the public view. Human Rights Watch was right to urge the UN to convene an international inquiry on the rendition of Ahmed Agiza and Muhammed al-Zery—with the aid of both Egypt and Sweden (Hersh 2004, 55). But the "full accounting" they seek needs to be opened up. We should widen the lens to get a better picture of what sorts of acts, including torture, have been taking place. As part of that inquiry, specific attention should be focused on the role of health caregivers. Without a clearer grasp of what has transpired, any moral assessment may be shortsighted or incomplete.

The second step is a call to moral duty on the part of the doctors, nurses, and other medical personnel. As noted by the World Medical Association, even though a doctor may be in a prison: "The doctor's conduct must not be in conflict with international human rights and ethical standards" (World Medical Association 2003). We must pay attention to the subjects, the patients, who are owed a minimal level of care. This includes such things as respect for human dignity, patient confidentiality, and the right of informed consent.[51] As one of the British detainees released from Guantánamo put it: "After awhile, we stopped asking for human rights. We wanted animal rights" (Prince and Jones 2004). Their rights as patients should be in the foreground for the medical personnel who treat them. They should be treated with dignity and respect.

Caregivers should not be either actively or passively complicit in any mistreatment of the detainee-patients. This includes participating in unnecessary procedures, particularly ones intended for humiliation rather than medical needs—as seen in the use of rectal suppositories in the "takeout" of suspects. Moreover, we should support those like Robert A. Fein, psychologist, head of the Intelligence Science Board, a group advising the intelligence agencies on effective and humane ways to question suspects. In his view: "even the word 'interrogation' is tainted by torture. He uses the term 'intelligence interviewing' for the skills he promotes." (Shane 2008). He is right to distance himself from the terms now associated with torture.

A third, related, step is to examine such egregious treatment as the use of indefinite detentions, hoods, brutality, and force-feeding. Such methods exhibit wanton

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[51] See guidelines and discussion, along with relevant links for medical professionals at Prison Healthcare Professionals, *www.prisonhealthcarepractitioners.com/index.shtml*

cruelty and disregard for human life. Though they may not result in death or pain akin to organ failure, they function as torture—particularly since they are often done together or in tandem. Medical personnel must never lose sight of the humanity of their patients. Philosopher Judith Jarvis Thomson, in another context altogether (the abortion debate), set forth standards of moral behavior: She calls for us *not* to be Good Samaritans—but to be “Minimally Decent Samaritans” (Thomson 1971). Surely this applies here as well.

Lastly, we must examine the scaffolding in place for doctors and other healthcare personnel to confront abuse, place charges, and bring torture to light. We need to go beyond targeting individual wrongdoers and look at systemic change. We can expect doctors not to participate in disrespecting or abusing patients (e.g., in conducting experiments without informed consent or in enabling torture or “harsh” or “enhanced” interrogation). However, individual caregivers are not always able to take personal risks in opposing the mistreatment of others.

There must be a framework for whistle-blowers to raise concerns. With such channels—legal as well as within the medical profession itself—medical caregivers can more easily resist coercion regarding torture. We need the culture and guidelines for speaking out, confronting abusers, and rejecting a protocol that violates basic human rights. We cannot just rely on individual heroes having the courage to act.

Abu Ghraib whistle-blower Sergeant Joseph Darby showed that confronting evil was at considerable risk; e.g., he had to have bodyguards for six months. In addition, Darby’s family had to live in protective custody due to death threats after he reported the prison abuse (Darby 2006). Those who confront torture should not have to place their lives on the line. And this is crucial for the medical personnel who see or suspect abuse.

There should be channels in place at all levels. Health caregivers need a structure setting out guidelines and procedures for reporting abuse. They should have access to advocates or legal counsel if necessary. A system must be in place for reporting wrongdoing. In that way, we honor the relationship between doctors and patients. Those patients who are detainees, ghost detainees, prisoners; even unlawful enemy combatants—are still human beings for whom medical caregivers owe a duty of care.

We must step back and reconsider what we are doing—and who we are becoming. We need to look at the moral risks we are taking. That process of making war on terror may be transforming us into something without conscience, remorse, or morality. The transformation is not yet complete, but for those who want to battle with this dark possibility—new methods, tactics, and deployment of forces will be required.

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Exporting the "Culture of Life"

Laura Purdy

Abstract The Religious Right is using every means to impose its restrictive view of sexual and reproductive rights on everyone under the umbrella of a so-called culture of life (CL). The CL prohibits the direct killing of innocents (but not, apparently, letting them die), and requires that all sexual activity be open to procreation, thus restricting access to abortion and contraception. All this is alleged to be based on God's will and to constitute the only objective morality. But there is no epistemological basis for this claim, the strictures are inconsistent, and the rules create unnecessary misery. Those most at risk from the sexual strictures are women, children, and gay men. The risks are greatly magnified in Third World countries because of poverty and lack of access to even the most basic health care. Yet the Bush administration is doing everything in its power to impose the CL on such countries by means of its foreign policy and aid programs.

Keywords Religious Right, foreign policy, gag rule, abortion, pro-life, religious ethics, family planning

> When the self is an idol, it naturally wants to be autonomous; a law of nature unto one's self, not wishing to submit to anything or anyone. This is the antithesis of Christian life. All Christians are to submit to the Lordship of Jesus Christ. And then God has defined the lines of authority even further by requiring wives to submit to husbands, children to submit to parents, and slaves to submit to masters. There is also an element of submission to the church that can be extrapolated from the concept of church discipline.
> http://www.christianworldviewnetwork.com/article.php/1637/Charley_Adams
>
> The theocratic right seeks to establish dominion, or control over society in the name of God. D. James Kennedy, Pastor of Coral Ridge Ministries, calls on his followers to exercise "godly dominion … over every aspect … of human society." At a "Reclaiming America for Christ" conference in February, 2005, Kennedy said: "Our job is to reclaim America for Christ, whatever the cost. As the vice regents of God, we are to exercise godly dominion and influence over our neighborhoods, our schools, our government, our literature and arts, our sports arenas, our entertainment media, our news media, our scientific endeavors—in short, over every aspect and institution of human society." http://www.theocracywatch.org/
>
> "Am I trying to Christianize America? You bet your boots I am! Jesus Christ's last commandment to the Church was: 'Go ye into all the world, and preach the Gospel to every creature.' (Mark 16:15). I am not only trying to Christianize America, I am trying to

M. Boylan (ed.) *International Public Health Policy and Ethics*,

Christianize every country in the world through the Gospel."—D. James Kennedy, "Christianizing America?" in *America, Return to God*, ed. Thomas Wang (Sunnyvale, CA: Great Commission Center International), p. 92.

"I don't know that atheists should be considered citizens, nor should they be considered patriots. This is one nation under God."—George Bush
http://www.geocities.com/CapitolHill/7027/quotes.html

"I want you to just let a wave of intolerance wash over you. I want you to let a wave of hatred wash over you. Yes, hate is good … Our goal is a Christian nation. We have a Biblical duty, we are called by God, to conquer this country. We don't want equal time. We don't want pluralism."—Randall Terry, Founder of Operation Rescue, The News-Sentinel, Fort Wayne, Indiana, 8-16-93. http://www.geocities.com/CapitolHill/7027/quotes.html

Introduction

Consider these two cases. First, a seventeen-year old girl is pregnant with an anencephalic fetus. But she lives in a location where abortion is banned. She is in need of care, and would need to travel elsewhere to obtain an abortion. A court holds that she can be denied permission to do this. Second, a woman has an ectopic pregnancy that will kill her if it is not terminated. But she, too, lives in a location that has banned all abortions, and doctors are afraid they will be prosecuted for the operation necessary to save her life.

Both situations have arisen because of laws promoted by the Religious Right (RR), rules allegedly necessary for a morally mandatory "culture of life" (CL).[1] In the first case, they require that this girl go forward with a pregnancy even though it is certain that her baby will die shortly after birth. In the second, they put the pregnant woman at risk of death even where the embryo has no chance of survival.

Such cases are emblematic of the CL: the RR focuses solely on its allegedly absolute ban on killing humans. It ignores the consequences of the ban, no matter how much suffering—or lost lives—it causes. It also imposes its judgment that a fertilized egg is as valuable as a developed individual on a world that, by and large, disagrees.

Many others and I argue that an emerging consensus among right-wing and religious forces in support of this so-called culture of life is undermining the liberal democratic ideal of autonomy in ethics and political life. Despite its attempt to claim the high moral ground, the motives, means, and alleged goals of the movement—at least as exemplified by the Bush administration and its allies (most notably the Christian Right)—are, at best, based on ignorance and are, at worst, thoroughly dishonest.

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[1] In these particular cases, the laws were influenced and promoted by the Catholic Church. However, with respect to its views about contraception and abortion, the Catholic Church can be seen as a member of the Christian Right, and, along with other non-Christian religions that share these perspectives, a member of the broader Religious Right.

In the US, the Christian Right has made considerable headway in its opposition to quite widely accepted liberal views about valuable life, family, equality, privacy, happiness, and autonomy, given its empowering political alliance with George W. Bush's administration. It emphasizes the stricture against killing humans (at the expense of by now well-established bioethical principles that prevent suffering and enhance autonomy) even as it pursues policies that fail to protect workers and citizens from workplace and environmental risks.

And, its pro-family rhetoric codes for views that roll back the moral and political clock. By insisting that sex outside of marriage is sinful, as is sex in marriage not open to conception, the Christian Right, at a stroke, deprives women of control over their reproductive lives and undermines the preconditions for participating as equals in a society that still makes few concessions for women caring for children. At the same time, it declares homosexuality sinful as well, returning to the bad old days when it was considered permissible—perhaps even virtuous—to discriminate (or worse) against homosexuals. And there is only one kind of family, the patriarchal family. In the patriarchal family, the wife is subordinated to her husband, and the children have no rights that might come into conflict with their parents' wishes.

The Christian Right's ambitions extend beyond the borders of the US, however: it aims to control the entire human population. And, as in the US, the Christian Right does not merely regard its right to assert these views as God's mandate, but it considers acting to impose them by political means intended to restrict alternatives as the justifiable exercise of its religious freedom.

In many countries, religious and political leaders share important parts of the Christian Right agenda. For example, its views about sexual and reproductive issues are consistent with those endorsed by the Vatican, along with those of the more conservative wings of Judaism and Islam. Thus it makes sense to think in terms of a RR rather than just a Christian Right.

The RR has not only hijacked the US government's foreign policy, but it has also begun successfully to lobby at the United Nations (UN). Once again, this activity is motivated by its conviction that its own religious freedom requires the imposition of its views on everyone else and that resistance to this program constitutes persecution. It appears oblivious to the obvious moral point that if anyone has a right to religious freedom, everyone does.

Many feminists and other progressives might not find this state of affairs a clarion call to defend liberalism, given their trenchant critiques of the concept. However, I believe that once the RR goal is understood, the need to defend a version of autonomy becomes compelling. Indeed, only a unified front on this issue—aiming to defend institutions that protect and promote carefully qualified rights to self-determination and privacy—would help unite opponents of the RR in getting back a country where people can work in fair and transparent ways toward their own moral and political visions. The alternative is the current countless compartmentalized holding actions against attempts to control every aspect of everyone else's, relegating out-groups to second-class citizenship (or worse).

The Culture of Life

The phrase “culture of life” (CL) is clearly intended to be a new, improved model of “pro-life,” a term that has looked a bit green around the gills ever since some of its adherents took to murdering doctors who do abortions. Yet, there seems to be as yet no careful theoretical articulation of the concept.[2]

What *is* clear is that the CL is much more limited than some its critics have noticed. Its proponents neither have, nor pretend to have, any interest in the *quality* of life, in promoting human welfare or happiness, or in reducing pain and suffering. The alleged focus of the CL is just that—life itself (and, only human life). Thus it is impervious to many objections based on those values, once the basic premise about killing is accepted. And, few seem willing to raise doubts about that basic premise, perhaps because it has some initial plausibility and also because nobody wants to be seen to question the alleged word of God.

My theses are that the CL is inconsistent and that it leads to misery. It is inconsistent because of its reliance on the frail reed of the killing/letting die distinction, and because of its (variably applied) deontological insistence that killing is wrong even if failing to kill leads to more deaths. It expands misery because misery caused by its policies constitutes no objection to them, and, in fact, it regards misery as the appropriate punishment for failing to follow its rules.[3] This misery falls disproportionately on the shoulders of women, children, and gay men, as they benefit most from respect for individual autonomy in sexual and reproductive matters. This respect for autonomy is so closely linked with the “life” allegedly promoted by the CL as to reinforce the suspicion that reinstating patriarchal control is one of its central motivating forces, a suspicion supported by the RR’s forthright assertions that women are to be subordinated to men. However, it would also be a mistake to ignore the role of economics in determining where the CL applies and where it is invisible despite its apparent relevance.

Before investigating these claims in more detail, however, we need to take a closer look at the epistemological basis for them.

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[2] It is possible that it is a mistake to imagine that any theoretical articulation of the concept is relevant here, if one is to take seriously Stephen Pizzo’s (2005) thesis that Bush’s evangelism explains all his decisions. Even if this is true, however, it seems important to try to understand what might be said on behalf of these positions.

[3] The connection with misery may be even more direct, if as Garret Keizer (2005) suggests that “the right talks about protecting life and tradition, but on some level … it is mostly interested in protecting pain.” It does so because of the theological belief that “pain holds the meaning of life.” It also does so because of its political belief that justice is based on pain. … Whoever owns pain owns power” (p. 56). This thesis clearly bears further investigation.

What Is the Religious Right and Why Must We Follow Its Commands?

While it may be misleading to think of the RR as a monolithic movement, its members share a common allegiance to the belief that ethics precepts come from on high rather than from reasoned responses to the human condition. Firstly, these precepts allegedly come from God, as interpreted by Scripture and self-appointed spokespersons. Secondly, this sacred source is taken to relieve its current proponents of any need for internal consistency or attention to other values ignored, or violated their application, such as preventing suffering, autonomy or freedom, or justice. Any such ethics will therefore inevitably come into conflict with the first principles of public health, or more broadly, human welfare.

Although all the members share these assumptions about the origins and nature of ethical precepts, there are significant variations in their beliefs. This disagreement both undermines the plausibility of this approach to ethics, and underlines its inability to compromise in the face of disagreement.

Thus not every policy of the Bush administration is supported by each group—witness Pope John Paul's opposition to the war on Iraq. But there is still much agreement about policies deemed to be central, and frighteningly, the most extreme policies are, in some cases, displacing more reasonable ones, such as the traditional Catholic definition of "extraordinary" care that would prolong life at the cost of increased suffering. I take Bush administration policy to represent "mainstream" RR views.

How does the RR attempt to take the moral high ground? It claims not only that its policies are required by God, but also that the sole alternative is a noxious moral relativism that denies the existence of ethical principles altogether. Its own interpretation of God's will must therefore form the basis of society, government, and law.

But this view constitutes a false dilemma that sees only two options when others exist. Ignored is the rich philosophical tradition of ethical and political theories that ground morality in human needs and desires, some of which provide for significant individual autonomy.

It also runs afoul of Plato's objections to the view that ethics is what the gods command. To avoid following arbitrary or wicked judgments, we must make a prior judgment about any authority's moral standing. But then its mere existence (or, in the case of God, alleged existence) creates no case for following its commands (except perhaps to escape punishment for failing to do so), and fails to relieve us of the labor of determining right and wrong for ourselves. Yet the RR expects us to take God's goodness on faith, despite the fact, that as W.K. Clifford argues, we are morally responsible for what we believe. Flushing out these facts undermines the RR claim that only (its) religion provides clear, objective, and compelling moral positions.

Fighting the RR's simplistic position requires that we recognize its roots in the economic right (ER). The ER, too, reflexively accuses opponents of "political correctness" or moral relativism.[4] But political correctness turns out to be any claim that that corporate profit should be limited in the public interest—a position that has been adopted by the RR as well.

And the accusation of relativism, although often repeated, is a misunderstanding of any moral system that deviates from the rigid and inflexible precepts propagated by the ER and the RR. To them, morality claims to be a matter of exceptionless precepts to do (or not do) a particular act—regardless of the consequences. Only this approach constitutes "principled" ethics, whereas consequentialist ethics that tailor means to the situation to achieve a specific goal or value is taken as "relativistic." Of course, means are adjusted to circumstances, and thus relative to them, but this is not at all the same thing as the kind of malignant relativism that denies any common principles or values. So there are really significant metaethical differences between the two camps, although the RR also wants to hold that only its particular principles or values are moral, thus erroneously excluding alternative ones from the moral realm altogether. The main benefit of this move is to relieve its members of having to argue for their principles rather than assert that no others exist.

Progressives also tend to recognize the importance (and the difficulty) of making nuanced moral judgments about a reality they perceive as more multifaceted than do many on the right. So their recommendations may be more tentative, more subject to revision as results come in. They also tend to be more willing to trust individuals to find their own course. This is seen as the policy most likely to lead to optimal results, given that individuals must live with the consequences of their own decisions (assuming that society creates safeguards to protect others from serious harm) and as intrinsically valuable (Mill 2006). The Right finds these approaches unacceptable, even frightening, and seems to be unable to differentiate them intellectually from the true moral chaos implied by relativism.[5]

Articulating liberalism more fully would help the public understand that this dichotomy (religious dogma/moral relativism) now being pressed on us by the Right is fallacious. The crucial point is that liberalism can provide a basic political framework essential for running society well, a framework compatible with significant latitude for individuals to choose their way of life—precisely what the right-wing fallacy denies. Liberalism holds that limits on freedom require justification, and includes a robust conception of autonomy that limits government power.[6] And although extreme versions of liberalism have rightly drawn fire for their failure to recognize our appropriate dependence on each other, it is clear that exercising significant control over one's life is essential for human happiness, as the next sections of this chapter will emphasize.

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[4] See Purdy, 1994.

[5] For a good articulation of this point of view, see Ira Chernis (2005). He asserts that the proponents of the CL fear "uncertainty, ambiguity, and change in the realm of moral values." Only commands from an authority can provide moral principles. Humans are fundamentally flawed and moral decision-making cannot be left up to them.

[6] "Liberalism," *Stanford Encyclopedia of Philosophy* (SEP).

In short, the RR would like us to believe that the CL's tenets come straight from God and therefore require neither justification nor explanation when they appear to contradict each other or come into conflict with other values (like reducing misery).[7] In a pluralistic democracy peopled with critical thinkers, this position would be dead on arrival. But since that is not the case, we need to examine its specific tenets.

Culture of Life: The Moral Agenda

The CL agenda sees the overriding value of human life allegedly uniting two clusters of issues, those arising at the beginning and end of life. Let us start by examining end-of-life issues.

End-of-Life Issues

According to Gilbert Meilaender, the CL holds "only" that it is wrong to intentionally end human life, except perhaps in self-defense; thus, it is not vitalism, the view that human life must be sustained no matter what. Both elements of this position are problematic. The first prohibits putting those suffering at the end of life out of their misery. It also prohibits abortion, no matter what the circumstances. The second sounds like a good idea but the framing of the Schiavo case as murder suggests that it nonetheless requires that unconscious life be sustained indefinitely.[8]

The RR's rhetoric in the Schiavo case was especially inconsistent and hypocritical in light of other Bush policies, such as the Texas Futile Care Law, permitting the state to withdraw life support from terminal indigent patients, even against their guardians' will (Niman, 2005a, b). In addition, he also approved the execution of numerous (questionably guilty) individuals. Then there is the war in Iraq, which may have killed some 600,000 Iraqis, not in self-defense.

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[7] See, for example, Steve Benen (2004), who cites Wendy Wright, senior policy director for Concerned Women for America, a conservative women's organization. She promotes abstinence because "it is just a plain healthier way to live." How do we know? "When we go outside the order set by God … it's harmful to us" (p. 124).

[8] It is true that her "defenders" tried to deflect discussion of this issue by maintaining that she was conscious (or potentially so), but that is clearly a red herring. But Meilaender himself seems to believe that refusing to end life trumps his rejection of vitalism: He argues that this is (1) because the body must be cared for, as it is an important part of us; and (2) that we may exercise some, but not total, control over our deaths. But one need not be a thoroughgoing Cartesian dualist to reject caring for the mindless body as ghoulish. Nor does death's inevitability give us any reason not to control what we can in the service of human well-being. For more arguments about this, see my review of Daniel Callahan's book in *Bioethics*.

Moreover, the prohibition on killing is applied inconsistently in another way: it focuses solely on the act of killing, ignoring entirely deaths resulting from failures to act, even when those deaths are foreseen even if not intended. A single-minded focus on intention, as suggested by Meilaender, could be useful to proponents of the CL in explaining why other Bush policies that are causing many other preventable deaths are held to be consistent with it. Among them are privileging corporations' willingness to increase life-threatening workplace risks or environmental toxins.[9] And tax cuts for the rich by defunding social programs providing life-saving services to the poor and failing adequately to address the racism that shortens the lives of people of color and the inequalities that, it now turns out, shorten the lives of all those in hierarchical societies (Daniels et al. 2000) and foreign economic policies that suit the interests of the US elite (Purdy 2004).[10] In every case, the intention is to achieve some "worthwhile" goal, not to let die those who stand in its way—even though it is clear that those policies will result in additional deaths. But the distinctions between killing and letting die, acting and omitting cannot bear the weight of those deaths. In my view, this state of affairs demonstrates how ad hoc the CL strictures about the end of life really are, and how, in practice, they turn out to be inextricably entwined with the economic interest of the RR's corporate allies.

Finally, virtually every other activity now proscribed by the CL as obviously immoral can also be redescribed in terms of worthy goals. Thus, physician-assisted suicide enables patients to escape serious suffering. And, we free up desperately needed resources when we let the irreversibly comatose die. And, to take cases from the beginning of life, we enable women to control their bodies and their lives by increasing (instead of decreasing) access to contraception, provide emergency contraception (EC) to raped women, and by allowing women with threatening pregnancies to end their pregnancies.[11] And, we enable teens to escape unwanted pregnancy and sometimes life-threatening STDs by making sure that they all get

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[9] Just one example: A recent *Mother Jones* expose of the U.S. Food and Drug Administration (FDA) failure to heed the warnings about Vioxx, a failure that is estimated to have caused between 88,000 and 139,000 heart attacks—causing somewhere between 25,000 and 55,000 deaths. This failure is a result of industry-friendly policies (Scherer 2005).

[10] To be fair, it is important to notice that every US administration for the last 20 years has pursued similar policies. Clinton's Iraq policy was especially egregious. Nonetheless, the point here is that the contradictions are most shameful when they are coupled with the rhetoric of the CL.

[11] From a theoretical perspective, the key question is why the sole arbiter of moral righteousness should be intention. Intentions certainly matter, but consequences generally matter still more. Otherwise whitewashed intentions can be used to try to justify any carnage. And even the long-standing (but morally questionable) Principle of Double Effect (PDE) requires attention to other factors that would rule many of these policies unacceptable, such as proportionality between an intended effect and its costs. Rather than intention, the RR might retreat to the deontological judgment that kill is just wrong, no matter what the consequences. However, that would make it difficult to explain why it is permissible to go to war, or to continence killing abortion doctors. Of course, it might attempt to argue that there are morally relevant differences between different types of killing, such that some are permissible, others not; but then one gets into the same sorts of discussion about justifying factors as with intention.

comprehensive sex education. And, we intend to prevent or cure horrible diseases by pursuing stem cell research, etc.

Beginning-of-Life Issues

The theoretical connection between these end-of-life issues and beginning-of-life issues is somewhat puzzling, as proscriptions against ending life do not necessarily imply that new life must be created wherever possible. So far as I can see, the only possible link would be transferring the proscription of killing from human lives to sperm. Only then might it be possible to understand the demand that only sex open to conception is morally permissible, as any other sexual activity will kill all the sperm in any particular emission. Attempting to discover the roots of this position must be left for another day, although one might well find them in the old discredited beliefs that sperm provided the all-important Aristotelian form, or indeed even the homunculus.

The lack of any obvious and compelling link unifying the strictures about the end and beginning of life raises serious questions about the justification of the sexual and reproductive agenda, questions rendered more urgent by the fact that beginning-of-life issues turn out to be inextricably entwined in an understanding of sex as so intrinsically wicked that it can be redeemed only by producing babies. Sex engaged in for pleasure warrants unwanted babies and disease, even where morally permissible ways to prevent them exist, and even if this leads to preventable deaths.[12] Only this understanding can explain the otherwise unintelligible collection of positions in this realm: opposition to comprehensive sex education, contraception, condoms, EC, abortion, and the human papillomavirus (HPV) vaccine.

For proponents of the CL, sex education is just indoctrination into the RR view that sex is for marriage and procreation only. Information about how to avoid or terminate pregnancy, and the risks of sexually transmitted disease is incomplete, inaccurate, or missing altogether.[13]

The alleged justification for this approach is protecting children against the dangers of sex. What are these dangers? First, concerns its intrinsic wrongness (in the wrong circumstances). And second, its consequences: babies and disease. This position requires that the intrinsic wrongness of sex be demonstrated, which the RR fails utterly to do. It also requires that "abstinence-only" effectiveness in reducing pregnancy and disease be demonstrated. Yet there is no credible evidence that it does reduce pregnancies or STDs,[14] and one study suggests that it may

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[12] Notice that there is good evidence that members of the RR are themselves unable to live anywhere near their own principles (Niman 2005b).

[13] See Waxman (2004) "The Content of Federally Funded Abstinence-Only Education Programs," prepared for Rep. Henry A. Waxman, December 2004, available at www.democrats.reform.house.gov.

[14] Ibid., p. 3.

increase risk.[15] Many studies show that comprehensive sex education delays sex and promotes the use of contraception.[16]

What abstinence-only sex education does is increase the dangers of sex to those who do not follow its rules. It is therefore hard to avoid the conclusion that the real goal is punishing rebels with babies and STDs, even where the babies cannot be well taken care of, and the STDs kill not only the miscreants but all the others with whom they subsequently have sex. This approach is thus incompatible with the CL, let alone any real concern for human welfare.

At the same time, some justify the war on contraception by such profound comments as, "I would like to outlaw contraception … contraception is disgusting—people using each other for pleasure" (Joseph Scheidler, Pro-Life Action League) and "I don't think Christians should use birth control. You consummate your marriage as often as you like—and if you have babies, you have babies" (Randall Terry, of abortion clinic bombing fame).[17] It seems to me that such comments reveal all too clearly the underlying hatred and fear of pleasurable sex, as well as the obsession with controlling it at all costs that seems to explain the RR position.

Only such a motive could explain other aspects of the CL approach to sex and reproduction, such as the belief that the public should be deprived of scientifically accurate information about contraceptives. Why else would the Bush administration pressure the Centers for Disease Control (CDC) to spread unfounded doubts about condoms' alleged ineffectiveness, deleting instructions for using them effectively, and results of studies showing that scientifically correct information about them does not promote sexual activity? (Union of Concerned Scientists 2004).

And, why else would it encourage pharmacists to refuse to fill prescriptions for contraceptives for reasons of conscience (no matter how poorly conceived[18])—even though it has been shown that access to EC headed off some 51,000 abortions in just one year and even in cases of rape? (Baumgartner 2004, 66).

And, why else would it pursue policies that reduce access to family planning services, both in the US and abroad? And why else would gay men's use of condoms to prevent the spread of life-threatening disease be condemned as immoral?[19]

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[15] Ibid., p. 4.

[16] Ibid.

[17] Both comments are cited by Stephen Pizzo, 2004. At least Terry seems to leave room for non-Christians to make their own choices, if they can find a pharmacist willing to dispense them! Pizzo's article describes the many members of the religious right who now hold crucial positions in the federal agencies such as the Department of Health and Human Services. Among them are Dr. Alma Golden, Tom Coburn, Dr. Joseph McIlhaney, Jr., Dr. W. Hager, Dr. Joseph B. Stanford, and Susan A. Crockett.

[18] For example, pharmacists may mistakenly believe that a given contraceptive is an abortifacient. See Feminist Daily News Wire (2005) "AMA Resolution Says Pharmacists Should Be Required to Fill Prescriptions." The National Women's Law Center reports that such "conscience clauses" have been passed by 4 states, and 11 more may do so.

[19] Or more revealing of such hostility toward homosexuals that it prefers to see them dead rather than happy.

As Katha Pollitt (2005) points out in her brilliant "Virginity or Death!": "If preventing abortion was what they cared about, they'd be giving birth control and emergency contraception away on street corners."

Clinching my case is the RR's hostility toward an HPV vaccine that could save thousands of women a year from cervical cancer (Harris 2005). Instead of celebrating the fact that the vaccine could potentially save 4,000 women a year from horrible deaths from cervical cancer in the US alone, Bridget Maher of the Family Research Council opines that, "Giving the HPV vaccine to young women could be potentially harmful because they may see it as a license to engage in premarital sex" (Pollitt 2005).

Finally, as we have seen, the RR strictures against abortion, as shown by the proposed legislation in South Dakota and elsewhere, are even more absolute than those of the Catholic Church, forbidding abortion even to save a woman's life.[20]

Nothing could show more clearly that pursuing its harsh and narrow sexual agenda is far more important to the RR than preventing unnecessary disease or death. It is thus evident that the CL is diametrically opposed to any public health ethic based on the harm principle. Indeed, despite its name, which might suggest concern about public morbidity and mortality, it is a devastating form of legal moralism that undermines the principles of public health. This state of affairs is even more evident in the international realm, as we will see shortly.

Some critics seem prepared to characterize these policies as merely "misguided." But it would require monumental stupidity to think that they are required by (or even consistent with) any tenable concern for life. More to the point, monumental stupidity alone cannot explain the RR's willingness to try to scare people into following its sex agenda by suppressing or twisting scientific evidence—what it calls "junk science" when others do it. Abstinence-only education, the disparagement of condoms, and insistence on a causal link between abortion and breast cancer are all evidence of its readiness to politicize science.[21] Why? Because it knows that the "moral" case it attempts to mount is unpersuasive because it cannot show the harm in alternatives to the CL sexual ethic. So science is hijacked to demonstrate harm after all. A strange approach to ethics from groups who question whether atheists could be citizens, or who, indeed, have no problem announcing that they will all burn eternally in hell.

The RR has no qualms about attempting to impose this nightmare of an ethic on all US citizens. It is also trying to impose it on the entire human population.

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[20] The Principle of Double Effect allows for abortions where the goal is to save the pregnant woman's life when the death of the fetus is a foreseen but not intended consequence. See also Susan Nicholson (1978) for a brilliant critique of its rules.

[21] UCS 2004, 11. The report goes on to lay out many more instances of political manipulation of science (ibid., 11).

The International Scene

According to the RR, this biblically mandated control over life and death decisions (along with every other aspect of life) is not just about the US. On the contrary, it holds for the entire world. What steps have its members taken to pursue this goal? It colludes with the Bush administration to push for these policies wherever it can. It lobbies at the UN, and it makes common cause with like-minded allies in foreign countries. We have already seen what the aims are, although the means may differ; because of poverty and other factors, the consequences may be far worse.

Most Americans are probably already familiar with the so-called global gag rule that prohibits foreign nongovernmental organizations (NGOs) receiving US funding from the United States Fund for International Development (USAID) or the Department of State from either counseling women about abortion or providing abortions, even with their own money.[22] Although the US version of the gag rule was found constitutional, in a poorly reasoned case, *Rust v. Sullivan*, it was repealed by Bill Clinton. Unfortunately for the women and children of the rest of the world, George W. Bush reinstated it for them on the first day of his presidency. The message clearly is that foreign women do not deserve the same right to autonomous choices as American women[23]; or, perhaps, that restrictions on American women will be imposed once again, as soon as the climate is right.

Moreover, the consequences for foreign women in impoverished countries are likely to be even more severe than for American women. Many women live in conditions that are almost unimaginable for Western women, where sexual and reproductive services are a matter of life or death: in Afghanistan, for instance, pregnancy is a leading cause of death, and one of every six women will die from it (Page 2006, 121). The statistics in every sector are horrifying, including the rapid spread of HIV/AIDS, especially in women.

Clinics offering family planning services of all sorts had to decide whether to accept these restrictions, putting their clients seriously at risk, or to refuse, significantly reducing the funds available for all services (including contraceptive services).[24] In the first case, their clients will not hear about the importance of getting safe, legal abortions rather than unsafe, illegal ones. Nor will they get information about

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[22] Chamberlain (2007) and International Women's Health Coalition. Indeed, this report reminds us that the prohibitions go much further: "[A]dditionally, the groups cannot engage in any public debate or disseminate any information regarding the health hazards of unsafe abortion, express support for any existing laws that support safe abortion, or provide legal abortion services with non-US funding."

[23] See Kaplan (2006) and *New York Times* (2003) "The War Against Women."

[24] According to Mary-Ann Stephenson, this policy has forced some clinics to close, cut services, or increase fees: "[S]hipments of US condoms and contraceptives have ceased to 16 developing countries. Family planning organizations in another 16 countries have lost access to condoms because they have refused to accept the restrictions" ("It Will Take All Our Energy to Stand Still: Bush's America is waging a global battle against women's rights," *The Guardian*, March 8, 2005; http://www.guardian.co.uk/comment/story/0,,1432589,00.html, accessed March 22, 2007.

whether abortion would be in their best interest or not, or even whether it is necessary to safeguard their health, and their life. In the second case, they are less likely to get help with the contraception or protection from STDs. Since HIV/AIDS is spreading quickly in many Third World countries, and women, for both physical and social reasons, are now most at risk, this policy is obviously at odds with the stated goals of the CL.

The Bush administration has also refused to contribute to the United Nations Population Fund (UNFPA). UNFPA does not support abortions, despite the allegation by an antifamily planning group that it has helped China advance its coerced abortion and sterilization program, allegations that have been demonstrated to be false.[25] What UNFPA does is provide "safe motherhood services, contraceptives, fistula repair, and HIV/AIDS prevention to women in 140 developing countries worldwide" ("Bush's Other War"). Failing to fund these items obviously increases deaths from a wide variety of causes.

In a related move, the Bush administration also now requires the NGOs (both US and foreign) it funds to show in a variety of ways that they oppose prostitution, even where those actions undermine the goal of limiting the spread of HIV.[26] Moreover, Bush's overall response to the needed (and desired) attempt to limit HIV worldwide, the President's Emergency Plan for AIDS Relief (PEPFAR) has become more of a vehicle for spreading the RR sexual and reproductive agenda, than for spreading protection from HIV. It emphasizes ABC—abstinence, be faithful, and condoms—with the condoms a distant third; one-third of HIV money must be spent on abstinence-until-marriage education (PEPFAR 2007). Because of this, rates of HIV are now going up in Uganda, whereas in countries like Cambodia where condoms are everywhere, they are going down (Kristoff 2007). This policy puts women especially at risk in a variety of ways, but most notably when they marry and their husbands either already have HIV/AIDS or are unfaithful.

These examples of exporting the CL, while just the tip of the iceberg, should be sufficient to show that RR activities are, if anything, even more harmful beyond our borders than within them.

Conclusion

So, is there a morally irresistible CL? Its theoretical basis is, at best, dubious. And, the plausibility of its principles is undermined by their collapse in the face of competing economic interests, and by the incompatible sex agenda now being sold as integral to it. An informed and critically inclined public would have no trouble rejecting this house of cards. Instead, the citizens are deeply divided about these issues.

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[25] For a full account of this story, see Page 2006, chap. 6, Pro-Lifers Abroad.

[26] "Bush's Other War." This useful document lists many other steps taken by the Bush administration to limit women's sexual and reproductive freedom, both in the international and national realms.

Only some form of liberalism that includes church/state separation can accommodate such diversity, leaving room for people to make their own judgments about the basis of morality, economic justice, and sexual ethics.[27] Only liberalism can make space for pointing out the hypocrisy of a movement that pretends to protect life, while attempting to suppress sex, conveniently deflecting attention from the deadly economic policies it condones.

Liberalism encourages individuals (and groups) to develop their own preferred ways of life, which might include preferences about how others should live—even in realms where no one is harmed. But although liberal principles support debate and discussion about such issues, they do not support political activity intended to deprive others of comparable choices about their own way of life. They do support a public health ethic based on good science and the harm principle.

How would a liberal society with a public health ethic based on the harm principle deal with the two cases I started out with? For the girl pregnant with the anencephalic fetus, her physical and emotional well-being is clearly more threatened by forcing her to go through with the pregnancy. Carrying a pregnancy to term is riskier to her health than an early second-trimester abortion. And, abortion would clearly be better for her mental health, not to mention far more humane, than forcing her to go through with the pregnancy only to watch her child die. The same goes for the woman with the ectopic pregnancy: her life can be secured by ending a pregnancy that cannot produce a child anyway. Putting her life at risk because of an arbitrary distinction between killing and letting die is morally untenable. In such cases, because of the constraints of biology, the CL savages women's lives to protect even doomed embryos or fetuses. It is hideously insensitive to the values most people hold, values that can be better justified than the inconsistent, cruel, and rigid values promoted by the CL.

This state of affairs makes it transparently clear that killing is not always the greatest evil, contrary to what the RR proposes. Liberalism leaves room for those who voluntarily adopt such a scheme to do so, but it also enjoins the RR against imposing it on those who do not.

These judgments get much more complicated beyond US borders, of course, since other countries may themselves have governments that fail to recognize the liberal principles that provide autonomy in such cases. In fact, both these cases are drawn from other countries (Ireland and El Salvador). But if the RR has its way, they will happen in the US too.

Yet if we appreciate the freedom liberalism bestows on us, then universalizability justifies—and requires—that we support it for all. Thus even if foreign governments fail in this respect, it is reasonable to take some steps to help those who are harmed by this failure to gain their voices. The extent of such steps is naturally a matter for debate, and will vary according to the circumstances. But such activity is politically

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[27] This liberal regime must ultimately be based on the harm principle. Many issues remain, of course, starting with the extent to which parents can restrict children's access to sex education. See Purdy, 1992 for an argument that children's rights to education trump parental views.

justifiable, whereas the current push by the RR is questionable. Given the consequences of that push, one might well hold that it deprives foreigners of rights members of the RR take for granted for themselves. Moreover, it constitutes (at best) criminal negligence or (at worst), murder. No doubt some who support the CL are incapable of appreciating these points. However, they are so obvious to anybody who thinks critically that it is hard to resist the conclusion that the RR is simply consolidating its own power, using the CL to cynically manipulate those who cannot think straight about its claims. Nothing short of life in *The Handmaid's Tale* (Atwood 1998) will satisfy it.

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Part II
Money and Poverty

International Health Inequalities and Global Justice*

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Abstract When are international inequalities in health unjust? This discussion falls short of providing an answer because we remain unclear just what kinds of obligations states and international institutions and rule-making bodies have regarding health inequalities across countries. To arrive at a real answer, we must carry out the task of explaining the substance of international obligations for the various kinds of cooperative schemes, international agencies, and international rule-making bodies in order to specify when the internationally socially controllable factors affecting health are justly distributed and regulated.

Keywords Global health care, distributive justice, Rawls, human rights, international property rights

Introduction

Disturbing international inequalities in health abound. Life expectancy in Swaziland is half that in Japan.[1] A child unfortunate enough to be born in Angola has 73 times as great a chance of dying before age five as a child born in Norway.[2] A mother giving birth in southern sub-Saharan Africa has a 100 times as great a chance of dying from her labor as one birthing in an industrialized country.[3] For every mile one travels outward toward the Maryland suburbs from downtown Washington DC on its underground rail system, life expectancy rises by a year—reflecting the race and class inequities in American health.[4] Are the glaring, even larger, international health inequalities also unjust?

All of us no doubt think these inequalities are grossly unfortunate. Many of us think they are unfair or unjust. Why should some people be at such a health

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* This essays relies upon material presented in Daniels (2008).

[1] 40 vs. 80+ years. http://www.os-connect.com/pop/p1.asp?whichpage=10&pagesize=20&sort=Country

[2] http://www.unicef.org/sowc00/stat2.htm, accessed August 23, 2005

[3] WHO/UNICEF/UNFPA, http://www.childinfo.org/eddb/mat_mortal/

[4] Michael Marmot, presentation at Harvard School of Public Health, 2006.

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disadvantage through no fault of their own, losers in a natural and social lottery assigning them birth in an unhealthy place? Others among us are troubled by the absence of the kinds of human relationships that ordinarily give rise to the claims of egalitarian justice that we make on each other—for example, being fellow citizens or even interacting in a cooperative scheme. Who has obligations of justice to reduce these international inequalities? And do those obligations hold regardless of how the inequalities came about? What institutions are accountable for addressing them?

When are International Inequalities in Health Unjust?

Health inequalities between social groups count as unjust or unfair when they result from an unjust distribution of the socially controllable factors that affect population health and its distribution (Daniels et al. 1999; Daniels 2008). It is possible to use Rawls' account of justice as fairness to give content to what an ideally just distribution of the socially controllable factors would be. Specifically, Rawls' (1971) principles of justice as fairness assure equal basic liberties and the worth of political participation rights; assure fair equality of opportunity through public education, early childhood supports, and appropriate public health and medical services; and constrain socioeconomic inequalities in ways that make the worst-off groups as well off as possible. Together, this distribution of the key determinants of population health would significantly flatten the socioeconomic gradient of health and would minimize various inequities in health, including race and gender inequities.

Judged from this ideal perspective, there are indeed many health inequities—by race and ethnicity, by class and caste, and by gender—in many countries around the world, both developed and developing. At the same time, not all health inequalities between social groups count as inequities. For example, the health inequality that results when a religious or ethnic group achieves better health outcomes than other demographic groups because of special dietary or restrictive sexual practices would not count as an inequity if appropriate health education were available to the other groups.

This account, however, only tells us when health inequalities between groups in a given society are unjust, not when inequalities between different societies are. It tells us what we as fellow citizens owe each other regarding the promotion and protection of health, but not what other societies owe, if anything, by way of improving the health of the population in less healthy societies. The account, for example, fails to address this issue: suppose countries A and B each do the best they can to distribute the socially controllable factors affecting health fairly, and, as a result, there are no subgroup inequities within them. Nevertheless, health outcomes are unequal between A and B because A has more resources to devote to population health than B. Is the resulting international inequality in health a matter of justice? Suppose we vary the case: Now B, whether or not it has resources comparable to A, fails to protect its population health as best it can, leading again to population health worse than A's. Is the resulting health inequality a matter of international justice? The Rawlsian account of justice and health informs us about intra-societal obligations to eliminate health inequities, but it is silent about important questions of international justice.

Recasting the problem as an issue of human rights, specifically a human right to health and health care,[5] does not help us answer these questions about international justice for two reasons. First, the international legal obligation to secure a human right to health for a population falls primarily on each state for its own population. Although international human rights agreements and proclamations also posit international obligations to assist other states in realizing human rights (CESCR 2000), the international obligations cannot become primary in the human right to health and health care. External forces cannot assure population health across national boundaries in the way they might intervene to prevent the violation of some other rights, even when they can afford some assistance. The primacy of domestic responsibility arises because assuring a right to “the highest attainable level of physical and mental health” requires securing a broad cluster of rights that impact on health by establishing legal structures and other institutions that properly distribute the socially controllable factors affecting health.

Second, even when a right to health is secured to the degree it is possible to do so in different states, health inequalities between them may still exist. Since conditions do not always permit everything to be done to secure a right in one country that may be feasible in another, the right to health and health care is viewed as “progressively realizable.” Reasonable people may disagree about how to best satisfy this right, given the trade-offs priority setting in health involves (Daniels 2008, Ch. 12). Consequently some inequalities may fall within the range of reasonable efforts at progressive realization of a right to health. In addition, because of their unequal resources, different states may achieve unequal health outcomes while still securing a right to health and health care for their populations. Arguments that depend on appeals to human rights cannot tell us whether these inequalities are unjust and remain silent on what obligations better-off states have to address these inequalities.

Though nearly all people recognize some international humanitarian obligations of individuals and states to assist those facing disease and premature death, wherever they are, there is substantial philosophical disagreement, even among egalitarian liberals, about whether there are also international obligations of *justice* to reduce these inequalities and to better protect the rights to health of those whose societies fail to protect them as much as they might. Nagel (2005), who affirms these humanitarian obligations, argues that socioeconomic justice, which presumably includes the just distribution of health, applies only when people stand in the specific relation to each other that is characterized by a state. Specifically, concerns about equality are raised within states by the dual nature of individuals both as

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[5] The right is affirmed inter alia, in article 25, paragraph 1, of the Universal Declaration of Human Rights, article 12 of the International Covenant on Economic, Social and Cultural Rights and article 24 of the Convention on the Rights of the Child. See http://www.unhchr.ch/Huridocda/Huridoca.nsf/TestFrame/267fa9369338eca7c1256d1e0036a014?Opendocument, accessed August 23, 2005.

coerced subjects and as agents in whose name coercive laws are made. Rawls (1999) also did not include international obligations to assure a right to health on the list of human rights that liberal and decent societies have international obligations of justice to protect.

This "statist" view encounters a strong counter-intuition. Remember the child who is so much more likely to die before age five in Angola than the one in Norway, or the sub-Saharan African mother who is 100 times more likely to die in childbirth than one in any industrialized country. Many of us think there is something not just unfortunate and deserving of humanitarian assistance, but something unfair about the gross inequality.

Those who claim the gross health inequalities are unjust have quite different, incompatible ways of justifying that view. For example, those who believe that any disadvantage that people suffer through no fault or choice of their own is unjust would assert that the disadvantage facing the Angolan child is therefore unjust. The underlying principle of justice is applied to individuals wherever they are in the cosmos and regardless of what specific relationships they stand in to others—contrary to the Rawls–Nagel account, which applies principles of justice to the basic structure of a shared society. The disadvantage of the Angolan child might also be thought unjust by those who, like Rawls or Nagel, think principles of justice are "relational" and apply only to a basic social structure that people share, but who, unlike Rawls or Nagel, believe we already live in a world where international agencies and rule-making bodies constitute a robust global basic structure that is appropriately seen as the subject of international justice developed perhaps through a social contract involving representatives of relevant groups globally (Beitz 1979, 2000). Fair terms of cooperation involving that structure would, some argue, reject arrangements that failed to make children in low-income countries as well off as they could be. Clearly, there may be more agreement about some specific judgments of injustice than there is on the justification for those judgments or on broader theoretical issues.

I shall briefly examine two ways of trying to break the stalemate between statist and cosmopolitan perspectives. One approach aims for a minimalist (albeit cosmopolitan) strategy that focuses on an international obligation of justice to avoid "harming" people by causing "deficits" in the satisfaction of their human rights (Pogge 2002, 2005b). It is a minimalist view in the sense that people may agree on negative duties not to harm even if they disagree about positive duties to aid. This approach handles some international health issues better than others, and to identify its limitations more clearly, I shall distinguish various sources of international health inequalities, some of which are not addressed by negative duties. A more promising (relational justice) approach, which I can only briefly illustrate, requires that we work out a more intermediary conception of justice appropriate to evolving international institutions and rule-making bodies, leaving it open just how central issues of equality would be in such a context (Cohen and Sable 2006). Properly developed, such an approach may address more of the sources of international health inequalities.

Harms to Health: A Minimalist Strategy

If wealthy countries engage in a practice or policy—or impose an institutional order—that foreseeably makes the health of those in poorer countries worse than it would otherwise be, specifically, making it harder than it would otherwise be to realize a human right to health or health care, then, Pogge (2005b) argues, it is harming that population by creating this "deficit" in human rights. Since this harm is defined relative to an internationally recognized standard of justice, the protection of human rights, Pogge concludes that imposing the harm is unjust. Moreover, if there is a foreseeable alternative institutional order that would reasonably avoid the deficit in human rights, there is an international obligation of justice to produce the rights-promoting alternative.

There remains some lack of clarity about how the baseline against which harm is measured is specified. When is there a "deficit" in a human right to health? Whenever a country fails to meet the levels of health provided, say, by Japan, which has the highest life expectancy? Or when it fails to meet whatever level of health a health-optimizing international order might achieve? Or is there some other, unspecified standard? Consider two examples.

The Brain Drain of Health Personnel

The brain drain of health personnel from low-income to Organisation for Economic Co-operation and Development (OECD) countries may most clearly exemplify Pogge's concerns. Rich countries have harmed health in poorer ones by solving their own labor shortages of trained health care personnel by actively and passively attracting immigrants from poorer countries. In developed countries such as New Zealand, the United Kingdom, the United States, Australia, and Canada, 23–34% of physicians are foreign-trained. In 2002, National Health Service (NHS) in the United Kingdom reported that 30,000 nurses, some 8.4% of all nurses, were foreign-trained.

The situation that results in developing countries is dire. Over 60% of doctors trained in Ghana in the 1980s emigrated overseas (WHO 2004). In 2002 in Ghana 47% of doctors' posts were unfilled and 57% of registered nursing positions were unfilled. Some 7,000 expatriate South African nurses work in OECD countries, while there are 32,000 nursing vacancies in the public sector in South Africa (Alkire and Chen 2004). Whereas there are 188 physicians per 100,000 population in the United States, there are only 1 or 2 per 100,000 in large parts of Africa. The brain drain does not cause the entire inequality in health workers, but it significantly contributes to it.

International efforts to reduce poverty, lower mortality rates, and treat HIV/AIDS patients—the Millennium Development Goals (MDG) agreed upon in 2000—are all threatened by the loss of health personnel in sub-Saharan Africa. An editorial in the *Bulletin of WHO* points out that the MDG goals of reducing mortality rates for infants, mothers, and children under five cannot be achieved without a million additional skilled health workers in the region (Chen and

Hanvoravongchai 2005). The global effort to scale up antiretroviral treatments (ARTs) poses a grave threat to fragile health systems, for its influx of funds—hardly a bad thing in itself—may drain skilled personnel away from primary care systems that already are greatly understaffed.

What about causes? There is both a "push" from poor working conditions and opportunities in low-income countries and a "pull" from more attractive conditions elsewhere. Is this simply "the market" at work, backed by a "right to migrate?"

Pogge's argument about an international institutional order has more specific grip than the vague appeal to a market. When economic conditions worsened in various developing countries in the 1980s, international lenders, such as the World Bank and International Monetary Fund (IMF), insisted that countries severely cut back publicly funded health systems as well as take other steps to reduce deficit spending. In Cameroon, for example, in the 1990s, measures included a suspension of health worker recruitment, mandatory retirement at 50 or 55 years, suspension of promotions, and reduction of benefits. The health sector budget shrank from 4.8% in 1993 to 2.4% in 1999, even while the private health sector grew (Liese et al. 2004). As a result, public sector health workers migrated to the private sector and others joined the international brain drain. Cost cutting imposed on the country led to cuts in the training of health workers, increasing the shortage. The international institutional order thus increased the push and at the same time harmed the health system in various ways.

The pull attracting health workers to OECD countries is also not just diffuse economic demand. Targeted recruiting by developed countries is so intensive that it has stripped whole nursing classes away from some universities in the South. In 2000, the Labor Government in the United Kingdom set a target of adding 20,000 nurses to the NHS by 2004. It achieved the goal by 2002. The United Kingdom absorbed 13,000 foreign nurses and 4,000 doctors in 2002 alone. Recruitment from EU countries was flat (many of these countries also face shortages in face of aging populations), but immigration from developing countries continued, despite an effort to frame a policy of ethical recruitment (Deeming 2004). Arguably, even if there were a diffuse economic pull, in the absence of active recruiting the harm would be much less.

The remedy for this harm is not a prohibition on migration, which is protected by various human rights. The United Kingdom has recently announced a tougher code to restrict recruitment from 150 developing countries. In addition it has initiated a US$100 million contribution to the Malawi health system aimed at creating better conditions for retaining health personnel there. The United Kingdom has thus taken two steps that are intended to reduce both the push and the pull behind the brain drain. Other countries have not followed suit.

International Property Rights and Access to Drugs

The minimalist strategy becomes harder to apply in a clear way to other international health issues. The problem of international property rights and the incentives they create goes beyond the issue of access to existing drugs, such as the antiretroviral cocktails that were the focus of attention in recent years.[6] Big Pharma has long been criticized for a research and development bias against drugs needed in developing country markets. Indeed, it has responded to existing incentives by concentrating on "blockbuster" drugs for wealthier markets, including many "me too" drugs that marginally improve effectiveness or reduce side effects slightly. Funding the research needed to develop a vaccine against malaria, for example, has fallen to private foundations.

Do intellectual property rights and the incentive structures they support create a foreseeable deficit in the right to health that can be reasonably avoided? Pogge (2005b) argues that they do. Nevertheless, many drugs developed by Big Pharma under existing property right protections have filtered into widespread use as generics on "essential drug" formularies in developing countries. Health outcomes in those countries are much better than they would be absent such drugs. Since many of these drugs would not have been produced in the absence of some form of property right protections, people are not worse off than they would be in a completely free market with no temporary monopolies on products.

Arguably, however, different property right protections and different incentive schemes would make people in these poor countries with poor markets better off than they currently are. Which schemes ought we to select? Pogge (2005a) proposes that we revise incentives for drug development by establishing a tax-based fund in developed countries that would reward drug companies in proportion to the impact of their products on the global burden of disease. For example, drugs that meet needs in poor countries with very high burdens of disease would yield greater payment to drug companies, even if the drugs are disseminated at a cost close to the marginal cost of production. The tax, he admits, would be hard to establish, but it would be offset in rich countries by lower drug prices. The program could be limited to "essential drugs" leaving existing incentives in place for other drug products. Even so, the tax and thus the incentives could vary considerably, presumably with consequences of different magnitude for the global burden of disease. How do we pick which alternative to use as a baseline against which a "deficit" in the right to health is specified? Pogge does not tell us.

Leaving aside the problem of vagueness, Pogge's proposal cannot be justified by appealing to the "no harm" principle alone. The proposed incentive fund would better help to realize human rights to health, as Pogge argues, but "not optimally helping" is not the same as "harming," and so the justification has shifted. (Labeling the outcome of optimally helping as a human right and a deficit from that right a harm equivocates on the standard meaning of "harm.") There may well be good reasons for an account of international justice to consider the interests of those affected by current property right protections more carefully than those

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[6] Patent holders on antiretroviral drugs led a fight, until recently, to restrict access to generic versions of their drugs. The consequence was a direct harm to those who might have benefited from antiretrovirals and died instead. Still, the emergence of these generics that do save other lives would not have happened had there not been the incentives created by the existing patent system—or so the dominant view about intellectual property maintains.

agreements now do—but that takes us into more contested terrain than the minimalist strategy.

International harming is complex in several ways. The harms are often not deliberately imposed, and sometimes benefits were arguably intended. The harms are often mixed with benefits. In any case, great care must be taken to describe the baseline against which harm is measured. Such a complex story about motivations, intentions, and effects might seem to weaken the straightforward appeal of the minimalist strategy, but the complexity does not undermine the view that we have obligations of justice to avoid harming health.

Where Do International Health Inequalities Come From?

Pogge (2005a) emphasizes the fact that 18 million premature, preventable deaths are associated with global poverty. It is tempting, then, to infer that country wealth determines population health and that if rich countries help to keep poor countries poor, they thus harm the health of those populations. If this inference is sound, it gives the minimalist strategy considerable power in addressing international health inequalities. Unfortunately, the inference is not sound, since the relationship between country wealth and country health is more complex than the inference presupposes. We need to examine the sources of international health inequalities more systematically.

We can divide the sources of international health inequalities[7] into three categories:

1. Those that result from domestic injustice in the distribution of the socially controllable factors determining population health and its distribution. Included here would be inequalities by race, caste, ethnicity, religion, gender, or geography in the distribution of the determinants of health. Also included are failure to fund adequately (relative to capacity) the health sector, including intersectoral public health measures, immunizations, and comprehensive community-based primary care; and misallocation of resources, for example, diverting funds from public health and primary care to hospital care serving best-off groups in response to their demand and greater political power.
2. Those that result from international inequalities in other conditions that affect health. These include inequalities in natural conditions, such as poor natural resources, including scarcity of arable land; or susceptibility to droughts and floods; or disease vectors, such as mosquitoes carrying malaria or dengue. They also include socially produced inequalities, such as significant inequalities in capital, in human capital, and in political culture.

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[7] Not all international health inequalities plausibly raise questions about injustice, just as not all domestic inequalities between groups raise those questions. For example, religious or ethnic differences in lifestyle (diet, sex, or social cohesiveness) might give rise domestically and internationally to health inequalities that we would not consider unjust.

3. Those that result from international practices—institutions, rule-making bodies, and treaties—that harm the health of some countries. The harms can be direct, as in the case of the brain drain of health workers, or more indirect, as in failures to build worker health and safety protections into international trade agreements, or through international loans or other means that may perpetuate poverty.

These sources of inequality are not exclusive. Some international practices (category three) may help create the social inequalities in the second category that in turn increase health inequalities; they may also make it more difficult for states to distribute the determinants of health in a just way (category one). Some of the inequalities in the second category may also contribute to the injustices of the first. The minimalist strategy would have great scope if category three sources dominated categories one and two, but this seems unlikely. Only more robust accounts of international justice can address the broader sources of inequality.

To see why the kinds of inequalities referred to in the second category cannot exhaust the problem of international inequalities in health, consider how much health inequality across countries is simply the result of wealth inequalities. Even if we do not believe that all international inequalities in wealth are unjust, we might believe some are, and if wealth inequalities then cause health inequalities, we would have reason to judge the resulting health inequality unjust in at least some cases. Indeed, if wealthy countries harm poor ones by sustaining their poverty through various international practices, and if poverty clearly causes poor national health outcomes, then the minimalist strategy may cover a significant part of the terrain of health inequality. Indeed, the wealth of a country has an effect on aggregate measures of health, at least up to some fairly moderate level of aggregate wealth, say $6–8,000 gross domestic product per capita (GDPPC). Above that level, there is little influence of aggregate wealth on aggregate health. This may be some evidence that international inequalities in wealth have some contribution to international health inequalities, and to the extent that wealthy countries cause or sustain that inequality, the minimalist strategy obtains a grip on the problem.

But even more striking than the fact that great wealth is not needed to secure high levels of population health is the amount of variation in life expectancy both above and below that middle-income figure. Some poor countries, with GDPPC less than $3,000, such as Cuba, or the even poorer state of Kerala in southern India (which has lower income per capita than the average in India), have health outcomes rivaling those achieved in wealthy ones. Among the wealthiest countries, there are also significant differences in life expectancy.

From these facts, we see that policy matters greatly: what is done with national resources explains much of the wide variation across countries that are equally rich or equally poor. Cuba invests great effort in public health, including ecologically sound environmental policies, as well as in basic education. It invests heavily in training health personnel (its doctor per population ratio is comparable to the United States), and it sends doctors abroad to worse-off countries. Indeed, it does so despite US economic and travel sanctions intended to undermine its government by inflicting economic harm.

Cuba's success in health outcomes despite the harms imposed by the United States does not show that other international practices play no causal role in producing poor health outcomes elsewhere. But the Cuban example shows how hard it is to specify the baseline against which harm is to be measured. The minimalist strategy supposes that international practices that make a country poorer than it would otherwise have been would thereby make it less healthy than it would otherwise be. But international practices may make a country poorer than it would otherwise be, but determined public policy may nevertheless result in much better health outcomes than is typical for countries with those levels of poverty. The harm to health can be specified only by assuming that no good health policy is put in place—but why that assumption holds when it does may have nothing to do with the economic harm.

Kerala, like Cuba, also invests heavily in basic education, securing high literacy rates even for poor women, as well as in public health and primary care. The positive treatment of women stands out as a contrast with practices in many other areas of India and South Asia in general. In the case of Kerala, it is popularly believed that the lack of gender bias in education and in reproductive and marriage rights is the result of a left-wing state government, but the story is more complex. Kerala, in contrast to the rest of India, had a history of matrilineal property transmission for 2,000 years. As a result, women could not be discounted as in many other states of India. Its cultural tradition was a base on which a more egalitarian social policy could take root. Given a culture in which women retain significant autonomy and power, both within and outside the home, more egalitarian education and control over reproduction are realistic social goals, and both contribute significantly to population health. Though Kerala, unlike Cuba, was not the victim of focused antagonism, its superior health outcomes were achieved despite a long period of slow economic growth. To the extent that the slow growth resulted from a lack of foreign investment prompted by fears of its left-wing government, we have an even stronger counterexample to the assumption that externally caused economic harm produces lower health outcomes.

Domestic social policy and social history matter in wealthy countries also. Many industrialized countries have better aggregate health outcomes than the United States, despite the 50% higher US health care spending than nearly any other country. To a significant degree, the better outcomes result from health-promoting policies: universal health care coverage, more robust protections against poverty and unemployment, better child care, more leisure, and better enforcement of workplace health and safety. Some of the outcome difference is a result of much more diverse US population, both ethnically (and racially) and geographically. The social inequalities that are often associated with such diversity contribute to the lower aggregate health outcomes in the United States, though it would be hard to quantify just how much. Better policy, as in the other industrialized countries, might mitigate these effects, but again, we cannot say how much.

One key factor contributing to poorer US health outcomes than other wealthy countries is the history of US racism, legally supported in the American South until 40 years ago. Racism played an important role in dividing the working classes so they could not pursue common interests, as workers' movements did politically in Europe. This background not only partly explains the absence of more egalitarian and health-promoting public policies, but it also explains some of the ongoing inequalities that better policies might not by themselves be able to eliminate (Kawachi et al. 2005). Even in a wealthy country, then, cultural practices that produce health inequalities both inside and outside the health system contribute to international health inequalities. One reason the United States performs less well on standard aggregate measures of health than most other industrialized countries is its homegrown production of race (and class) health disparities.

Gender bias in other regions contributes to international health inequalities the way racism has in the United States. We can attribute much of the higher prevalence of HIV/AIDS among young women and girls in sub-Saharan Africa to the health impact of cultural and legal policies that disempower women. The example of race in the United States and gender inequality in Africa and Asia illustrate one reason that category two and category three sources of health inequality cannot cover the terrain of international health inequalities. These domestic practices arise independently of the level of country wealth and of international agreements, institutions, or practices that may in other ways contribute to health inequalities.

Of course, racism and gender bias do not exhaust the ways in which domestic injustice can contribute to international health inequalities. Internal demands on relatively scarce resources by politically and economically more powerful, better-off groups may distort policy in ways that leave worse-off groups more vulnerable to health risks and less able to access remedies for those risks. Wealthy landowners and industrialists may have so much political power that they can resist efforts to tax them, leading to underfunded public health systems. Domestic injustice in the distribution of the determinants of health contributes significantly to international inequalities in health, and it is unlikely that we can explain away all domestic responsibility for the injustice by pointing to the additional contributions of some international practices.

In short, good health policy in even poor countries can yield excellent population health, and poor health policy even in wealthy countries, like the United States, can produce worse-than-expected performance. Together these observations count as some evidence in favor of a point that many agree on regardless of other disagreements about international obligations: Primary responsibility for meeting rights to health and health care in a population should rest with each state. The fact that some poor states can and do produce excellent population health makes this point dramatically.[8]

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[8] In *The Law of Peoples*, Rawls (1999) makes the claim that international inequality in wealth or income is quite compatible with well-ordered societies producing justice for their populations. He argues that if two well-ordered societies make different decisions about population policy, with the result that one becomes wealthier than the other over time, then the wealthier one should not have to make transfers to the other in accordance with some international "difference principle" aimed at making the worst off as well off as possible. Arguably, an analogous point holds for health policy and health inequalities.

Even if primary responsibility for population health rests with each state, that does not mean the state has sole responsibility. Where we can explain why states cannot do as well as others because of being harmed by international practices, the minimalist strategy applies. Where other international inequalities are important, but they cannot be attributed to international practices, there may still be room for other considerations of global justice.

Do international health inequalities that clearly result from domestic injustice constitute international injustice? Are other states or individuals in them obliged to try to reduce them as a matter of justice? For example, if the US population does worse than Norway's solely because of American domestic injustice, not attributable to category two or three sources, does that mean there is no issue for international justice? That conclusion would seem to ignore the fact that victims of domestic injustice are still victims of injustice—at a disadvantage through no fault of their own. Does the obligation to improve their lot fall only on the local state?

What about international health inequalities that clearly result from category two international inequalities and are not the result of category three practices? Suppose, for example, that country A is wealthier and healthier than country B. Nevertheless, B is well governed and arguably "progressively realizes" a right to health for its population as best it can within its resource limits. Perhaps this captures the difference between Norway or Japan and Cuba or Kerala (imagine Kerala is a country of 30 million people, not an Indian state). Is the resulting international health inequality unjust?

Because there are significant international health inequalities that are not plausibly addressed by the minimalist strategy, we must take on more robust approaches to international justice if we think they are unjust, or we must concede that these inequalities are not, after all, matters of justice.

The New Terrain of Global Justice: Where the Action Is

Global justice is a hotly disputed area of philosophical work, in part because it is so new. Not only are the complex economic and social forces underlying globalization themselves fairly recent developments, but the international agreements, institutions, and rule-making bodies that regulate those forces are just emerging and evolving, forming a moving target for our understanding. Their powers and effects are newly grasped and felt, and moral understanding of their consequences and their potential is in its infancy. Working out what international justice means for these international institutions, including what it means for global health, is the crucial task facing political philosophy and international politics in the next generation. The process will involve working back and forth between judgments, based on arguments and evidence, about what is just in particular practices or decisions of the operation of international agencies or rule-makers and more theoretical considerations. We need time for reflective equilibrium to do its work. To motivate exploring this intermediary ground, we need good reason to resist the pulls of both the cosmopolitan views and the strongly statist views that form the poles of the current debate.

Resisting the Pull of the Cosmopolitan Intuition

Earlier, I invoked the powerful intuition that the vast gulf in life prospects between the Angolan child and the Norwegian one is not just unfortunate but unfair. Many people think such dramatic health inequalities are unjust when they occur between the rich and the poor or between ethnic or racial groups within a country because morally arbitrary contingencies, such as the luck of being born into one group rather than another, should not determine life prospects in such a fundamental way. The same contingency, however, applies to being born Angolan rather than Norwegian, and it seems no less morally arbitrary and troubling. By abstracting from all relations that might hold among people, including the institutions through which they interact and can make claims on each other, the intuition seems to support egalitarian forms of cosmopolitanism.

The support the egalitarian intuition appears to give to cosmopolitanism derives in part from theoretical considerations that carry weight in many ethical theories, including nonegalitarian ones. A feature of many ethical theories is that persons or moral agents deserve equal respect or concern regardless of certain contingent differences between them. Equal concern or respect is, of course, a notion that is interpreted quite differently by utilitarians, who count each person equally as a locus of welfare even if they do not assure equal outcomes for each person, and many egalitarians, who want some kind of equality of opportunity or outcomes. Whatever the differences in the content of equal respect, there is considerable theoretical agreement on what counts as the contingent or morally arbitrary differences that equal respect must ignore: mere physical distance, the color of skin, religion, gender, and ethnicity. Nationality seems to be part of the same family. The egalitarian intuition about the Angolan and Norwegian children thus draws power from the broader theoretical agreement about what generally counts as a mere contingency and therefore a morally arbitrary difference between moral agents.

The agreement about what counts as contingency and morally arbitrary difference, however, slides past a significant point of controversy. If we think of nationality as one among many traits an individual may have, it seems no less contingent than other troublesome ones, like race. In the relevant sense of “could,” we could have been born into one race or another, one nationality or another. But, if we think of nationality as a set of relationships in which one stands to others, and if we think that being in certain political relationships with others, including interacting through certain kinds of institutions, has moral import, then being a member of one nation rather than another may be a less morally arbitrary fact than it first seemed. Of course, showing that this political relationship has important moral implications, for example, for considerations of distributive justice, requires an argument, especially in light of the power of the view that ethical considerations apply to individuals in abstraction from these relationships. Indeed, the political view may seem plausible only in light of a theory that helps explain why this political relationship, or a range of other kinds of relationships, is so important. It would beg the question against a relational view, such as Rawls (1971, 1995), simply to affirm the intuition we have been discussing.

One of the strengths of a relational view such as Rawls' is that an account of the requirements of justice will have to include an explanation of how institutions that are just can remain stable and sustain commitment to them over time. Justice must be in this sense feasible. Indeed, principles of justice are not acceptable as such if conformance with them in a society's basic structure does not over time lead to a stable or feasible social arrangement. Strains of commitment, for example, must be tolerable, that is, less demanding than for alternatives.

By abstracting justice from any account of the institutions that can deliver just outcomes in a sustainable way, the cosmopolitan view risks falling into hand-wringing. It can lament injustice, but it has failed to set itself the task of showing that justice is a stable product of institutions structured in certain ways. Making justice a set of outcomes among individuals, abstracted from the institutional structure through which individuals cooperate, is utopian in a strong sense: we have no real description of what can produce it. Although the cosmopolitan may admit that institutions and political relationships are instrumentally important in achieving what justice requires in the treatment of individuals, just outcomes are specifiable independently of those institutions and relations. The basic structure of a nation-state, on this view, may be instrumentally necessary for achieving domestic justice, just as a global state may be instrumentally necessary for global justice. At any level, the institutions may be viewed as unjust if they fail to yield just outcomes for individuals. But cosmopolitan theory by design says nothing informative about how a commitment to justice can be sustained by any of these institutions. Nor does it allow for any variation in the concerns of justice that might be appropriate to institutions of different types.

Though none of these points constitutes a refutation of cosmopolitanism, they may move us to resist its pull and to consider seriously a relational view of justice. We then face the prospect of a pluralist world. Justice may be one thing for people who stand in the relations defined by nation-state and maybe another for those who are members of different states and interact through other kinds of institutions globally.[9] Principles of justice that govern nation-states might then differ from those that govern intermediary institutions among such states, and both may differ from what considerations of fairness might mean among individuals

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[9] Michael Blake (2002), for example, argues that liberal egalitarianism within nation-states raises questions about relative inequality, whereas global justice permits only considerations of absolute inequality.

in yet other associations. Justice, on this relational view, is a multilayered construction. Though we have well-developed relational accounts of justice for members of the same state (Rawls 1971, 1995), we have barely begun the process of thinking about what justice means or requires for international institutions and rule-making bodies.

Resisting Strongly Statist Versions of Relational Justice

An important obstacle to exploring this international space comes from one version of a relational theory of justice, a strongly statist alternative to cosmopolitanism. Nagel (2005), stimulated by Rawls' (1999) articulation of what a liberal state's foreign policy ought to include, argues that socioeconomic justice, with its concerns about equality of opportunity and economic inequality, requires that people stand in the specific relationship to each other as defined by a nation-state. Within such a state, socioeconomic justice has application because the terms of fair cooperation must be justifiable, that is acceptable, to all, since all citizens are at once subject to coercion and a party to laws made in their name. Outside the state, there is a moral order, but it is limited to more fundamental humanitarian obligations to assist those facing grave risks and having urgent needs; it must also not violate some fundamental human rights, and we must keep our agreements. We do not, however, have obligations of justice to distribute health fairly, or to protect equality of opportunity, or to assist other societies to become as well off as they can be with regard to the satisfaction of rights to health or education or political participation.

Why is it only within a state that we are obliged to mitigate or eliminate morally arbitrary inequalities and pursue social and economic justice? For Rawls, Nagel says, "What is objectionable is that we should be fellow participants in a collective enterprise of coercively imposed legal and political institutions that generates such arbitrary inequalities" (Nagel 2005, 128). We can ignore extra-societal inequalities but not intra-societal ones, despite the fact that both have great impact on people's lives, because there is "a special involvement of agency or the will that is inseparable from membership in a political society" (Nagel 2005, 128) and so cannot arise internationally. This will is essential to the "dual role each member plays both as one of society's subjects and as one of those in whose name its authority is exercised" (Nagel 2005, 128).

As subjects of a state, individuals are exposed to coercively imposed rules, in contrast to the constraints imposed by voluntary cooperative enterprises for mutual advantage. The coercively imposed rules are imposed in the name of all citizens, who are putatively the authors of the rules. Consequently, they must take responsibility as authors and insist on the justifiability of the rules to all involved. In this context the concern for arbitrary inequalities becomes a matter for all to address.

In contrast, Nagel argues, international institutions and rule-making bodies, such as the World Trade Organization (WTO), the World Health Organization (WHO), the World Bank (WB), or the International Monetary Fund (IMF), do not directly coerce individuals, as states do, nor do they make rules directly in the name of individuals. Where international rules or agreements are made, as in establishing the North American Free Trade Agreement (NAFTA), they are the result of voluntary agreements or bargains made by states and are not made in the name of citizens of those states. Since these two features are missing, Nagel concludes, the kind of engagement of the will that holds for citizens of states is missing from international institutions. Consequently, the condition that necessitates a justification of inequalities and a mitigation of morally arbitrary inequalities is missing. More specifically, whereas (to use his examples) Nagel's relation to the New Yorker who irons his shirts is a contract mediated by a complex configuration of laws defining contracts and property rights that forms a system of social justice, trade agreements within the Americas that establish his relations with the Brazilian who grows his coffee constitute much "thinner" agreements or "pure" contracts that pursue mutual self-interest at the state level. They contain no assurance that background conditions of justice are met and give rise to no obligations to make such assurances.

Nagel rejects the idea that we might work out a "sliding scale" of obligations that falls in between state-mediated justice and the cosmopolitan view, that is, in the space in which I am proposing we work out our obligations. He simply asserts that a "sliding standard of obligation is considerably less plausible than either the cosmopolitan … or the political … standard" (Nagel 2005:142). Since these international institutions "do not act in the name of all the individuals concerned, and are sustained by those individuals only through the agency of their respective governments or branches of those governments," they are missing "the characteristic [the engaged will] in virtue of which they create obligations of justice and presumptions in favor of equal consideration for all those individuals." Nagel's plausibility claim is question begging because it merely asserts that the statist and cosmopolitan views exhaust the plausible alternatives.

We should resist Nagel's strong statism for two reasons. First, some international institutions impose conditions in a manner that is coercive and that arguably involves the wills of those in the participant states. Second, some obligations of justice may arise in institutions that are not coercive. Cohen and Sable (2005, 29) address the first reason by noting that when the WTO sets certain standards, there is no way for citizens of a country to opt out of their application.

> Opting out is not a real option (the WTO is a "take it or leave it" arrangement, without even the formal option of picking and choosing the parts to comply with), and given that it is not—and that everyone knows that it is not—there is a direct rule-making relationship between the global bodies and the citizens of different states.

In effect, there is coercive application of rules, albeit by agencies not directly elected by the various citizenries. This mediated agency, however, is common within complex states and still involves rules made in the name of the citizens.

There is further evidence of the involvement of wills of citizens in various cases where there is disagreement with the rulings of an international body. For example, protestors, both individuals and organizations, including official international workers' organizations, have demonstrated against some free trade agreements that were signed onto by their own nations. The protest is against the rule-making body, not primarily their own governments for endorsing them. They argue that they resent being implicated, even through the agency of their governments, in a policy they disagree with, such as the failure to impose appropriate labor health and safety considerations or environmental considerations into trade agreements. In effect, these protestors of the WTO and other associations and agreements believe there is a need to justify the terms of the agreements to all affected by them. Similarly, many Americans are embarrassed that the George W. Bush administration has refused to be part of the World Court, has walked away from international treaties to address global warming, and has tried to exempt itself from the Geneva Conventions regarding the treatment of prisoners of war. They think the international agreements impose obligations appropriately "in their name," whereas their President's unilateralism shamefully rejects what they want to uphold.

Consequently, even if Nagel is right about the characteristic by virtue of which egalitarian considerations arise within states, that is, the dual role of citizen as both subject and author of coercive rules and thus the engagement of citizens' wills, he is arguably wrong about the *scope* of institutions within which we may find functionally equivalent conditions that have the same moral import. We find examples that include coercion and that arguably engage the wills of citizens—enough to make them advocate, protest, and appeal to these organizations to consider their claims. Even if Nagel is right about what makes this dual role morally relevant, then some egalitarian concerns may still be appropriate even outside the state.

We may also resist Nagel's strong statist position because obligations of justice can arise in international institutions even if they are not coercive and do not engage the will of citizens as subjects and authors in the way Nagel says is necessary. Cohen and Sable (2006) argue that considerations about inclusion, falling short of fully equal concern or egalitarianism but still within the domain of justice, arise within a range of international institutions. Concerns about inclusion have implications for governance. If worker organizations were suddenly excluded from participation in the International Labor Organization (ILO), that would be seen to violate important concerns about inclusion (Cohen and Sabel 2006). Similarly, if a policy enables better-off groups or states to advance their interests and leaves worst-off groups with little or no benefits, and if significantly better benefits could be gained by the worst-off groups at little sacrifice by others, then there has been inadequate inclusion of the interests of all in the deliberations of the institution (Cohen and Sabel 2006). Nagel is then wrong to insist that only humanitarian concerns apply internationally.

Illustrations of Obligations of Justice in International Organizations

Cohen and Sabel (2006, 153) sketch three types of international relationships that might give rise to obligations of justice going beyond humanitarian concerns, international agencies charged with distributing a specific good, cooperative schemes, and some kinds of interdependency. Each may give rise to obligations of justice, such as concerns about inclusion. These may range from an obligation to give more weight to the interests of those who are worse off if it can be done at little cost to others, to obligations of equal concern, perhaps yielding far more egalitarian obligations. I shall illustrate each of these relationships and the obligations they give rise to with examples focused on key issues of global health.

The WHO plausibly illustrates the idea that institutions charged with distributing a particular, important good, such as public health expertise and technology, must show equal concern in the distribution of that good. The organization would be charged with being unfair if it ignored the health of some and attended more to the health of others. For example, this point about showing equal concern arises in other debates about the methodologies WHO employs. Cost-effectiveness analysis (CEA), which WHO uses in suggesting interventions appropriate for resource-poor settings, ignores issues of equity in the distribution of health and health care. These criticisms of CEA thus challenge the unconstrained use of CEA by the WHO whether it is using the methodology to determine health policy within a specific country or across countries. WHO is constrained by its mission of improving world health to consider equity in distribution in all contexts in which it works—within and across countries.

Concerns about equity show up in WHO's programmatic discussions as well. WHO paid attention to equity in the distribution of ARTs for HIV/AIDS (Daniels 2005). WHO also sponsors a Commission on the Social Determinants of Health that has a strong focus on equity in health. Both these examples illustrate behavior compatible with, and required by, the institutional charge to WHO. Either this is a misguided focus of energy for WHO, as seems to be implied by Nagel's strong statist view, or it is an implication of the obligation of justice to show equal concern that arises within institutions charged with delivering an important good—whether they operate within states or across them.

Consider now the international bodies that establish rules governing intellectual property rights, including those that are key to creating temporary monopolies over new drugs. Such a scheme is "consequential" in that it increases the level of cooperation among affected parties in the production of an important collective good, research and development of drugs, and it does so in a way that has normatively relevant consequences (Cohen and Sabel 2006, 153, n.12). Suppose we conclude that this mutually cooperative scheme generates considerations of equal concern, or at least that it must be governed by a principle of inclusion.

We might then view quite favorably Pogge's (2005a) suggestion about structuring drug development incentives so that they better address the global burden of disease. Earlier, I said Pogge's proposal could not be defended on the minimalist grounds that it avoided doing harm because of the problem of specifying the relevant human rights baseline. Now, however, we have a new basis on which to defend the justice of Pogge-style incentives. Such an incentive scheme, supplementing existing property rights or modifying them appropriately, would greatly enhance the benefits to those who are largely excluded from benefit for a significant period of time, and it would do so at only modest cost to those profiting from the endeavor. Minimally, it illustrates what a more inclusive policy should include; one can build into it even stronger egalitarian considerations, if the cooperative scheme gives rise to concerns about equality and not simply inclusion. Exactly what form the policy would take, or the justification for it deriving from the form of cooperative scheme involved, remains a task for further work. With these issues worked out, we might then support Pogge's incentive schemes as a way of moving some countries closer to satisfaction of a right to health, connecting the effort to human rights goals as he does.

Consider again the example of the brain drain of health personnel from low- and middle-income countries to wealthier ones. Nagel (2005, 130) notes that nations generally have "immunity from the need to justify to outsiders the limits on access to its territory," though this immunity is not absolute, since the human rights of asylum seekers act as a constraint. Still, the decisions different countries make about training of health personnel and about access to their territories have great mutual impact on them. There is an important interdependency affecting their well-being, specifically, the health of the populations contributing and receiving health personnel. The British decision in 2000 to recruit 30,000 new nurses from developing countries rather than try to train more greatly affected the fate of people being served by health systems in southern Africa. I noted earlier that the underfunding of salaries for African nurses and doctors, in part a legacy of Structural Reform Programs imposed by the IMF and World Bank, but clearly continued by local governments, helps create the "push" factor driving these workers abroad.

Arguably, this relation of interdependence brings into play obligations of inclusion, perhaps those of equal concern, going beyond in any event humanitarian considerations. In addition to Pogge's "no harm" or minimalist approach, we thus have available obligations of inclusion requiring us to consider the interests of all those in the interdependent relationship. These obligations can be translated into various policy options that address the brain drain: it may be necessary to restrict the terms of employment in receiving countries of health workers from vulnerable countries; it may be necessary to seek compensation for lost training costs of these workers; it may be important to contribute aid to contributing countries aimed at reducing the push factors; it may be necessary to prohibit active recruitment from vulnerable countries.

We might combine these relationships of interdependence with the relationships and obligations that arise from cooperative schemes. The International Organization for Migration, established in 1951 to help resettle displaced persons from World War II, now has 112 member states and 23 observer states. It "manages" various aspects of migration, providing information and technical advice, and arguably goes beyond its initial humanitarian mission. Suppose it took on the task of developing a policy that helped to coordinate or manage the frightening health personnel brain drain.

Minimally, it might seek internationally acceptable standards for managing the flow—standards on recruitment, on compensation, and on terms of work. More ambitiously, it might seek actual treaties that balanced rights to migrate with costs to the contributing countries, countering at least some of the pull factors and even providing funds that might alleviate some of the push factors underlying the brain drain. In seeking these, it might work together with the ILO, the WTO, the WHO, and the UN. Such a cooperative endeavor would reflect the common interest in all countries of having adequate health personnel—and thus being able to assure citizens a right to health and health care—as well as the common interest in protecting human rights to dignified migration.

Conclusion

Earlier I posed the question: When are international inequalities in health unjust? This discussion falls short of providing an answer because we remain unclear just what kinds of obligations states and international institutions and rule-making bodies have regarding health inequalities across countries. To arrive at a real answer, we must carry out the task of explaining the substance of international obligations for the various kinds of cooperative schemes, international agencies, and international rule-making bodies in order to specify when the internationally socially controllable factors affecting health are justly distributed and regulated.

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Poverty, Human Rights, and Just Distribution

John-Stewart Gordon

Abstract Poverty is a serious threat for human beings and their well-being. People are simply unable to live a good life when they are faced with severe problems, e.g., bad education, poor housing, poor sanitation, poor hygiene, or malnourishment. However, one of the most urgent problems with regard to poverty is bad access to primary health care and the allocation of health care resources for millions of people around the world. These people are deprived of human flourishing, and life is for them, in general, “solitary, poor, nasty, brutish, and short.” In this chapter, I present an ethical argument that shows that people have a moral right to primary health care, and that wealthy developed countries are morally obligated to help the needy. Primary health care, and hence access to it is, as I will argue, a global public good that is protected by human dignity and the human right of protection from unwarranted bodily harm.

Keywords Equality, global public good, human rights, justice, poverty, primary health care, public health

Introduction

Aristotle is right in saying that all people strive by nature for human flourishing (Nicomachean Ethics I, 1). But, it should be clear, that this most important human aim has to be promoted by adequate material means. What about extremely poor people? Although poor people normally try their best to face up to the problems of their poverty, they have lesser opportunities to live a good life, to strive for human flourishing, and thus to gain well-being. Poverty is not only due to individual socio-economic status, this claim would be premature, instead, it is—to a great extent—due to social structure, which “shapes the lives and life chances of individuals” (Graham 2004, 299). The consequences are bad education, poor housing, poor sanitation, poor hygiene, and malnourishment to name just a few. That is, the living standard of the very poor is all in all very low (i.e. bad quality of life) and, thereby,

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they are deprived of human flourishing.[1] One of the most important strategies in international public health policy is to counter this situation, first, by improving the health of the poor by providing better access to primary health care and better allocation of health care resources, and second, by promoting equality and equity (WHO 1998).

Sen (2004) rightly maintains that investment in welfare, education, and health successfully ensures development in its broadest sense, which requires the removal of impediments to people's capability. But, as a matter of fact, he is one of only few authors who present an *ethical* argument, in order to give a justification for improving the health of the poor. Most people emphasize that ill-health is a serious obstacle to economic progress, which is—of course—true, but their main argument rests solely on the point that investing in the health of the poor brings improvement in productivity and has enormous wealth-creating potential (economic argument). Leon and Walt think that "these sorts of utilitarian/human capital arguments need to be kept in perspective, and should not overshadow the ethical imperative concerning inequalities in health" (Leon and Walt 2004, 6), which is certainly true.

In this chapter, I shall present an ethical argument that shows that people have a moral right to primary health care, and that the wealthy developed countries, which are able to help the poor, are morally obligated to do so. Of course, also in Western developed countries problems occur in ensuring full access to primary health care for the poor (e.g., USA) but, in this chapter, I would like to focus on the poor of non-Western developing countries such as those of sub-Saharan Africa, developing countries in East Asia, or in South America. Many people may think that their own community has a strong duty to help its citizens and provide them with adequate health care, but that their community is less obligated to help direct neighbors, and is morally not at all obligated to help people who live far away and suffer from inequitable access to primary health care. In this chapter, I will not go any deeper into special details of international public health and present analyses of different health care systems within a given country or across different countries, or try to draw conclusions with regard to, e.g., the relationship between life expectancy and the quality of life in different countries; instead, I will face the demands of cultural relativism, which is a great obstacle for claiming that human beings have a moral duty to provide other human beings with adequate access to primary health care, and which is a global public good. In doing so, I hope to provide other researchers, policymakers, and politicians who are engaged in international public health policy with an ethical argument that could be used as a tool to convince other people to help improve the health of the poor and so promote equity.

In the first part, I will analyze the notion of ethical relativism in order to counter the stance of the moral relativist who denies the existence of a moral right to provide other people with adequate access to primary health care. The second part

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[1] "[I]t is abundantly clear that a large proportion of the world's population does not have access to anything approaching an adequate level and standard of health care provision, and is denied treatments and medical care that are of undoubted efficacy" (Leon and Walt 2004, 7).

contains the ethical argument for a just distribution of health care resources by using the concept of human rights in arguing for the claim that primary health care is a global public good. The third part provides a brief discussion of four objections to the ethical argument. The last part ends with some closing remarks.

Ethical Relativism and International Public Health Policy

Why is ethical relativism a serious threat for international public health policy? Before I answer this question, I would like to say something more on the notion of ethical relativism. There is a long ongoing philosophical debate on the question what is and how to deal with the demands of ethical relativism. The notion of ethical relativism is due to three different parts of basic ethics: empirical ethics, metaethics, and normative ethics. The meaning of the notion of "ethical relativism" varies from part to part and from ethical stance to ethical stance. Hence, I will give a short description of my use of the notion in question.

Empirical ethics: ethical relativism respectively descriptive relativism (sometimes called "cultural relativism") means "that *beliefs* or *standards* about moral issues are relative to different individuals and different societies: that is, different individuals and different societies accept different moral beliefs or standards and thus disagree about the answers to moral questions" (Carson and Moser 2001, 1).

Metaethics: ethical relativism has, at least, two noteworthy versions: (i) extreme metaethical relativism, and (ii) moderate metaethical relativism. According to the first stance, proponents hold the view that all moral judgments are neither objectively true nor false. According to the second stance, proponents hold the view that (a) some moral judgments are objectively true or false, and (b) some moral judgments are not objectively true or false. That is, there are just a few correct or objectively true answers to certain moral questions, on the one hand, but not regarding most moral questions, on the other hand. Additionally, the second stance proponents take it for granted that there are just a few moral questions which can be answered, while they think that most of the moral questions cannot. Generally speaking, "different individuals or societies can hold conflicting moral judgments without any of them being mistaken" (Carson and Moser 2001, 2).

Normative ethics: ethical relativism respectively normative relativism "states that different basic moral requirements apply to (at least some) different moral agents, or groups of agents, owing to different intentions, desires, or beliefs among such agents or groups." The most common form of normative relativism seems to be social normative relativism, which states "that an action is morally obligatory for a person if and only if that action is prescribed by the basic moral principles accepted by that person's society" (Carson and Moser 2001, 2).

The sophisticated moral relativist typically holds the view that (i) cultural relativism, (ii) extreme metaethical relativism, and (iii) normative relativism are true. In doing so, they deny any moral rights or obligations that are outside their own community. That is, the demands of international public health policy to help other people in foreign countries—who suffer from poverty and who are in need of being supplied with health care resources, etc.—cannot convince the moral relativist, because there is no commonly shared moral basis. But let us take a closer look at this argument, which rests on two premises. The first premise is a factual statement about the differences between moral codes, that is, moral rules (moral codes) differ according to different communities. The second premise is a value claim, that is, moral rules of a community are authoritative for this community, only, and "this is good." The general conclusion is that no community has a moral right to demand anything from other communities, no matter what the reasons are.

The argument of the moral relativist is invalid. Why? The first premise rightly states that moral rules differ according to different communities, but, as a matter of fact, there are some universal moral rules which can be found in every sound community, e.g., do not murder, do not insult other people, do not torture, do not rape, do not steal, and help needy people. It seems to be that without a hard core of universal moral rules a community is not able to survive long enough and to promote human flourishing. However, it is wrong to say by virtue of empirical evidence that all moral rules differ according to different communities. The notion of "moral rules" has to be modified in the second premise with regard to the point we mentioned previously (a hard core of universal moral rules exists). Even the moral relativist, as Williams (1972) rightly points out, has to acknowledge the fact that he himself makes a universal claim in stating that other communities should respect his community's conception of ethical relativism. Furthermore, the institution of slavery or racism, the burning of widows, child labor, the denial of women's right to vote, and sexism, etc., are social practices which could not be morally evaluated if ethical relativism were true.[2] But, as a matter of fact, "it does make sense to be able to say that practices of one time or place are more or less ethically acceptable than those of another" (Macklin 1995, 241). Of course, moral beliefs and practices of other cultures and former times can be criticized and compared. If not, we are not permitted to condemn the Nazi atrocities, Stalin's Gulags, or Amin's regime in Uganda, a severe consequence that people normally are not willing to accept. Below, I will present an argument to support the claim of why it is possible to make moral claims on others. However, this short evaluation of the premises shows that the conclusion of the moral relativist seems not to follow. There are cases that may justify moral demands by virtue of the existence of universal moral rules.[3]

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[2] This holds, normally, for moral evaluations from outside the community, but it is also possible, of course, that within a given community disagreement may occur when beliefs about moral issues are relative to different individuals or different groups, that is when (the body of) beliefs are not only due to different communities.

[3] Macklin states with much plausibility: "If human rights is a meaningful concept, and if there are any human rights, then normative ethical relativism must be false. Human rights are, by definition, rights that belong to all people, wherever they may dwell and whatever may be the political system or the cultural traditions of their country or region of the world" (Macklin 1999, 243).

Of course, one could say more on this issue, but, if I am right, the moral demands of international public health policy on "wealthy" developed countries to help the poor in foreign countries by improving the health of the poor and to promote equity could hardly be defeated by the conception of ethical relativism. Ethical relativism would be a serious threat to international public health policy, if it were a true stance, because one would not be able to claim that other—especially wealthy—developed countries are morally obligated to help the poor. According to this case, it would be, then, solely up to the vagaries of the donors and their alms. The poor people are not suppliants, but have a moral right to adequate access to primary health care and to be treated with respect.[4]

Primary Health Care As a Global Public Good[5]

In this part, I shall argue, first, that primary health care is a global public good, and hence it follows, second, that this good has to be fairly distributed among all people, since global public goods are protected by human rights, which are universally valid.

What is a global public good? According to Kaul et al. (1999, 2), a global public good has to meet two criteria: (i) that their benefits have strong qualities of publicness (i.e. nonrivalry in consumption and nonexcludability)[6] and (ii) that their benefits are quasi-universal in terms of countries, people, and generations (i.e., humanity as a whole should be the beneficiary of the global public goods). In other words: a global public good provides all people in all places at all times with benefits and has a great utility for the well-being of the people once it is produced. However, by virtue of their criteria, "public goods typically face supply problems, and so are often referred to as a case of market failure … as a result supply and demand cannot reach an equilibrium, public goods are undersupplied and resource allocations are sub optimal" (Kaul et al. 1999, 6).

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[4] Of course, some people might object, "Why should one be moral?" (or Why should one help other people?), but I strongly think that those people—one may call them moral relativists—should not be regarded for a sound ethical discourse. Aristotle—unlike Plato (1903; Politeia II)—rightly says in his ethical main writing, Nicomachean Ethics (EN I), that his teachings are for those people who already care for the ethical life. My article is not about to convince extreme moral relativists who are unwilling to engage in this line of thinking, it is about to promote the ethical reasoning of people who are already serious about ethics and the central question of living a good life.

[5] In the following, I will use the notions "health" or "primary health care" as global public goods more or less interchangeable, though at the same time I acknowledge the fact that there are, of course, differences.

[6] Nondivisibility (i.e. nonrivalry in consumption) refers to the ability of all people to benefit from the public good once it is produced. Nonexcludability refers to the inability to exclude any individual or group from the benefits of the public good once it is produced.

Most people see poverty as one of the most influential factors in poor access to primary health care. Hence, Kaul et al. are right in stating, that, e.g., "a poverty alleviation program for sub-Saharan Africa could be a global public good if, by meeting the needs of local populations, it were also to contribute to conflict prevention and international peace, reduce environmental degradation of potentially international consequences and improve global health conditions" (Kaul et al. 1999, 12). And, Chen et al. (1999, 292), with great emphasis: "[T]he control of many global diseases of the poor can be considered a public good. For example, the successful eradication of smallpox, the near elimination of polio and the primary health care movement are global efforts for the public good."

To me it seems obvious that primary health care is a global public good. But what are the consequences? What is the very advantage of the idea that primary health care is acknowledged as a global public good? If one is able to prove that global public goods, especially the global public good of primary health care, stand in a special relation to human rights, one may be able to provide an ethical argument to support the claim, that all countries are morally obligated to improve the worldwide access to primary health care, by virtue of the existence of human rights.[7] But, what is the content of the supposed human rights? The notion of human rights is linked to the notion of human flourishing. To promote human flourishing means to ensure certain kinds of important basic goods such as: (i) human dignity; (ii) food, clothing, shelter; (iii) protection from unwarranted bodily harm, etc. These basic elements represent the first generation of human rights. I see a strong connection between the idea of human dignity and "protection from unwarranted bodily harm," on the one hand, and the problem of access to primary health care, which is due to poverty and to the lack of interest[8] by many responsible politicians, on the other hand. If poverty is responsible for people not having access to primary health care, which leads to "unwarranted bodily harm," one should acknowledge the fact that this is a human right violation, namely the violation of the human right of "protection from unwarranted bodily harm," which leads to the deprivation of human dignity. And, if this is the case, all people and all nations—at least those in the United Nations Charter—are asked to improve this life-threatening situation for millions of needy people by providing them with better access to primary health care. Chen et al. (1999, 294) rightly maintain that

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[7] In this article, I am not able to give a justification for the existence of human rights, since this would be far outside the focus of this chapter. Here, I take the existence of human rights and their sound justification—for the sake of argument—for granted. Though, of course, I have to admit that the justification of human rights is a very difficult task to deal with.

[8] In *Injuries, Inequalities, and Health: From Policy Vacuum to Policy Action*, Anthony Zwi gives two reasons why he thinks that there is a limited response to injuries in so many settings with regard to international policy. His reasons also hold for the phenomenon of the lack of interest, he maintains: "One important reason is that the poor suffer most, but also have least influence over policy decisions. As a result, there is limited public concern: it affects 'them, not us,' and therefore does not attract attention. Furthermore, the poor in most settings have limited political influence and may have more difficulty engaging local policy-makers with their concerns" (Zwi 2004, 274).

> "[t]he world-wide diffusion of information and normative convergence that preventable human suffering should not be tolerated may increasingly move the public to perceive good health universally shared as a basic human right. Good health is both an instrument as well as an expression of global solidarity, reflecting ultimately the indivisibility of health."

But, what follows from taking the claim, that primary health care *is* a basic human right (or could be justified by a basic human right), seriously?[9] The answer to this important question is the second issue, which concerns the just distributions of primary health care resources, in order to provide the poor with an adequate access to primary health care. The argument is: Human dignity is not a privilege that a few people have, but is something which belongs to all human beings by nature (Gordon 2006, 191). But, what is human dignity? One has to admit, at first sight, that the notion of human dignity is hopelessly opaque, but, at second glance, the notion becomes clearer when one acknowledges the fact that human dignity is something that makes out of human beings "true" human beings—the essence of humanity. Pufendorf (1672) shows in his system of natural law (De iure naturae et gentium libri octo) that the very idea of the equality of human beings is due to the conception of human dignity.[10] People are morally equal; they have equal moral rights and share equal moral obligations by virtue of their human dignity. But, as a matter of fact, the primacy of strict equality is challenged in circumstances of distributions. A just distribution is not always a distribution of equal shares. Aristotle is right in stating that equals should get equal shares and unequals should get unequal shares; all people, according to Aristotle, should be treated equally according to a special standard (Aristotle EN V, 6). I think—with regard to the general idea of just distributions—Michael Walzer is right in maintaining that nearly every sphere needs its own standard of distribution. That is, a just distribution is not (always) a strict distribution of equal shares. But, unequal shares have always to be justified. And, if no sound justification is in sight, the distribution is unjust and should be altered.

What about the questions of access to primary health care and of just distribution? As we have already mentioned, primary health care is a global public good that benefits all people. If a human right promotes this global public good, then all needy people have a moral right to access to primary health care and to all morally acceptable means by which it can be ensured that primary health care resources may be provided. This means, in the end, that there is a strong moral obligation for those people (and communities) who are able to help the poor by reducing their poverty, if poverty alleviation is the main key to improving access to primary health care.

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[9] It may seem that I do not need the human rights argument to back up my main thesis, since the argument of global public goods seems to be sufficient for a sound justification. So, why am I presenting two independent arguments? It is my contention that both are parts of one major sophisticated argument, and thus cannot not be reduced to one argument alone. One needs the strengths of both parts in order to present a powerful argument, so as to justify that all people should be provided with adequate access to primary health care, and to reduce their poverty.

[10] This thought—mediated by John Wise—also had a strong influence on the conception of the American Declaration on Independence (1776) according to the idea of equality.

The poor of non-Western developing countries, such as sub-Saharan African countries, developing countries in East Asia, or South America have a moral right according to the idea of human dignity and this is justified by the conception of the human right to be supplied with adequate health care resources. Lack of access to primary health care is an unwarranted bodily harm, which should be improved by all morally acceptable means.

Objections

First, one may object that the language of human dignity and human rights are too opaque to justify any moral rights, such as providing the poor with adequate access to primary health care, which obligate other people and foreign communities. There are no justified moral rights that support the idea of distributing health care resources equally.

Most people who use the language of human dignity and human rights relate these notions to the very idea of absoluteness, which then makes it opaque. The idea of absoluteness is originally due to the conception of a divine entity that equipped human beings with a certain dignity. This dignity, in turn, justifies universal human rights. But, as a matter of fact, the talk of divine entities, which function as a sound justification—at least in most areas of philosophy— has vanished into thin air in favor of secular thought. In my view, there is no necessity to link the notions of human dignity and human rights to the idea of absoluteness. I think that Rawls' idea of an "original position" seems to have enough power to justify the language and thus the phenomenon of human dignity and human rights: All people agree under the veil of ignorance in the "original position" to accept the idea of human dignity and a hard core of human rights, e.g., to provide adequate access to primary health care for everyone. According to this conception, there is no opaqueness in sight, since it is solely up to the people who decide about the basic guiding principles (here, the principle of beneficence), that ensure human well-being. Hence, it seems to be plausible to say that all people should have adequate access to primary health care, if they need it. And if they do not have any access, at all, they should be helped by any morally acceptable means. That means, all people who have accepted the contract made in the "original position" and who are able to improve access to primary health care, are thus morally obligated to do so. Hence, they are morally obligated to provide others with health care resources.

Second, it is unclear, whether the account holds that one should help people because they are poor and thus do not have adequate access, or that one should help people because they suffer from health inequalities as such?

The first point is that inadequate access to primary health care is per se unjust regardless of someone's individual socioeconomic status—the people in question may be wealthy or poor. The second point is that, normally, poor people—especially most people in developing countries—face the problem of inadequate access, and hence are vulnerable according to lack of important vaccines, basic medication, or exposure to severe diseases which in turn are due to bad sanitation. However, poverty is a serious threat for international public health. If I am right in maintaining that primary health care is a global public good and thus should be made accessible to all people, one must do everything possible to ensure a just distribution of health care resources because to deny this would be a violation of a basic human right (protection of unwarranted bodily harm caused by life-threatening poverty). But, who should pay the bill for it?

Third, who is responsible for providing all people who suffer from inadequate access to primary health care with adequate resources? Who should pay for it? Should all "wealthy" people pay, or all Western developed countries, or how should one proceed? These are hard questions, but I will try to give a short outline of a possible strategy.

Many developed and developing countries alike signed the Declaration of Human Rights (United Nations Charter) in 1948 (and later on). All these countries acknowledge the fact that human rights violations—e.g., inadequate protection from unwarranted bodily harm—should be prevented. If access to primary health care is a global public good protected by a human right, then all participating nations have a legal—and moral—duty to provide their members (as well as nonmembers, by virtue of the universal idea of human rights, but this demand may be restricted on the grounds of limited economic means) with adequate access to it. The best way to manage this is, first, that all participating countries should pay a special tax into a joint fund to help those countries (5% of the country's income, say) that are not able to provide their own citizens with adequate access to primary health care. Second, all developing countries should be released from their debts in order to spend this money on their citizens in order to provide them with adequate health care resources. Third, all partaking countries should be forced to provide their citizens with basic education, which is a main tool for poverty alleviation. Fourth, poverty alleviation programs should be carried out. Fifth, all participating countries should be forced to solve conflicts not by war, but by consensus. Sixth, the participating countries should impose a special tax—perhaps every five years (5% of their citizens' income, say)—on those citizens who earn sufficient money (i.e., who are not below the average income) and every year, according to business, companies (3% of their income, say) to jointly fill the fund. Seventh, in addition to normal public primary health care centers, special international primary health care centers, financed jointly by the fund, should provide a broad net of access to primary health care in all participating countries. These are the core elements of providing better access to primary health care.

Fourth, it seems to be wrong from a libertarian viewpoint to make a redistribution of very large sums of money, mainly from Western developed countries (e.g., USA) to non-Western developing countries (e.g., sub-Saharan African countries), in order to support people who live in poverty and suffer from bad access to primary health care. They have no right to take "my" money, so that they can live a better life. What about "me" and "my" rights?

The libertarian viewpoint may be true at a first and superficial glance, but on a second more searching appraisal there are at least two striking reasons why this viewpoint is fallacious. The first point is that it is not concerned with providing people with secondary or tertiary luxury goods, it is about helping people to survive in an unpromising situation, where the people are unable to help themselves. Most of them would die without foreign help. What they need is to be provided with basic goods. As we have seen, all people have a human right to live and to be provided with adequate means of primary health care. Libertarians are right in claiming that there are (respectively should be) strong property rights and that no one should easily have the opportunity to redistribute one's means. But, if people die solely by virtue of being extremely poor and without access to primary health care, then—at least—those countries who signed the United Nations Charter are morally obligated to help the poor to survive and to provide them with adequate means to restore their lives. The human right of "protection from unwarranted bodily harm" trumps the libertarian's right of absolute protection of one's property. The dignity of men is unimpeachable—but property is not! The second point is due to Aristotle who maintains in Nicomachean Ethics I that his teachings are only for those people who are already advised in ethical reasoning. The libertarian's views on the above issues seem to reveal that they fall below a certain commonly shared limit of ethical reasoning. Most people would not join a community of people who only think about protecting their property and additionally share a total lack of feeling for other people who had been adversely struck by the lottery of life. Luck can turn and libertarians should better be prepared for this, though a just society would not leave somebody behind—not even libertarians. And this "leaving somebody not behind" is the crucial point of showing compassion and taking care for one another in a globalized world of justice.

Conclusions

In this chapter, I have entirely focused on the question of why should one help the poor from non-Western developing countries (e.g., sub-Saharan Africa) with regard to the issue of adequate access to primary health care. Most people who suffer from inadequate access to primary health care are very poor, or live in rural areas which do not have any primary health care centers. These people are deprived of human flourishing because the lack of adequate access to primary health care and basic education lead to poor quality of life, with severe diseases and short life-expectancy for the people. But, why should anyone—especially the Western developed countries—help these people? It is my contention that health—and hence adequate access to primary health care—is a global public good which is protected by human dignity and the human right of protection from unwarranted bodily harm. At least, those countries that signed the United Nations Charter have the moral duty to do everything possible to provide all people with adequate access to primary health care. Inadequate access to this global public good is a human rights violation—that is, inadequate protection from unwarranted bodily harm. All participating nations maintain that human dignity also requires that all people are understood to be morally equal. If this is the case, all people without access or inadequate access to primary health care have a rights claim to this global public good by virtue of their moral equality. Therefore, all participating countries in the Charter are morally obligated to provide all people with adequate access to primary health care, which means that just distributions should take place (e.g., through jointly funded provision and special taxes). Access to adequate primary health care and basic education are preconditions for living a good human life.

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Why Should We Help the Poor? Philosophy and Poverty

Christian Illies

Abstract One might question whether we need ethics at all in the debate on global poverty, or whether the demand to help seems self-evident and the choice of particular actions should be left to specialists on developmental aid. In this chapter, it is argued that the answers are yes and no: *No*, because we can leave particular recommendations to experts once we know precisely what we should promote—but also *yes*, since we must know the exact end of our (demanded) action. Empirical poverty-research without specified ends is blind; it requires the prior identification and rational justification of particular ends. This, however, is the task of ethics because no empirical science can lead to normative insights. Since it is highly controversial whether philosophical reflection can provide such a justification, a transcendental argument is outlined: if there is something good, then it is good that the good is actively supported, and if a capability to do so is a necessary requirement for this support, then it is also good that human beings have this capability. Human freedom is the paramount capability to self-determine one's life and actions. It is an essential condition for supporting the good. It follows that a certain kind of freedom (namely the one necessary for supporting the good; here called "moral freedom") must be regarded as a necessary end for any morality. We are obliged to help others so that they can help.

The chapter ends with showing in which way the end "moral freedom" tells us why we should help the poor and can provide practical orientation for doing so.

Keywords Poverty, ethics, justification of ends, transcendental arguments, freedom, capabilities, Sen

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Poverty as a Philosophical and Practical Problem

In a world where almost 1 billion people (out of 6.55 billion) earn less than $1 per day,[1] and where everyday almost 16,000 children die from hunger-related causes,[2] it seems more than obvious that we should help the poor. 'We' are the 1 billion people who live in the 57 countries of the developed or industrialised world, the ones who have the means to support others.[3] Who can look at the painfully emaciated children of Niger without feeling the urge to do something? But why should this require any philosophical reflection? Surely we should not waste time on philosophical enquiry; surely we must do something? (More radically: 'The philosophers have only interpreted the world, in various ways; the point, however, is to change it.'). Clearly, it is not easy to know the *right* response. How does one, for example, choose between giving money for the drilling of a well in Zimbabwe and giving start-up money to local entrepreneurs in Rwanda? To know how best to respond seems a practical problem that requires international agricultural policy experts, and the acumen of NGOs or other specialists on developmental aid—but not, perhaps, philosophers.

This chapter argues for a more constructive role of ethics in this debate. Empirical knowledge is necessary but not sufficient for practical decisions; by itself it does not tell us who should do what in order to achieve which end. Experts can only give advice if we have prior knowledge of the precise ends that we desire to achieve—and to identify obligatory ends is precisely the task of philosophy, or so I will argue in the section 'What We Need to Know in Order to Act Morally'. But can ethics provide rational justification of ends? I will provide such a justification. In the section 'Why Should We Help the Poor?' an argument is developed for asserting that a form of individual freedom is a fundamental value of all morality. In a concluding section, it will be sketched in which way the justified end gives practical orientation for helping the poor ('Helping to Help—A Conclusion').

What We Need to Know in Order to Act Morally

Actions are purposeful goal-directed behaviour; they are performed in order to realise or archive an end by way of some means. This can also be expressed as follows. If someone acts genuinely, she intents the end of her actions to be realised in a certain way, and she implements a kind of direct control or guidance over her behaviour. What is required for someone to act? Amongst the basic conditions is

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[1] *World Development Indicators 2007*. The World Bank. March 2007.

[2] Black et al. 2003. "Where and why are 10 million children dying every year?" *The Lancet* 361:2226–2234.

[3] *Human Development Report 2006*. United Nations Development Programme. November 2006.

the capability of the agent to set herself an end and to select practical means, i.e. the particular behaviour, by which she manages to achieve the aspired end.[4] This account of action does not alter in the case of imperatives, i.e. demands to realise an end by way of certain behaviour. All this seems to be a conceptual truth about action in general.

Let us look at poverty again. 'Help the poor!' was introduced above as a widely accepted, or seemingly self-evident, demand to act in a certain way. But, as it stands, it does not describe a *particular action*; it does not tell us exactly what we should do. Even if it gives our assistance some direction ('the poor'), we must specify the particular end (e.g. an improvement of the material conditions of people in Niger, the provision of access to medication in Congo, food for the homeless in the United Kingdom). Also the *means* must be selected (e.g. donating money, organising transport of goods to a war region, working as a volunteer in a soup kitchen), and the specific actor or addressee of the demand has to be identified (e.g. myself, another, a charity, the state). To be sure, we can *describe* any specific act of help, e.g. 'Peter is giving US$100 to UNICEF', in general terms: 'Peter helps the poor'. Yet for Peter or anyone to *act* a particularisation is necessary. We cannot do things in general, but only in particular. And due to our limited resources and capabilities, we can perform only very few of the unlimited possible particularisations of helping the poor. That is why we must be highly selective. We have neither the time nor means to help everyone who is in need in all possible ways. For this reason Kant calls the duty to help others an *imperfect* duty, it will always be imperfectly satisfied (while 'perfect duties' can be perfectly satisfied, like the duty not to murder)[5]: I must decide whom to help—but also whom not to help.

How, then, do we get to the particular action? If we do not want the selection to be arbitrary, nor to be based merely upon subjective likes or dislikes, we must look for criteria for the selection of particular acts. This will be the most rational way to proceed (which is, of course, a truism).[6] What does it mean to choose an action rationally? The choice of its particulars must be guided by practical reason. The means must be selected as efficient and adequate to achieve the end, and the end must be chosen for good reasons. Though most attention has been given to means and ends, the rationality of an action also depends on the choice of agents.[7] It can

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[4] Obviously this is simplified because the performance of a certain activity can sometimes itself be the end, e.g. if someone hikes. For the present purpose, however, the model of actions above suffices.

[5] *Grundlegung zur Metaphysik der Sitten*, AA IV, 421–424. This does not imply that imperfect duties are optional—they are hard demands, not mere moral afterthoughts. The same distinction is made today mostly by talking about 'negative' and 'positive' duties.

[6] I will not discuss it here whether this is giving rationality too much authority. After all, any attempt to argue for or against rationality being our ultimate guide is itself in the realm of reason—and thus an at least implicit acknowledgement of its uncircumventable authority (See Thomas Nagel, 1997).

[7] One can add further aspects of an action that are open to rational scrutiny, e.g. time and place. There can be good reasons for an agent to do something now or rather tomorrow; to do it here or rather somewhere else.

be rational, depending on the context, for me not to act at all, or for me to do something, or to support someone else in doing something. It must be noted that the three areas where reason can guide actions are mutually interwoven; the criteria involved in the selection of ends, of means, and of particular addressees, are all dependent upon each other. Who should do something, for example, depends (at least partly) on the available means. Yet the most obvious dependency is between the means and the ends. The end of an action is decisive for the appropriate (and thus rational) means to achieve it. Ends have a logical priority; they are the first thing that we need to know when we specify an action. And the more precisely the end is stated, the more particular actions can be inferred. This can be illustrated with the demand to help the poor. The end (the provision of help for the poor) is not sufficiently specified as to allow us to say what to do in a particular situation. Practical reason may tell us that we should look for the most efficient means of achieving the end; that one should act in a way that a maximum output is achieved from a given input—and that not much resource is wasted. Can experts tell us what the most efficient responses will be? No, because we need to know exactly what the aspired outcome is. And here the demand is simply underdetermined; there is no efficient way to help the poor in general.

We questioned in the beginning whether we need ethics at all in face of global poverty, or whether the demand seems self-evident and the choice of particular actions should be left to specialists on developmental aid and the like. The answer will be yes and no. *No*, because we can leave particular recommendation to experts once we know precisely what we should promote—but also *yes*, since we need to know the exact end of our (demanded) action—and this is the contribution of ethics. No empirical science can provide normative knowledge. The subject matter of economic, social, or political sciences consists of highly complex constellations and interrelations of events in complex systems of human interaction; but they cannot tell us by themselves what achievements are desirable within these systems. (In Kantian terms, they can provide us with merely hypothetical imperatives.) Ethics is the discipline that deals with exactly this normative question; it searches, at least in its more rationalistic tradition, for reasons why we should aim at, or desire, something; it provides rational justifications of ends. Thus for particular moral actions, ethics and empirical knowledge have to work together; the first gives the desired goal, the second the knowledge of how to achieve it. And that is why ethics plays also an important and even indispensable role in the practical problem of poverty: it gives our efforts to combat human suffering a clear direction that allows us, in situations of limited resources and means, to focus on the most rational actions. (These actions can look very different if we follow John Rawls, who focuses on freedom and opportunities, or Peter Singer, who asks for the maximisation of the satisfaction of conscious preferences.) And, *vice versa*, ethics needs empirical knowledge about poverty, its conditions, and the possibilities of overcoming particular forms of it, because without it, we would only know the end—but not the actual path to it. Empirical poverty-research without ends is blind, or, as we might put it, ethical reflection without empirical research is empty. This is the role of ethics.

But can it fulfil it? While it is generally accepted that we can choose right *means* rationally, it is much debated whether there can also be a rationality of *ends*. Aristotle thought so; for him the rationality of ends is assessable by the virtuous. But David Hume and Max Weber argue that all we have is the rational selection of means, and that ends are not rationally chosen but given by other sources, such as emotions. Let us therefore turn to the challenge of justifying morally demanded ends—and in particular, for those precise ends which underlie the demand to help the poor.

Why Should We Help the Poor?

Is it possible to justify moral demands on the basis of compassion? Schopenhauer, amongst others, has developed an ethical theory of compassion, according to which someone is moral when he feels the distress of other people and tries to mitigate their pain. But compassion is insufficient as an ethical theory because it does not give precise ends for actions, and thus it fails to provide orientation for particular acts. More so, the compassion of agents is often too idiosyncratic; it depends on cultural and religious contexts and subjective dispositions, on likes and dislikes. Moreover, it focuses on individual suffering *when it is apparent* (e.g. the emaciated child in Niger that we see on a photography) and is therefore guided by contingencies. Compassion gives agents strong impulses to do something in a particular situation, but can hardly be seen as an argument for choosing rationally between different actions.[8] How, then, is a rational justification of ends possible? Intuition or mere conceptual analyses leave more questions open than they answer; at least, it is hard to see how they could provide a legitimisation. One might suggest deducing them, but this only works if we have some prior normative notion, some value or principle, which then would be in need of justification itself.

Faced with this problem in the context of his theoretical philosophy, Kant developed a new methodology that proves also to be promising in ethics. Such argument goes roughly as follows: We start with some X that we take for granted, for example that we have experience, and look for a necessary condition Y, of this X being possible. If there is some Y, for example that all experience is in time, and if it is a *necessary* condition for it being possible (because we cannot imagine any experience that is not in time), then we can regard a judgement *that*

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[8] That is why Hannah Arendt saw compassion as dangerously de-politicising. The vagueness is to a certain extent also due to the person who suffers. How much the very same situation makes someone a possible object of compassion differs and depends, for example, on how she experiences her situation subjectively, how well she expresses her suffering and in which way it is communicated.

Y is the case as being justified (at least as much justified as X). Kant calls this a transcendental deduction; today it is called a 'transcendental argument'.[9] Kant expanded his new methodology to ethics; he wanted to justify the categorical imperative transcendentally. The third part of the *Grundlegung der Metaphysik der Sitten*, documents his attempts—but they also show his failure, mainly because he cannot identify a firm starting point (X) for practical reason. In his later work, Kant admits this problem rather frankly and gives up his transcendental aspirations in ethics.[10]

Let us be more optimistic about the methodology Kant introduced. What could be a starting point for a transcendental argument for ethical reflection? A possible candidate is that we have a *notion of good and bad*. We leave it open as to what the form or content of this notion is. We merely begin with a general positive or negative evaluation of some kind, in such a way that this X could be accepted by the different ethical systems, by virtue-ethicists as much as Utilitarians, Deontologists, and Hedonists. They all regard some things (actions, states of affair, habits, consequences, etc.) as good (positive, advisable, recommended, etc.).

What does it mean to call something good? Whatever our ethical system is, it seems obvious that the good X (state of affairs, action, duty, etc.) *should be supported or realised*. A deontological theory of duties spells out directly what should be done. Consequentialist theories conclude from their notion of good (e.g. general happiness or preference satisfaction) that we should bring this good state about by acting appropriately. Virtue-ethicists will agree that it is good to have or develop certain virtues or to realise the good that is given by praxis (as MacIntyre would argue). We can spell this out generally as a conceptual truth about goodness: calling something good *means* that it is something we should have *an active pro-attitude towards*. (And, obviously, the inverse can be said about our notion of bad.) If someone denies this ('Z is good but it does not need to be respected'), then she seems not to understand 'good' properly. It is a conceptual truth—in Kantian terms an analytical truth—that it is good to support the good. Of course, that does not imply that *all* possible ways of supporting something good are themselves good or recommended; it is only in general good to have this active pro-attitude. Particular cases still demand particular considerations; and whether a *specific* realisation of this

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[9] It should be added that transcendental arguments are faced with several problems, for example: How do we find out whether something is a necessary condition for the possibility of something else? And what can serve as a self-evident starting point? (Already Fichte supposed that Kant is presupposing too much.) A more modern objection reads: Even if we can demonstrate transcendentally that we must *think* that something is in a certain way, how can we be sure that it *is* like that—maybe the way we must think has nothing to do with how things really are. In the current debate this point has been made famously by Barry Stroud (but has been discussed earlier by Hegel).

[10] *Kritik der praktischen Vernunft*, p. 46 (in *Kant's Werke*, vol. 5). We find a "total reversal of positions" (Karl Ameriks 1982, p. 211. From now on, Kant considers the categorical imperative as a *Faktum der Vernunft*. Whatever that exactly means (probably it is an appeal to intuition[10]); it is certainly no longer a transcendental argument.

pro-attitude can rightly be judged as good will depend on the circumstances (e.g. whether an action violates some other good). Further, it does not imply that everything that someone regards as good must be acknowledged from our perspective as good; we might disagree heavily—but whatever someone regards as good, he is committed to approve of the pro-attitude towards this 'good'.

Starting from this general positive evaluation of a practical pro-attitude towards the good, we can ask the transcendental question: what is the necessary condition for the possibility of having an active practical pro-attitude? Well, that there are beings that are able to have this pro-attitude. The existence of pro-attitudes without someone having them is unimaginable. There cannot be a smile without some one smiling (the Cheshire cat's smile in *Alice in Wonderland* being a notable, because intentionally logically absurd, exception!)—and there cannot be an active pro-attitude without *someone* having this attitude. We can be even more specific: as far as we know, the only beings with active pro-attitudes towards the good are human beings who act intentionally. And the necessary condition for an active pro-attitude is not merely the existence of human beings, but also that they are capable of having this attitude—that human beings *can act* in a supportive way. If we think about the conceptual analysis of actions above, we can specify these necessary conditions further. There must be beings that have some understanding so that they can behave purposefully, set themselves ends, and select the appropriate means. Moreover, they must have some understanding of what the *right* thing is—otherwise they cannot actively support the good.[11] Further, they must have the necessary freedom to realise their end and implement a kind of direct control over their behaviour. This freedom to act, in combination with the right understanding, directed towards doing good, might be called 'moral freedom'.[12]

Here the argument has come to its completion. If there is something good, then it is good that the good is supported, and if the capability to do so is a necessary requirement for this support, then it is *also good* that human beings have this capability, that is moral freedom, and that they exercise it. (And the starting point does not even have to be a concept of good, it could also be of duty or rights.) We have made a transcendental move towards the goodness of a certain freedom (and could also add: of right understanding etc.) *qua* being the necessary condition Y for X being possible (X is having an active pro-attitude towards the good). Thus, moral freedom, as human freedom in support of the good, is *itself* good. This justification is not a deduction; the suggested transcendental reasoning does not start with any particular notion of good in order to derive norms—it begins with *any* notion of

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[11] Needless to add that they can be wrong about the good, and history as much as daily life gives plenty examples of this error. But this is a different problem. It is still a necessary condition that humans can be right about the good for them to actively support it.

[12] In a Kantian tradition, this would amount to the *autonomy* of the agent, that is his or her ability to conform his or her behaviour to universal laws that obligate it. In the *Grundlegung*, for instance, Kant says that autonomy is "freedom of the will" (4:447), but also that the "categorical imperative … commands neither more nor less than … autonomy" (4:440).

good that we may happen to have. The first time the argument makes an explicit statement about what is good is when it states that it is good to support the good.

We can put the result as a normative principle: *exercise and promote moral freedom!*[13] For each of us it means that we should realise our freedom, and we should do it in a manner that supports the freedom of others so that they can do the same. Thus irrespective of what we hold to be morally good, we are also transcendentally committed to acknowledge the goodness of moral freedom and to enlarge its realm.[14]

Roger Brownsword has recently developed a similar argument for the support of human dignity 'as a value that transcends disputes about whether we are doing the right thing in a particular case'.[15] He starts from the idea of a 'moral community' being uncircumventable for any ethical dispute about what we should do, that is a community 'committed to doing the right thing, that holds commitments sincerely and in good faith, and treats its standards as categorically binding and universalisable.'[16] In a second step, Brownsword asks, in a transcendental manner, what are the conditions of this community being possible and reaches at 'a degree of personal freedom and responsibility'; this he regards as a precondition of 'the dignity of human choice and responsibility'.[17] While the justification suggested above asks for transcendental conditions of the possibility of promoting the good in general, Brownsword is raising a similar question in a Wittgensteinian manner—he is focusing on the embedding of any such investigation in a communal praxis. His approach has the advantage of linking the argument immediately to practical concerns, but it gives rise to a difficulty. If we look at the moral community we live in, it is not relevant to include people far removed from us, such as the poor in Niger. In order to sustain our moral community we do *not* seem to need their 'freedom and responsibility'. (Or Brownsword will have to demonstrate that any moral community is ultimately a *global* community.) It is here where the suggested conceptual-transcendental argument is stronger. By focusing on the conditions of *any* notion of good and bad, it transcends the limits of any particular community or ethical praxis and concerns all beings that are capable of promoting the good, including the poor who need help most urgently.

Does this transcendental argument work? There are possible reservations. A first objection might be raised about the starting point. A moral-nihilist sceptic might ask: why should we assume that there is anything good *at all*? Nietzsche would

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[13] Obviously, this comes rather close to Kant's second formula of the categorical imperative. "Act in such a way that you always treat humanity whether in your own person or in the person of any other never simply as a means but always at the same time as an end!" *Grundlegung*, p. 429 (in Kant, *Kant's Werke* 1968, vol. 4).

[14] A related argument has been developed by Herbert Hart; who reasons that "if there are any moral rights at all, it follows that there is at least one natural right, the equal right of all men to be free". Cf. H.L.A. Hart (1967, p. 53).

[15] Roger Brownsword (2007, p.13).

[16] Ibid, p.14.

[17] Ibid.

surely call this assumption a deception; all we have is mere will to power. As it stands, the argument does not address (let alone refute) this radical normative scepticism; it remains *internal* to ethical reflection. But that seems enough for our purpose; the point is not to secure a normative notion against radical scepticism; this would demand a much more elaborate argument (e.g. by showing that we are inevitably committed to making judgements about something being morally good or bad[18]). We can therefore bracket radical scepticism by setting the starting point in a hypothetical fashion: *if there is any notion of good and bad*, then we must promote moral freedom.

A second and practical reservation might be: does it make sense at all to talk about 'moral freedom', or is this a *contradictio in adiecto*? If someone is free, then she seems free to do whatever she wants, not merely to promote the good. Thus any restriction of freedom towards the choice of some end is already limiting the very freedom it is supposedly about. That is correct and still not a fatal objection. Of course, promoting the freedom of others never guarantees that this freedom will be used in the morally right, namely freedom-supportive, way. If we liberate others, we also enable them to use their newly gained freedom in an immoral way. But this does not mean that we cannot promote freedom in a way that enables us or others to act morally or that makes it more likely (though the risk of it being abused remains inevitable). If, for example, people are in extreme need it is unlikely that they will be able to become engaged in any good-promoting activity; they are busy keeping themselves alive. Humanitarian aid is therefore an essential step towards the promotion of the moral freedom of the recipients. It is also possible to increase moral freedom by educating people in developing a greater sensitivity for the sufferings of others. Another way is character formation, if we understand character as the individual 'conditions' that can 'help or hinder fulfilling the laws of … morals'.[19] Having character is an important subjective help, but, again, it does not determine whether or not one will be morally good. One can always use one's freedom to abdicate freedom.

Helping to Help: A Conclusion

Let us return to our original question. What does the demand to promote freedom amount to, with respect to practical decisions and actions against global poverty? It gives a precise direction for our moral obligation: we should aim at a situation in which all persons, including the poor, have moral freedom and can exercise it—we are obliged to help others so that they can help: not life as such, nor the happiness of all people, but the dignity of 'human moral choice and responsibility' (as we might term it following Brownsword) stands at the centre of moral concerns.

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[18] See for example: Alan Gewirth (1970) and Illies (2003, ch. 5).

[19] Kant, *Metaphysik der Sitten*, AA vol. 6, p. 217.

What difference does it make in practice? When we look at people in extreme need, the end ‘moral freedom’ will also call for humanitarian aid in the form of immediate alleviation of people’s suffering, because to be alive and having access to basic goods is a necessary precondition for any freedom whatsoever. In the long term, however, this concept will focus on enabling people to strive for something other than the provision of certain goods or the satisfaction of specific needs. The point of help is to open *possibilities of acting* and this will determine the choice of means. Moral freedom is a form of *positive freedom*, that is, a person’s actual ability to do something—rather than merely her *negative freedom* arising from non-interference. (This does not mean that negative freedom plays no role; it remains the precondition for any positive freedom and must therefore be secured.)

In many ways, the end ‘moral freedom’ will result in practical demands that are closely related to Amartya Sen’s capability approach. In his seminal paper ‘Equality of What?’ Sen critiques a focus on utility or basic goods because of the unequal ability of people to use these goods. Sen argues that true equality is only achieved if we look at equal ‘basic capability as a morally relevant dimension taking us beyond utility and primary goods’.[20] With ‘capabilities’ Sen refers to ‘a person being able to do certain basic things […], e.g., the ability to meet one’s nutritional requirements, the wherewithal to be clothed and sheltered, the power to participate in the social life of the community’.[21] In more abstract terms, capabilities are about self-determination; they refer to ‘the various combinations of functionings (beings and doings) that the person can achieve. Capability is, thus, a set of vectors of functionings, reflecting the person’s freedom to lead one type of life or another […] to choose from possible livings.’[22] Only when all functionings are guaranteed can people truly act out of personal choice (and to provide them is seen by Sen as the task of society). The capability approach has concrete consequences for developmental help: For example, one should not begin with economic, but with institutional and social reforms, such as improvements in education and public health, to provide the capabilities that precede a fair economical growth.

Sen’s approach (and in particular Martha Nussbaum’s version thereof) is closely related to the suggested moral-freedom approach; in all these approaches the furthering of a human ability is central to all morality. But while the suggested approach is ‘one-capability approach’ (because the transcendental argument justifies only moral freedom as a central end), Sen takes a broader line; his approach does not focus on a particular capability (and the conditions for its exercise). To be sure, he also *includes* moral freedom as the capability to act morally; at least some of his remarks can be read in this way. In an economic study of India, he and Jean Drèze write:

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[20] Equality of what? p. 220.

[21] Equality of what? p. 218.

[22] Amartya Sen (1992, p. 40).

> Participation also has intrinsic value for the quality of life. Indeed being able to do something not only for oneself but also for other members of the society is one of the elementary freedoms which people have reason to value. The popular appeal of many social movements in India confirms that this basic capability is highly valued even among people who lead very deprived lives in material terms.[23]

An even stronger reference to moral freedom is to be found in Sen's concept of 'agency', one of the two aspects of being a person (the other aspect is one's well-being). *Qua* being agents, humans are striving—and are even committed[24]—to act morally. As Sen writes: 'the agency aspect is important in assessing what a person can do in line with his or her conception of *the good*'.[25] Nevertheless, neither moral capability nor the development of agency is of central ethical value for Sen; he sees them rather as a consequence of the presence of other capabilities. For him people with full capabilities will act, after a deliberative process, in a constructive and just way; although one cannot help but fear that this is a rather questionable optimism about human nature.

Sen's main problem, however, is the demanded support of capabilities *tout court*. Why should all capabilities be valuable, independently of what they are used for?[26] This is neither plausible, nor does it find any rational justification. When Fagin trains Oliver Twist to be a good pickpocket, this is surely not an applaudable expansion of Oliver's capabilities; and similarly much military help for developing countries has obviously expanded the wrong capabilities—namely the ones which aid military aggression. Needless to add, Sen does not wish to include them; but in order to discriminate between good and bad capabilities, the capability approach needs rational criteria—and this is exactly what the transcendental argument provides. (Martha Nussbaum also tries to develop such criteria by suggesting a list of essential human capabilities that she understands as fundamental entitlements in need of political elaboration.[27] Although her list is plausible, it remains problematic because of its lack of proper justification.)

Is the promotion of a moral capability a sufficient or too narrow a foundation for ethics? Do we not have to include *other* moral values for a comparative empirical investigation about what to do? Moral freedom as the only end seems to be under-specified. The suggested approach might lead to very few demands and will not call for changes in grossly unjust situations as long as the people involved exercise their freedom to act morally. When Sen speaks of human agency he raises a similar criticism. The 'well-being' aspect of human beings includes a plurality of interests of a

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[23] Amartya Sen and Jean Drèze (1995, p. 106).

[24] Sen is following Adam Smith's idea of commitment being essential to a person.

[25] Amartya Sen (1985), p. 206.

[26] See for this critique Crocker 1995, p. 167f.

[27] Only then are we able to operate the capability approach according to Nussbaum: "Once we identify a group of important functionings in human life, we are then in position to ask what social and political institutions are doing about them" (Nussbaum 1992, p. 214).

person which have to be considered, while a ‘monist’ focus on agency is rather limited: ‘There is no way of reducing this plural-information base into a monist one without losing something of importance’.[28] In other words, people can surely act morally on a very minimum level; even a starving person might still show her humanity—and often much more than people who have all sorts of material goods.

But let us look again at what exactly the transcendental argument claims to justify. The point was that we need to evaluate the *general* capability to support any good. Therefore moral freedom must be understood in a broad sense—it is not limited to the capability of supporting some specific, but rather *any possible* good thing. Thus to promote moral freedom includes opening the individual’s possibilities of new ways of acting morally. People who are very poor, for example, can surely still do some good things (they can share the little that they have, they can listen to someone in sorrow, and so on), but there are many things they cannot do because their range of action is severely limited. With more material means of acting, but also through education and information, they will be able to expand their reach. An obvious example is the difficulty that many of the rural poor have in acting to conserve nature’s diversity; tropical deforestation and land depletion is often the only way for people to make ends meet. Here, sustainable agroforestry systems that allow for long-term coexistence of the poor and their environment would not only be the most plausible goal, but resulting from the transcendental justification of moral freedom, it is the best way to guarantee this freedom in the long run. Such a rich notion of ‘moral freedom’ will include all that Sen covers with the ‘well-being aspect’ of the human being.

The promotion of moral freedom must be based upon a promotion of negative ‘freedom from constraint’ and also the supply of basic goods (such as food and shelter). To provide these is the obligation of those who are in a position to help those whose moral freedom is under threat. But there are also duties that everyone has with regards to himself. If moral freedom is intrinsically valuable, then we need to care for our own moral freedom as much as for the (conditions of the) moral freedom of others. We are obliged to inform ourselves about others’ needs, but also to develop the skills and ‘talents’ that we need for the acquisition of such information[29]—for example respect for human dignity and rational self-governance, but also other talents that might widen our range or (moral) actions, such as sensitivity for another’s suffering.

Thus the moral-freedom approach will have to be embedded in a hierarchy of rights and goods that must be secured as preconditions of this freedom, it will also include duties towards ourselves—but it will not stop there.[30] Since moral

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[28] Sen 1985, p. 208

[29] Kant has reminded us forcefully how important it is to develop our own “talents”.

[30] One example of the hierarchy of goods-claims approach can be found in Michael Boylan (2004), ch. 3.

values are transmitted through specific moral communities, it will also be important to support *them*: different cultural and religious traditions deserve respect and even support *insofar* as they provide people with an idea of the good—and insofar as the good can only be realised within such moral communities. It is here that the moral-freedom approach transcends the individual as its target; it will consider the individual as part of a group or tradition. But the value of a community is not prior to, or higher than, the individual's value; communities are valuable to the extent that they enable individuals to be morally free. The community's value is also restricted in a second way: Although the moral-freedom approach is open to, and compatible with, very different moral systems (moral freedom is a kind of *meta*-value), it ends exactly where moral freedom is not affirmed. Cultural or religious communities that promote oppression of others or even the limitation of equal moral freedom of its members do not deserve promotion, at least inasmuch as they are directed against general moral freedom. Here the moral-freedom-approach turns into a critical endeavour; help for the poor demands the support of their communities only *as long as they support the moral freedom of its members*.

A danger of paternalism seems to lurk behind the demand for freedom. Do we limit our help for others and their communities proportionally to the extent that they do what we want them to do, namely to support moral freedom? Yes, if paternalism is defined as a practice in which any value of the agent is imposed upon the person most affected by the decisions to be made—but no, if we take the pivotal idea of moral freedom seriously and act in its support. Moral freedom is the condition of any moral system, as the transcendental argument has shown, thus also of the moral system of any other person (if his moral community does not accept it, then it is to this extent logically self-defeating). Thus to respect moral freedom is the best way to respect the values of other people and their power (and freedom) to make decisions. It is therefore not particularly meaningful to call the moral-freedom approach 'patronising'; the point is not to force a value upon others but rather to support a meta-value that is the condition for the possibility of any moral system.

This is also the reason why the moral-freedom approach cannot be seen as a subtle form of *instrumentalisation*. We do not manipulate others, or the poor, so that they help others—we promote their *freedom* to do so; that is why we can never be sure how they will act. Freedom cannot be instrumentalised without losing its central feature, namely it being the capability of self-determination. Thus any successful application of the moral-freedom approach will have to be guided by deep respect for the dignity of all human beings as free agents—or it ceases to be a support of moral freedom.

This is the particular end that Ethics contributes to the demand to help the poor. If we take this demand seriously and look for concrete actions that follow from it, we will have to turn to experts and ask them about the ways in which we can expand the moral freedom of agency in concrete situations.

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Health Care Justice: The Social Insurance Approach

David Cummiskey

Abstract There are four basic models for health care systems: the private market insurance model, the national single-payer model, the national health service model, and the social insurance model. The social justice debate over health care usually focuses on the comparative efficiency and quality of competitive private market insurance and the universal coverage and equity of national health care systems. It is a mistake, however, to think that a universal right to health care services requires a single-payer, government-run, national health care system. The social insurance model of Germany, France, Japan, and many other countries, deserves more attention, as it incorporates the strengths of both market models and national health care models.

Keyword Social insurance, health care justice, right to health care, health care financing, health care reform

Introduction

There are four basic models for health care systems: the private market insurance model, the national single-payer model, the national health service model, and the social insurance model. *Private Market Insurance* systems are for-profit, contractual insurance agreements between individuals and private insurance companies, which are often mediated, negotiated, and financed by employers for employees. A *National Single-Payer* model is a national, government-funded, health payment system. This is the dominant system in Canada and Australia, and the definition also fits the national Medicaid and Medicare systems in the United States. A *National Health Service* system is single-payer and also government-run, with public hospitals and clinics, and medical providers as employees of the NHS system. The British NHS is the paradigm case of this model. *Social Insurance* models are the most common and least understood system of universal health care. Most of the European universal health care systems, including the World Health Organization (WHO)'s top-rated French system, are social insurance systems. The Japanese

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health care system, which is rated by the World Health Organization as the best for mortality and morbidity, is a social insurance system as well.

The social justice debate over health care usually focuses on the relative merits of private market insurance versus the nationalization of health care. The social insurance model deserves more attention, as it incorporates the strengths of both market models and national health care models. It is simply a mistake to think that a universal right to health care requires a single-payer, government-run, national health care system. In addition, the distinction between public and private financing of health care insurance needs to be reconceptualized. Indeed, the "public" financing of social insurance is in many ways similar to the financing of a private market system. Specifically, the social insurance model is funded primarily by employer and employee contributions like private markets. Moreover, the social insurance funds are not run by the government, and yet as in nationalized health care, there is still a public guarantee of basic health care for all.

The Right to Health Care

The right to health care raises a complex array of difficult questions. The nature of the right, the content of the right (i.e., the health care services that are due), the financing of the health care services, and the relationship between patients, providers and payers all raise contentious issues. Here we will focus on the nature of the right and the financing of the health care system. The "right to health care" itself is best conceived as a universal human right that requires society to provide secure and reasonable access to basic health care services. This conception of rights follows J.S. Mill's classic account and Thomas Pogge's recent expanded conception of human rights.[1]

Pogge argues that:

> [b]y postulating a human right to X, one is asserting that any society or other social system, insofar as this is reasonably possible, ought to be so (re)organized that all its members have secure access to X … Avoidable insecurity of access, beyond certain plausibly attainable thresholds, constitutes official disrespect and stains that society's human-rights record. Human rights are, then, moral claims on the organization of one's society.

One way to secure a human right is to have a government-based *legal* entitlement. In the case of the retired elderly, for example, a national social security system, with a legal entitlement to a basic income, may help to secure the basic human right to subsistence for all. It is natural to assume that human rights must be secured by legal entitlements. Alternatively, however, in a traditional Confucian culture, the needs of the elderly are secured by a strong sense of *filial piety* and the responsibility that children assume for the care of their parents and elders. A strong sense of filial responsibility and internalized social expectations motivates adult children to

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[1] J. S. Mill 1979/1861, Chapter 5; and Thomas Pogge 2002, p. 64.

support and care for their parents and relatives.[2] Indeed, filial responsibility may in fact do a better job than a legal entitlement right in securing adequate social security for the elderly. In most cultures, a sense of *parental responsibility* similarly accounts for the basic needs of almost all young children without any direct state social security support. Direct state action is thus one way to secure a right, but it is not the only way. What is important is that human rights are secured. Whether this is done by direct legal entitlements and protections, or social conventions, or civil society and nonstate actors, is secondary; effectively securing the right is primary.

This conception of rights, including the right to health care, leaves open the particular means of securing the right. In principle, if not in actual practice, a market system that in fact provided health insurance at an affordable price could secure the right to health care. In practice, of course, a private market system must be supplemented with alternative funding, or free care, for individuals without adequate wealth or income. A market-based system can also use tax policy in the form of tax deductions and/or tax credits as a supplement and incentive to make health care and private health insurance affordable for the working poor and middle class. In addition to private markets, however, government-based systems like Medicaid and Medicare are usually necessary to provide secure access to health care services for the many who otherwise simply could not afford it.

In the United States, 47 million people, or 14% of the population, do not have health insurance. The uninsured are defined as individuals without any health insurance for the entire year. In addition, even more people, an additional 15–20 million, lack insurance coverage for part of a year. Since the poor and elderly have Medicaid and Medicare insurance provided by the government, the real health insurance crisis is faced by the near-poor and lower-middle class. Of those with household incomes under $25,000, 24% or 14.6 million are uninsured. These families really cannot afford private health insurance and so government programs must be expanded to provide or subsidize insurance for this income group. (In 2003, the average premium for individual health insurance coverage was $148 per month and family premiums were $240–489 per month depending on the region.)[3] Another 15 million households earning between $25,000 and $50,000, or 21%, are also uninsured. These families often could buy insurance but it would involve significant financial sacrifice to do so. Proposals to provide tax breaks or other assistance to help finance health care for this income group may also be appropriate. Surprisingly, however, 8.3 million households earning between $50,000 and $75,000, and 8.7 million earning $75,000 or more are also uninsured. More households earning over $50,000 (17 million) are uninsured than poorer households earning under $25,000 (14.6 million).[4] For these families, the decision not to have health insurance is more of a choice; they have the means to buy

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[2] On Confucian ethics and rights, see Ihara (2004) and Cummiskey (2006).

[3] Kaiser Family Foundation, Update on Individual Health Insurance, August 2004 http://www.kff.org/insurance/upload/Update-on-Individual-Health-Insurance.pdf.

[4] United States, 2005 Census: http://aspe.hhs.gov/health/reports/05/uninsured-cps/index.htm#fig2; and *New York Times*, Magazine, June 10th, 2007, p. 69.

insurance and decide to spend their money on something else that they believe is more important. Since United States hospitals must by law provide emergency room care without regard for ability to pay, and since routine health care is less expensive than health insurance, this choice not to have insurance often is rational for the healthy individual. The overall social consequence, however, is that too much routine care is provided by hospitals and cost-effective preventive care is too often neglected. Consequently, the cost of health care for all is thus substantially higher.

Household Incomes of the Uninsured in the USA
Under $25,000: 14.6 million
$25,000–50,000: 15 million
$50,000–75,000: 8.3 million
$75,000 or more: 8.7 million
Households earning over $50,000: 17 million uninsured

As these income statistics suggest, most of the uninsured are also employed. In 2004, in the United States, 46% of the uninsured had full-time jobs and 28% had part-time jobs. Of the uninsured, only 26% are unemployed. For the most part, uninsured workers work for smaller employers, with 26% working in firms with 10 or fewer employees and another 21% in companies with fewer than 100 employees.[5] The United States problem of the uninsured is not simply a problem of health insurance for the unemployed and poor. If all employee benefit packages included health insurance, the problem of the uninsured would be three quarters solved. Unlike nationalized health care, the social insurance model (explained below) uses mandatory employment-based insurance as the core of universal coverage.

The United States already incorporates a diverse array of health care insurance into a complex system that blends private for-profit markets, nonprofit insurance organizations, and the national, single-payer, Medicaid and Medicare system. The Federal Employees Health Benefits Plan and the State Children Health Insurance Program (SCHIP) are additional government-based health plans. The United States also has the (more NHS-style) Veterans Health Administration with government-run hospitals.

As an alternative to introducing social insurance, as proposed below, it is possible that simply expanding federal health insurance programs and mandating employment-based insurance could go far toward solving the problem of the uninsured without fundamentally altering the private insurance market. In this way, universal access to affordable insurance for all can be addressed by a mixed market system. This is the approach favored by Democratic presidential candidates in the 2008 election. This is also the approach the United States' States of Oregon and Massachusetts have taken towards universal coverage. Republican proposals, on the other hand, emphasize tax deductions, tax credits, and market mechanisms to expand access to health insurance. Both types of proposals have promise, and, in a mixed system, there is no reason why both expanded government-based plans and increased market/tax incentives cannot coexist.

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[5] United States, 2005 Census.

On the other hand, a national system of free public health care that is radically underfunded, seriously understaffed, and lacks an adequate health care infrastructure clearly will not secure access to basic health care services. For example, India offers a government-based legal right to health care for all, but the government program finances only 17% of health care expenditures and private insurance makes up the remaining 83% of expenditures. This statistic strongly suggests that the legal entitlement does not adequately secure the right. Although a nationalized single-payer health care system provides a legal right to health care services, laws alone do not secure rights.

It is simply a mistake to equate a right to universal access to health care services with a requirement to have a nationalized, single-payer health care system. Indeed, social insurance may be a better alternative for building an *additional* health care financing system in both the United States and in developing countries that have an inadequate public health care sector.

The Social Insurance Model

In addition to private insurance markets and government-based national health services, we have to add the extremely successful social insurance systems. The social insurance model originated in Germany with the formation of employment and union-based sickness insurance funds. Although first set up by workers, employers soon joined in the financing of theses funds. Over time, the funds grew and spread across Germany. Starting in 1883 under Chancellor Bismarck's rule, these funds were shaped into a broad and increasingly universal system of health insurance that included regional, territorial funds. The social insurance model is thus often called the Bismarckian model. Nationalized systems are called Beveridge systems and are named after the United Kingdom's Beveridge Report (1942) that led to the British National Health Service in 1948. The alternative Bismarckian model of social health insurance is found in much of Europe, including Austria, Belgium, France, Luxembourg, the Netherlands, Switzerland, as well as in Japan. Both France and Japan have some of the best health indicators in the world. France was rated the best health care system by the World Health Organization and Japan has the highest life expectancy and the lowest infant mortality rate in the world. Health care justice may be best served by the third way of social insurance.

The particular characteristics of social insurance systems vary from country to country. In broad terms, social insurance systems typically involve the following nine characteristics:

1. **Multiple Health Insurance Funds.** Often called "sickness funds," these are nonprofit, quasi-public but independent (nongovernment) organizations, which collect revenues and pay health care providers.
2. **Fund Membership.** Funds were originally occupation-based but now include regional funds, such as funds for small businesses and the self-employed. Membership is based either on type of occupation or geographical region.

3. **Choice.** Social insurance systems may include choice in fund membership and it may include complete choice of providers.
4. **Control.** Representatives of employees and employers are responsible for managing the funds within the constraints of general government mandates, which include basic coverage standards.
5. **Financing.** The health (sickness) funds are financed primarily by employer and employee contributions. Employee contributions are based on ability to pay through a percentage of wages or income, which is set nationally by the funds and/or the government. Employer contribution levels are set nationally by the funds and/or the government.
6. **Risk-Pooling.** Social insurance systems provide insurance to all eligible persons without regard to risk or previous health status. Social insurance always includes a system of risk-pooling, and/or general government contributions, to promote risk-based equity across funds.
7. **Mandatory.** Health insurance is (typically) compulsory for all either through the social insurance funds or individual private insurance. Employment-based funds include all dependent family members.
8. **National Fund.** The employment-based social insurance systems must be supplemented by a general government fund (or funds) for the poor, unemployed, and retired. General government funds also often subsidize co-pays and deductibles for low-income workers.
9. **Private Market.** A private for-profit insurance market provides additional complementary and/or supplemental coverage of services and/or co-pays and deductibles.

Social insurance systems achieve *universal coverage* without a single-payer national government-based health system. Social insurance health care systems are *nonprofit* systems and the fund managers are focused on *balancing costs and care* in the interests of patients/payers. The patients pay for the system in a more direct fashion than in an NHS or single-payer system, and thus efficiency and costs are more directly relevant to patients. In practice, since social insurance fund managers represent patients, the funds can be *more responsive* and more efficient than nationalized health systems. Since social insurance is not a single-payer system, equity across funds is achieved by *risk-pooling*. One of the most bizarre aspects of private for-profit health insurance is its business imperative to sell insurance to those most likely not to need it. Unlike for-profit markets, health funds do not strive to deny health care coverage to the sick. Enrollment in social insurance funds is open to all and coverage cannot be denied based on risk assessment. In short, the funding of the heath care system is more direct than in a nationalized health system, the system is more responsive, universal coverage is required, and the balancing of cost and care is more immediate. It is thus not surprising that patient satisfaction is high.

Norman Daniels has argued that for physicians and providers, saying “No” to patients in a private market system of health care is harder to justify than in a national health care system (Daniels 1986). The first reason for this difference is that market insurance systems are built on profit and so are not “closed systems.” A denial of expensive, marginally beneficial care to one person does not have any clear impact on health care costs, access or quality for others. In a market, micro-decisions that limit care for cost–benefit reasons are just as likely to simply increase corporate profits. In a closed system, on the other hand, limiting access to marginal services for the sake of providing other more beneficial, more cost-effective services provides a more reasonable basis for allocation decisions. Second, in a private market there is no public system for setting priorities and balancing considerations of cost, quality, and access. In a government-run system, especially in democracies, the health care system must be publicly defensible and is thus more likely to be responsive to citizen interests as payers and patients.

Social insurance systems are also closed systems with public accountability, and on both counts are indeed preferable to the nationalized models. Since national government systems are funded by general taxation, they compete with all other government services. Health care cost savings might go to better or cheaper health care, but it could just as easily go to any other government program. As a patient I have no reason to assume that cost savings will go to more efficient care or even lower taxes for all, as opposed to increased funding for defense or corporate tax breaks. In a social insurance system the funding of health care is direct and thus the link between cost and benefits is even clearer than in a nationalized system. In addition, politicians and government officials have many responsibilities, concerns, and constituencies. There is no reason to assume that benefit packages and services will be very responsive to the overall best interest of the people. Social insurance fund managers are more directly representative of payers and patients, and they are clearly responsible for the costs and quality of the health care system. Social insurance systems are thus likely to be more deliberative, responsive, and transparent than both for-profit markets and national health services.

David Eddy has provided an interesting analysis and reconceptualization of the alleged conflict between the individual and society in allocating health care services (Eddy 1991). When health care allocation decisions are made in response to sick patients, more cost-effective care, especially preventive care, is often neglected. From the perspective of the ill patient, the preventive care is obviously too late. If, however, allocation decisions are made from the perspective of a healthy person deciding on a health care insurance plan, the benefit of more cost-effective care is obvious. The conflict is not between sick individuals and society; it is between the position of a healthy person insuring against illness and the position of perhaps even the same person when they are already ill.

To sharpen the point, consider Eddy's example of funding increased preventive screening for breast cancer as opposed to funding high-dose chemotherapy with autologous bone marrow transplant (HDC-ABMT). For the sake of analysis, assume that HDC-ABMT costs $150,000 and that this treatment offers a 5% chance of a complete cure of an otherwise terminal condition. For a 50-year-old woman who is likely to live 30 more years, this treatment would increase life expectancy by 1.5 years (30 × 0.05). Alternatively, suppose that this $150,000 was used for breast cancer screening, at $100 per screening, for women between 50 and 60 years old. This would amount to 10 years of mammograms for 150 women. On the reasonable assumption that annual screening for this age group can reduce mortality rates by 40%, this results in an increase of 12 person years of life. Screening as opposed to HDC-ABMT has eight times (800%) increased efficacy, which is of course an 800% increase for the lives of real individual people. If you are a 50-year-old contemplating whether your health insurance policy should cover either screening or HDC-ABMT, it is clearly rational to choose screening. It is only when health care decisions are made at the bedside, when someone already has cancer, that a person would choose to fund HDC-ABMT instead of screening; once you have cancer, early detection screening provides no benefit. The advantage of a closed financing system and open deliberations is that allocation decisions are made from the perspective of a person deciding what to cover as insurance against illness, and this perspective provides a reasonable and public justification to all for the policy decision not to fund, for example, HDC-ABMT.

Private for-profit insurance markets lack the sense of solidarity found in public universal health care systems. Profits transform the relationship, and cost-effective allocation decisions are perceived as serving the bottom line of corporate interest rather than overall patient interest. Rather than a public decision made in the name of a common and shared interest, we have a private market decision denying potentially life-saving care (or alternatively, a decision to cover a procedure that is less cost-effective and not in the long-term interest of all). In an NHS system, the decision is not distorted by profits but it is still probably made by distant government officials (government bureaucrats, as they say). Social insurance funds are managed by boards representing patients and their employers, and thus are most closely representative of the perspective of persons deciding what to cover as insurance against potential illness.

Both employees and employers want to maximize health outcomes and minimize the costs, which inevitably cut into paychecks. Clearly the more that goes into the health care fund the less is available for take-home pay. Indeed, the overall employment compensation package (wages and benefits) is generally balanced in different countries with different rates of employee and employer contributions. The less (or more) that employers contribute directly to health care funds, correspondingly more (or less) is the direct employee pay; i.e., if salaries are higher, then employer fund contributions are lower, and if fund contributions are higher, salaries are correspondingly lower. Overall compensation packages remain roughly equal across European Union countries with social insurance.

As a final point, social insurance systems can include complete *freedom of choice* in health care providers and funds. On the other hand, the United States private market often denies coverage or increases deductibles for "out of network" providers, and thus restricts patient choice. Furthermore, despite the for-profit market in the United States, patients actually have little market choice or ability to shape benefits and costs. Insurance packages are so complex that employees must defer to employers and insurers, and in most cases they just accept the coverage offered. Private for-profit insurance funds are not run by managers representing employees/patients and employers, and by design must focus on profits to stay financially viable.

On the other hand, choice and competition between social insurance funds can introduce *market forces* that drive efficiency and quality (Paton 2000; Busse 2000). The quasi-public status of social insurance funds provides an interesting mix of public and market characteristics. The lifeblood of private insurance is profits. Social insurance can provide "market forces" focused exclusively on efficiency and health. The life and health of the patient, not the corporation, come first; is it thus surprising that the mortality and morbidity rates are better in countries with social insurance?

The Public–Private Distinction Reconsidered

It is actually a mistake to think in terms of pure models of either private or public health care delivery systems. The United States health care system, for example, is a mixed system with government expenditures of approximately 46% and private expenditures of 54%. The United Kingdom's NHS, in contrast, accounts for 86% of health care costs with 14% private expenditures. The Canadian "single-payer" system accounts for 70% of health care costs. China's communist system is supposed to guarantee a low level of health care for all through a publicly funded system of clinics and hospitals. The Chinese public system accounts for 38% of expenditures and is supplemented by a 62% private market. India's national health care system primarily funds health care through subsidies to health care facilities that offer low-cost or free care to patients. In India, however, the universal health care system accounts for only 17% of expenditures and private expenditures account for 83% of health care costs.[6]

Government and Private Health Care Expenditures

UK	86% government	14% private
Canada	70% government	30% private
USA	46% government	54% private
China	38% government	62% private
India	17% government	83% private

If over 80% of health expenditures are private, it is reasonable to conclude that the *legal* entitlement right to health care in India simply does not provide reasonable and secure access to health care for all. Indeed, on the basis of these statistics, and the per capita government expenditures (India $16 per capita and the USA $2,725 per capita), the United States seems to do a better job than India in actually securing an expansive and effective right to basic health care. Indeed, the United States government also spends substantially *more* per capita on health care than Canada ($2,215 per capita) or the United Kingdom's National Health Service ($2,209 per capita)—despite the fact that it does not provide universal coverage.

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[6] The statistics are from the World Health Organization and these figures are from 2004 in international dollars. See http://www.who.int

Theses statistics do not tell the whole story on the ground, but they do suggest that we need to focus on the more complex mix of public and private financing of health care. Canada's "single-payer" system is supplemented by a 30% private market. The United States private market is supplemented by a 45% government NHS. Consequently, we can say that the United States health care system is 45% "nationalized" and the Canadian "single-payer" system is sustained by 30% private for-profit market. It is thus a mistake to simply contrast the supposed market-based system in the United States with national health care systems. The important question is whether the public–private mix actually provides secure access to health care services.

The health care systems of most countries include a complex combination of public and private insurance. The social insurance health care systems of France and Germany, according to 2004 WHO figures, divide expenditures at about 77% government and 23% private, and Japan divides expenditures at 81% government and 19% private; but *these numbers are misleading*.

As we have seen, these social insurance systems are largely employment-based systems funded by employer and employee contributions. What this means is that for France and Germany, 77% of expenditures flow through the nonprofit health care funds; but not in the more simple form of a single-payer nationalized health care system like that found in the United Kingdom or Canada. The health funds are instead quasi-public, independent, nongovernment organizations, and they are only partially funded by general tax revenues.

Similar to private market insurance systems, social insurance systems are largely funded by employer contributions and employee premiums. For example, in Japan in 1990–1991, the employee premiums and employer payroll taxes funded 56% of health care expenditures (as opposed to only 32% in the United States) and public *government* expenditures in Japan were only 31% (as opposed to 45% in the United States). Out-of-pocket payments accounted for the remainder of private expenditures (Japan 12% and United States 22%).[7] In other words, in 1990–1991, *nongovernment* expenditures in Japan's social insurance system were 68% of total expenditures, as compared to 54% in the United States. Similarly, in Germany the employment-based social insurance system accounted for 57% of all expenditures (covering 88% of the population). Nonstatutory private financing accounted for 25% of expenditures. So, nongovernment expenditures in Germany's health care system account for over 80% of total expenditures.

The French system has a complex financing system of employer and employee contributions directly to particular funds based on wages, and an additional "general social contribution" (GSC) based on total income. The GSC is in some ways more like a general tax, but it is earmarked for social health insurance and thus maintains a clear connection between health care financing and benefits. The funds

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[7] Victor Rodwin, *Japan's Universal and Affordable Health Care: Lessons for the United States?* (with the assistance of Llyn Kawasaki and James Littlehales) New York: Japan Society, 1994. http://www.nyu.edu/projects/rodwin/lessons.html

themselves are quasi-public funds with independent managers. In France, 74% of funding is employer/employee-based, with only a 4% general government share.[8] There are, however, large co-pays in the French system (with government subsidies for low-income families) and also limits on benefits. As a result, increasingly social insurance is supplemented by a complimentary private insurance plan. Indeed, in 2000, 86% of the French population purchased supplementary insurance coverage and this additional market accounted for 12% of total health care expenditures. Another 10% was financed by direct out-of-pocket expenses for a total of 22% additional private costs.

In 2003, 70% of the Swiss also purchased private insurance to supplement the mandatory social insurance plan. The total costs of private insurance (11%), out-of-pocket costs (28%), and other insurance amounted to almost 40% of health care expenditures. Although 60% of Swiss expenditures flow through the mandatory health funds, once again only 25% is funded by general tax revenues with the remaining 35% funded by employer/employee contributions.[9]

We have seen that in many important respects, social insurance schemes resemble the United States employer-based private insurance system. In addition, they also typically have a substantially smaller government-based national health care system than that found in the United States.

Health Care Funding Source for USA and Social Insurance Systems

USA	32% employee/employer	22% private	46% government
Japan	56% employee/employer	22% private	32% government
Germany	57% employee/employer	25% private	10% government, 8% other
France	74% employee/employer	22% private	4% government plus other
Switzerland	35% employee/employer	40% private	25% government plus other

(Private costs include out-of-pocket costs and supplemental private insurance. Other includes alcohol, cigarette, and taxes on pharmaceutical companies.)

Private Markets and Social Insurance

Social insurance funds are quasi-public, nonprofit organizations, and these characteristics, of course, make the social insurance model fundamentally different from a private for-profit insurance market. But from the point of view of the employee's pocketbook, there is no significant difference in how these two systems are funded. The difference is in the results—social insurance funds are simply more likely to

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[8] France and Germany statistics are from the European Observatory, *Social Health Insurance Systems in Western Europe*; p. 106.

[9] Banafsheh Siadat and Michael Stolpe, *Reforming Health Care Finance: What Can Germany Learn from Other Countries?* December 2005; p. 7, 13–14: http://www.uni-kiel.de/ifw/pub/kepp/2005/kepp05.pdf.

be responsive to patient and employer interests in quality, costs, and efficiency, rather than to profits and stock prices.

Indeed, the French social insurance system also incorporates fee-for-service payment of doctors and unrestricted freedom of provider choice for patients.[10] It is thus hard to make sense of the common, too simple-minded contrast between United States market-based and French *"socialist" medicine*. The French, German, Swiss, and Japanese "socialist systems" have significant free market dimensions (perhaps more so than the United States), and the United States market is supplemented with one of the largest per capita National Health Systems (i.e., Medicaid and Medicare) in the world.

As we have seen, the statistics on public and private funding are confusing because, in social insurance systems, the "public share" is funded primarily by employer premiums and direct payroll employee contributions, rather than general tax revenues; in addition, the "public" health funds are not run by the government. In the United States, employers and employees also pay for health insurance directly, but the funding goes through a private for-profit, insurance market instead of a quasi-public, nonprofit, social insurance fund. Social insurance schemes do typically mandate universal coverage, but the health care delivery system is not run from the top down by the government, and it is not funded from the top down with general tax receipts. Instead the health care system is organized into many health care funds that are run by boards selected by employees and employers. Although there is significant government oversight and regulation of funds, as WHO surveys of satisfaction with the heath care system indicate, the fund boards tend to be responsive to the concerns of the members and sensitive to the demands for affordability, efficiency, and efficacy.

All advanced health care systems are expensive. It is clearly simply false to describe health care as "free" in either NHS or social insurance countries. NHS systems are financed by general taxation and thus citizens pay for health care when they pay taxes. The quality of care and access is strongly influenced by government spending on health care, which is limited by tax revenues. If an NHS system increased national spending from 8.1% of gross domestic product (GDP) to the United States spending level of 15.4% of GDP, this would surely have an overwhelming effect on access and services. Since social insurance systems are funded more directly by employers and employees, they are no more "free" than is private for-profit market insurance. However health care is funded, it costs real money, and the particular amount of money is a percentage of the GDP that is not spent on other things. It is an advantage of social insurance that the link between cost and benefit is direct and transparent, but health care is not free. Health care spending in France is 10.5% of GDP, and in Germany it is 10.6%. Social insurance systems may spend a greater percentage of GDP on health care than NHS systems, but this is the result of a public system that sets costs and determines benefits. The higher spending may be directly related to the tighter connection between financing and benefits, and thus the perceived value of better health care. On the other hand, the nationalized system in Canada spends 9.8% of GDP, and the Italian NHS is the second-ranked health

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[10] The European Observatory on Health Systems and Policies Report, *Health Care Systems in Transition: France 2004*; p. 14.

care system in the world while spending only 8.7%. Japan's social insurance system has the best health outcomes with spending at only 7.8%. It is thus hard to draw any tight correlations between spending levels and overall quality. What is clear is that high-quality health care services are never free.

Some argue that employment-based social insurance systems burden employers and weaken *business competitiveness*. This view is probably a mistake. First, if employment-based insurance is mandated for all businesses, as it is in a social insurance system, then there is no competitive disadvantage to any one business. Second, if social insurance leads to better health outcomes, this directly benefits employers with less lost time and lost productivity due to illness. This is one of the reasons that employers in Germany first supported, and why employers in all social insurance countries continue to support, employment-based social insurance plans. It is in the common interest of all employers to have a standard health care benefits package at a set cost. Third, if benefit packages are set nationally or across broad regional funds, employers do not have to negotiate with particular insurers over annual premiums and benefits. Managers of social insurance funds represent employees as a class and employers as a class and set a common benefits package for all. Contribution rates are often set nationally and progressively as a percentage of income. Additional private insurance coverage can be purchased by individuals, if they so desire. Fourth, if there is a national system of risk-pooling, the premiums and costs to particular employers are not affected by the annual risk assessment of private insurers. More consistent health care costs allow for more reliable long-term planning and capital investment. Finally, if health insurance is not tied to a particular employer, the market in labor will be more fluid and this should benefit employers and employees alike with a more productive and competitive work force. In all of these ways, a social insurance system is significantly better for business than a private insurance market.

In the United States, one of the many problems with the health care system is the economic burden on employers and businesses. There is also always the risk in a free market system of a "race to the bottom" where employers have incentives to drop or weaken health care benefits to stay competitive with others businesses that do not provide insurance. The result is a Hobson's choice between an inability to compete with competitors, if reasonable health benefits are provided, or providing no health benefits, with worse health outcomes for employees, less employee satisfaction, and negative public relations. Neither choice is attractive. As a result, to create an equal business playing field and prevent the race to the bottom, many employers, including large low-cost business like Wal-Mart, have joined with workers to support comprehensive health care reform that includes universal coverage.[11]

At the core of national health care or social insurance is a sense of *social solidarity* manifest in a commitment to cover the heath care of all. Some argue that by adding deductibles and co-pays, the sense of social solidarity that is expressed by universal health care coverage is undermined. There is room for debate and disagreement

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[11] *New York Times*, Business, November 13, 2007. A Health Plan for Wal-Mart: Less Stinginess by Michael Barbaro and Reed Abelson http://www.nytimes.com/2007/11/13/business/13walmart.html?ex=1196139600&en=af3ed9092bbffcc4&ei=5070&emc=eta1.

about the wisdom of deductibles and co-pays as mechanisms to help control costs. Assuming, however, that they are justified on overall cost–benefit grounds, they need not offend justice and equity. As argued at the outset, the right to health care requires that access to health care be socially secured. As long as the deductibles and co-pays are reasonable and affordable to all, they do not threaten secure access to health care services. It is important to have deductibles and co-pays for the poor either waived or government paid, but for those who can afford to pay, how can it offend justice to have most payments through payroll and some payments at the point of service? Indeed, the total cost to the individual should be *less* if the initial assumption of cost-efficiency is accurate. If no one is made worse off, and indeed all are probably better off, then there is no violation of justice here.

Private supplemental insurance also raises concerns about the justice of a *two-tiered health care system*. There are two kinds of supplemental private insurance: (i) one provides insurance coverage for procedures or costs that are not covered by national or social insurance, and (ii) the other provides coverage for procedures and services that *are* covered by the national or social insurance. The reasons for this complementary coverage include avoiding waiting lines for public services or upgrading service through more luxurious private hospitals.

The first kind of private insurance, providing additional coverage, is not controversial. The second form of supplemental coverage is more controversial. A health care system that incorporates the first kind of supplemental insurance but prohibits the second kind of complementary private care essentially enforces equity by prohibiting private coverage of basic health care services, but it permits purchasing private insurance for additional services or to cover co-pays and deductibles. An analogy in public education would be a system that prohibits private schools from replacing public schools, but allows private tutors or other educational options that supplement public education. Since such a system restricts freedom of choice, it needs to be justified by some demand of justice or utility. If the private market does not make anyone worse off (i.e., if the benefit to some hurts no one), then it is not a violation of justice. Does the addition of a private system, offering services that are otherwise covered by the public universal system, make anyone worse off?

With private school education a case can be made that the initial educational inequity can result in a long-term competitive advantage, undermining equality of opportunity. Nonetheless, private schools are permitted. We will not here explore why this is so and whether it is justified, all things considered. The case of health care is different. A better private hospital room, for example, is purchased perhaps with greater wealth, but it is not the *source* of a competitive advantage. In general, if society allows significant inequalities in wealth, these inequalities buy better housing and cars and toys. Similarly, private health care allows some to spend their money on private hospitals or providers that they think are worth the extra costs. If inequalities in wealth are justified, why can't it be spent on better health services (i.e., services that go beyond the basic health care services due to all), rather than yachts or penthouses?

One objection to private health insurance is that it enables the better off to jump the queue (or line) and avoid waiting times for access to health care procedures, a consequence that seems unfair to many. Two points here. First, if the queue is unacceptably long so that it is a threat to health, then this is a threat to basic health services and needs to be addressed directly with increased funding and access. In fact, long wait times are more characteristic of NHS systems than social insurance systems. I suspect this is due to the greater responsiveness to patients of social insurance funds and a greater willingness to directly fund adequate health care. On the other hand, if adequate health care is secured by the public system, and the wait-lines are the result of public funding decisions, then the objection to "jumping the queue" is merely an objection to jumping to the front of the line. But people using the private system do not jump to the front of the line; they jump out of the line and switch to the private market, giving up their spots to others. They also freely add more money to the overall health care system through private contributions over and above the tax or employment-based contribution already made. By using private health care, they pay for and support the public health care system that they do not use. This shortens the lines for public services for others and so how is this unfair? In addition, in many countries physicians must work primarily in the public sector with private practice as a supplement. If this is so, the private sector also directly increases the income of medical personnel without raising overall taxes. So, even in systems with significant wait-lines, it is not clear that the addition of a private system hurts anyone and it may also be beneficial overall.

One additional important issue here is whether the private system drains personnel from the public system thus causing a greater shortage of providers. This is most likely an issue in systems that are underfunded generally, but the problem can also be addressed through regulation requiring public service of all private physicians. The question of justice, however, should be focused on the overall impact of the private system on the universal public system and not on the individuals opting for more expensive private care. If the public system is adequate, and secures the right to health care for all, then an additional private system does not offend justice.

One last complication in judging these matters is the difficulty of specifying the basic health care package that is due to all. Clearly, countries with greater overall wealth and more developed health care systems also have an expanded sense of what is due to all. As an objective matter, one can look to see which interventions have the most cost-effective impact on morbidity and mortality outcomes as one indicator of relative importance. This is just a start, however, and many other considerations complicate these judgments. When benefit packages are set through a deliberative democratic process, as they often are in social insurance systems, we have at least a procedurally just system for setting priorities.

Poverty and Public Health

In developing economies, where vast wealth cannot be spent on hi-tech hospitals, public health measures are clearly the most important investment in the health of the people. Clean water, adequate sewage treatment facilities, adequate nutrition, and immunizations have the largest impact on mortality and morbidity. To take one example, in Tibet over the last 50 years infant mortality rates have dropped from the extremely high level of 430 per 1,000 in 1951 to 35.3 per 1,000 by 2000. Life expectancy for Tibetans increased from 36 years to 62 years since the 1950s.[12] These results are due primarily to general public health efforts. In countries with serious poverty, nothing can fight chronic poverty and affect public health as much as free public schools with free lunches, clinics, and immunizations. Education helps break the cycle of poverty; free lunches help fight malnutrition and keep kids coming back to school; and clinics and immunizations directly fight illness and disease. In developing countries, broad public health measures and universal education should be the focus. In the context of serious poverty, more expensive biomedical interventions simply cannot be the first priority of the national government.

As countries develop and markets and employment expand, however, private insurance markets also take off and are available for the emerging middle classes. I suspect in the context of free markets, the emergence of a two-tiered health care system is somewhat unavoidable. Given the clear advantages of social insurance systems, we can expect that laws and regulations that promote social health insurance funds through mandatory employment-based health insurance are likely to mitigate, and, over time, undermine the degree of inequality in access to health care services. It is an advantage of a social insurance system that it can in this way build a broader health care infrastructure on the backs of a growing employment base. Indeed, this is the history of social insurance in Europe; perhaps we can learn from Europe's success.

Conclusion

We have seen that universal health care coverage through social insurance has many of the advantages of private market insurance without the disadvantages. The debate on health care justice needs to focus on social insurance and avoid the false dilemma of having to choose either national single-payer health care or the private for-profit insurance market.[13]

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[12] The United Nations Economic and Social Commission for Asia and the Pacific: http://www.unescap.org/esid/psis/population/database/chinadata/tibet.htm. For a general health analysis, see Zang T. "Physical Quality of Tibetan Population," *China Population Today* vol. 3–4, August 1997, pp. 11–12: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12321518&dopt=Abstract.

[13] I am grateful to all of the members of the Colby, Bates, and Bowdoin (CBB) London program on "Medical Ethics and Health Care Policy in the UK and US" during the Winter/Spring term of 2003. I have also benefited from working with John Butos on libertarianism and the right to health care.

Health Care Statistics Cited

Household Incomes of the (47 million) Uninsured in the USA	
Under $25,000	14.6 million
$25,000–50,000	15 million
$50,000–75,000	8.3 million
$75,000 or more	8.7 million

Employment Status of the Uninsured in the USA

26% unemployed, 28% part-time jobs, 46% full-time jobs
Businesses with 10 or less employees: 26% uninsured
Businesses with 100 or less employees: 21% uninsured

Government and Private Health Care Expenditures		
UK	86% government	14% private
Canada	70% government	30% private
USA	46% government	54% private
China	38% government	62% private
India	17% government	83% private

Health Care Funding Source			
USA	32% employee/employer	22% private	46% government
Japan	56% employee/employer	22% private	32% government
Germany	57% employee/employer	25% private	10% government, 8% other
France	74% employee/employer	22% private	4% government plus other
Switzerland	35% employee/employer	40% private	25% government plus other

(Private costs include out-of-pocket costs and supplemental private insurance. Other includes alcohol, cigarette, and taxes on pharmaceutical companies.)

Health Care Spending as apercentage of GDP; Per Capita and Government Per Capita (Figures from World Health Organization)			
USA	15.4%	$6,096	$2,725
Switzerland	11.5%	$4,011	$2,347
Germany	10.6%	$3,171	$2,440
France	10.5%	$3,040	$2,382
Canada	9.8%	$3,173	$2,215
Italy	8.7%	$2,414	$1,812
UK	8.1%	$2,560	$2,209
Japan	7.8%	$2,293	$1,864
India	5.0%	$91	$16
China	4.7%	$277	$105

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Investments, Universal Ownership, and Public Health

Henrik Syse[1]

Abstract This chapter examines the role of investors, and asks whether they may be able to affect positively international public health. It is often said that most investors primarily take a short-term profit perspective. This chapter introduces the role of universal ownership by large fund managers (mutual funds, retirement funds, and sovereign wealth funds) around the world. Ethics and long-term self-interest can here work together as an engine for positive social change.

Keywords Ethical investing, mutual and sovereign fund management, globalization, Norway

Introduction: "Lifting the Market"

Wherein lies the link between financially motivated investments and public policy questions such as protection of the environment, social justice, and public health? Should investment managers, whose main job it is to safeguard *financial* returns, care about, or try to influence, the way in which their investment objects (most notably, the companies in which one they own stock) impact on society?

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[1] This article is based on an article published in *Corporate Governance*, vol. 15, no. 3, 2007, 427–437 (Gjessing and Syse 2007). I am grateful to my coauthor Ola Peter Krohn Gjessing for his major contributions to that article, many of which (including several formulations and references) are carried over into this article. However, I take full responsibility for the views of the present article. Materials from the previous article are being used with the permission of the original publisher. Thanks to editors Jim Hawley and Andrew Williams as well as the editorial staff and referees for *Corporate Governance* for their valuable input into the previous article, and to the referees for this book for equally valuable suggestions. While this article describes some of the work and philosophy of Norges Bank Investment Management (NBIM), it presents the views of the author, which are not necessarily the same as the official policy of NBIM. The final work on this article was done at the International Peace Research Institute (PRIO), Oslo, and I am grateful for the time and financial resources offered me there.

M. Boylan (ed.) *International Public Health Policy and Ethics*,

Given the division of labor, morally and legally, that exists between legislative authorities, companies, civil society, and financial institutions, it is by no means clear that the financial institutions (nor the individuals and institutions who invest their money through them) have a major responsibility for social side-effects of those investments. Indeed, the world's largest philanthropic endowment, the Gates Foundation, initially replied to charges of irresponsible investing that it was not the job of the *investment* side of the organization to further the goals of the *charitable* endowment.[2] Investments are there to generate returns, not to "do good" *per se*. Furthermore, investors with many small holdings (which is typical of pension funds, reserve funds, and endowments) can do little—or so they often say—to influence their investee companies in any significant way.

However, as the Gates Foundation itself has also admitted, the picture is not as simple as that. Investors, even those with small and widely diversified holdings, do have ownership rights that they can use—such as voting their shares; voicing their opinions at general meetings; requesting information from, and meetings with, company representatives; or communicating with standard setters and authorities about the rules of the market place. Furthermore, widely diversified investors such as pension and reserve funds often have much in common, making up for the limited individual size of their holdings. The commonalities between them are not least reflected in the long time horizon of such funds: they plan to be in the markets for many decades, often with a wide and relatively stable market exposure. They are what we often call *universal owners*: they own not only slices of companies and sectors, but they in essence own a slice of the whole world market, and they plan to do so for a while. This means that, aside from whatever charitable or moral interest in social and environmental questions that individual fund owners or managers might have, a *financial* portfolio interest dictates that one should factor in the link between one's investments on the one hand and the external market effects of the actions of one's investee companies on the other.

This reasoning lies at the foundation of the ownership policies of Norges Bank Investment Management (NBIM), where this author used to be Head of Corporate Governance. NBIM typifies the kind of "universal owner" that increasingly populates the global market place. Total returns for such investors will in the long run most likely be impacted by a number of factors—often beyond the traditional financial and corporate governance agenda. Therefore, a similarly wide spectrum of issues should be on the radar screen.

In this article I will discuss how the concept of universal ownership can be of help in a process to define a rational governance (or "ownership-rights") strategy for investors, which could include public health and similar public policy issues.

Let us first make the following point clear: Universal ownership is about the factors influencing *absolute returns*, that is, actual returns in the form of (inflation-adjusted) surpluses or deficits of the portfolio as a whole, as well as of those parts of

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[2] See, for instance, the *Los Angeles Times* story on January 7, 2007, http://www.latimes.com/news/nationworld/nation/la-na-gatesx07jan07,0,4205044,full.story?coll=la-home-headlines. The Gates Foundation has later said that it would review its investment guidelines and policies.

the market that influence the portfolio. This is important to remember, because absolute returns are largely irrelevant to the many players in the investment community who are mandated solely to produce *relative returns*, meaning they are measured relative to a predetermined benchmark or index, and they are instructed to "beat the market," meaning the index or that part of the index against which they are measured. The special features of active universal ownership as a performance-generating activity warrant the deviating target of absolute returns—or in simpler words: lifting the entire market, often with a long time horizon (and thus a certain amount of patience), rather than just beating an investment target for a given, shorter period. This point is mentioned here to remind the reader that investment policies that aim to increase the overall profitability, functionality, and legitimacy of the wider market (i.e., increase the absolute returns) are not necessarily commonplace to investment professionals. Yet they are increasingly becoming a familiar part of the core thinking within the investment community. This is what we will now delve into.

The concept of universal ownership seems to have become relatively well established, as evidenced, for instance, by contributions to several recent conferences and publications.[3] There is a growing literature on the topic, fueled by among others the inventors of the concept, Robert A.G. Monks and Nell Minnow.[4]

Universal ownership addresses the economics of well-diversified investment portfolios, drawing on now well-understood lessons from welfare economics, as explained by Nobel Prize-winning economist Joseph Stiglitz and others.[5] Monks draws on these insights into market failure, and adds: "*nothing is external to a global shareowner*. Institutions having investments in all countries have virtually no incentive to permit environmental and hiring practices in the poorest countries that can only have the impact of competing with their own investments elsewhere."[6] The same can be said of defying competition laws (or even fighting their very existence) or permitting non-optimal corporate governance practices that may not concern the investor financially speaking in each and every case, but which represent risks to accountability and hence to the prospects of performance in the broader equity market.

The Impetus Behind Active Ownership

For many pension funds and similar funds, active ownership was until quite recently not prioritized highly—to the extent it was considered at all—primarily due to the costs of exercising ownership rights, combined with the small individual

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[3] See, for instance, www.stmarys-ca.edu/fidcap/about-csfc/Overview/CG_Fid_Cap_UO.html, www.corpgov.net, and www.mercer.com/pressrelease/details.jhtml/dynamic/idContent/1246780. See also issue 3 of vol. 15 of the journal *Corporate Governance* (which includes Gjessing and Syse 2007).

[4] For instance, Robert A.G. Monks discusses the special hallmarks of what he calls "The New Owners" in Monks (1998). For recent contributions, utilizing the vantage point of the institutional investor, see Thamoteram and Wildsmith (2006), and Gjessing and Syse (2007).

[5] See, for instance, Stiglitz (2000).

[6] Monks (2001, 105; emphasis in original).

holdings often held by such investors in individual companies. That position has over time been challenged by several factors.[7]

First, there has been a growing expectation among the public that funds of a large total size take ownership seriously, as a matter of moral as well as financial responsibility.

Second, there was the occurrence of major scandals, such as Enron and WorldCom, which led to doubts about whether the owners had been looking after their investments in a prudent way, and whether owners had been active enough in stressing the basic moral and legal expectations that managements and boards must always be held to by their owners.

Finally, as many pension and reserve funds have grown in size, the question of—and debate about—what constitutes the most prudent form of long-term investing has forced active ownership, encompassing environmental, social, and governance-related issues (often shortened ESG), onto the agenda.

It is important to note, however, that active ownership being financially motivated does not preclude its integration into a more explicitly *ethical* framework. The Norwegian Finance Ministry, for instance—which owns the Norwegian Government Pension Fund—has specified active ownership and corporate governance as crucial parts of the fund manager's (NBIM's) and the fund's *ethical* guidelines. The rationale for this is stated in terms of long-term securing of financial wealth, with the crucial annexed point that this overall goal cannot be realized without ethical, social, and environmental sustainability.[8] One could possibly argue that this is disingenuous: How can such attention to social and environmental matters be *ethical* in any real sense, if raising the ethical issues is merely instrumental to an overarching financial goal, namely, long-term securing of financial wealth? However, the ethical component must be said to be more than *merely* instrumental (although it is that, too): it also addresses the right of the fund's owners to know that ethical concerns are indeed integrated into the management of their capital, and it addresses the legal and moral responsibilities that the fund's owners and managers have towards those who are affected by the fund and its capital. These are independent and weighty concerns, which in themselves speak in favor of adopting an ethical framework around fund management. That this also comes across as instrumental *from the fund manager's point of view*—in other words, that the fund manager engages in these issues because it is in line with his or her primary task *as a fund manager* (namely, to secure returns)—does not in this author's view diminish the

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[7] For a good overview of the change from a passive to a more active view of institutional shareholder ownership, see Kim and Nofsinger (2004, 78–87).

[8] See http://odin.dep.no/etikkradet/english/bn.html for an overview of the ethical guidelines. This web site also includes an overview of the work of the Council on Ethics, which is situated outside of the fund manager (NBIM) and gives direct advice on ethically based *exclusions* from the portfolio. The latter are made with reference not to the sustainability or returns of the fund, but with reference to the moral problem of being complicit in the worst forms of human rights abuse through one's investments, however small. The threshold for exclusions is set high, however, meaning that active use of ownership rights remains the main avenue of influence, since the fund (given its size and need for risk limitation and diversification) remains widely diversified rather than positively screened in its investments.

weight of the ethical concerns, although it may limit what *sort of* ethical concerns the fund manager should raise in his or her specific role as fund manager.

What Universal Ownership Means for the Investor[9]

The idea that large institutional investors can be characterized as universal owners is now, as mentioned, quite well established. The basic premise is that the absolute returns of such funds are strongly influenced by the performance of the global equity market.

For this reason, such a fund's long-term financial interest lies with the ability of the global markets to produce sustainable economic growth, and with the functionality of the equity market.[10] Thus, for the fund managers it is relevant to explore how the universal owner concept may influence ownership priorities.

Firstly, we should recognize that free and open markets can facilitate value creation, resource allocation, and development and utilization of ideas globally. Secondly, we must acknowledge that grave market failures such as weak competition, widespread corruption, or excessive harm arising from externalities (such as deteriorating public health or destruction of the environment) may call on public or collective action. The prudent universal investor is therefore concerned both with the freedom and openness of the market on the one hand and its regulation on the other.

Two distinct channels are at an investor's disposal. As a *shareowner* in companies the investor may exert direct influence over its investees, via formal or informal mechanisms, alone or together with other investors. As a major *market player*, the investor may influence standard setting in the markets, both regarding commonly accepted market practices and regarding rules and regulations.

Possible Issues for a Universal Owner

Engagement represents cost, possibly high cost. Beyond voting at company general meetings, therefore, an investor will need to prioritize within the wide range of possible issues that arise upon the recognition of universal owner interests.

Ideally, a fund manager, managing a "universal-owner" type of fund, should rank possible issues according to the likely financial effects of alternative engagement plans. Such analysis would start with an estimate of the economic importance of

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[9] In the following, the term "investor" is used mainly to denote the fund manager or fund management institution (i.e., the "institutional investor"), although it sometimes clearly overlaps with—or even fully includes—the actual end owners of the capital.

[10] Strictly speaking, this interest applies to all reasonably diversified equity investors, not only to investors with shares in thousands of companies. The point is rather that (1) with a very high degree of diversification, the overall market risk dominates over other risk, and (2) with a high number of investee companies, internationally well-diversified funds have a global reach extending to a majority of large-cap companies worldwide.

each problem and the damage it inflicts on long-term fund performance, go on to assess the magnitude of the positive effect that active engagement could have, and finally evaluate the fund's ability to affect such a development.

In practice, such thorough analysis is difficult, as we do not have exact metrics to assess the welfare economics resulting from the interplay of many market mechanisms, and we lack good tools to estimate aggregate effects across diversified portfolios.[11] But we know that some market imperfections or failures can have significant financial importance. For operational purposes—when designing an ownership policy—a realistic approach would be to assess, in rather broad terms, the financial impacts for equity investors of various hindrances to efficient markets, and combine that with a judgment of whether the investor is in a good position to influence the matter.

For example, the issue of climate risk can be assessed in this way. Increasing levels of emissions of greenhouse gases are believed to cause a gradual heating of the Earth's surface, possibly driving rising sea levels, changes to ocean currents, and changing patterns of precipitation, floods, and droughts. This, including the possibility of unforeseeable and abrupt shifts in weather systems, may negatively and severely hamper business opportunities in developing as well as industrialized regions.[12] Greenhouse gas emissions are prominent examples of negative externalities. Thus, the first test is passed: we are talking about serious risk, and possibly high cost to long-term portfolio performance, caused by market failure.

But what about the second test: are institutional investors in a good position to bring about change? Fighting man-made climate change must encompass a parallel deployment of a range of measures. Governments must, among other things, give businesses and consumers better incentives by imposing corrective costs on emissions, via taxes, emissions trading, or other forms of regulation.[13] Authorities may

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[11] For this (and other) reason(s), corporate governance and related issues (that which we above abbreviated ESG: environmental, social, and governance factors) are customarily labeled "extra-financials": their effects on investors' portfolios are hard to measure in exact financial terms, whether on a company or a market level. Several fund managers have, however, worked to show that active investment strategies using corporate governance improvements as a tool to create excess return are indeed successful. A well-known example is the British investment manager Hermes' "Focus Funds" (see http://www.hermes.co.uk/focus_funds/focus_funds_home.htm). See also Strenger (2001) for an overview of the argument that large institutional investors profit from attention to corporate governance and related issues.

[12] The Stern Review on the economics of climate change, published on October 30, 2006, estimates, based on recent scientific evidence, that the aggregate costs of the impacts and risks associated with climate change could lead to a 5–20% welfare reduction globally. In contrast, the costs of action to reduce greenhouse gas emissions to avoid the worst impacts of climate change could be limited to around 1% of global GDP up to the year 2050. See HM Treasury (2006). Some of the calculations of the Stern Review have been criticized, but there seems to be widespread agreement about the Review's main conclusion: that the costs of continuing along a business-as-usual (BAU) track when it comes to carbon emissions will have greater financial and human costs than adopting the necessary measures to significantly reduce the emissions.

[13] There is, admittedly, still some controversy among governments on the exact contours of the climate change threat. However, if we accept that there is a need to end the rapid growth in man-made emissions, there is little doubt that governmental action will be needed.

also support better energy technologies, and support safe carbon capture and storage. All this is mainly in the domain of public policy. Voluntary restraint may help slightly, but it will certainly not be enough.

The most important aim of climate policy is to achieve stabilization and eventual reduction of greenhouse gas emissions, with minimum harm done to value creation and welfare. Speed is of the essence, as emissions are growing considerably. The main issues at the time of writing include whether major emitters such as the US, China, and India will come on board for targeting emissions reductions and adopting core policies, securing binding international cooperation beyond Kyoto's 2012 horizon. The question of continually improving, safeguarding, and possibly expanding the European emissions trading system is also high on the agenda.

It may seem that there is little investors can do here—beyond voicing their general concern and interest—since it is governments that hold the key to the real solutions. However, it is an interesting fact that universal owners (i.e., widely diversified investors with a long time horizon) cannot be certain that portfolio companies do not spend funds campaigning and lobbying *against* investor interest, that is, against more proactive climate policies. Such lobbying, often through powerful industry associations, could have real influence on policy, and widespread (albeit mostly anecdotal) evidence indicates that it has.[14] This gives room for exchange of views between owners and managers of companies, especially since interaction with regulators is likely to be controlled tightly by top management and even the board, the latter being the owners' main interface with the company. So, even if investors cannot directly wield decisive influence on climate policies, that being the domain mainly of public policy, they may be in a position to influence the lobbying activities of the firms they own.

One could object to this conclusion by saying that the investor, having few and relatively light tools only, cannot have real impact on an issue of such huge proportions. But this argument can also be turned around, by saying that engaging on—in other words, addressing critically and openly—corporate lobbying, legitimate and mainly unregulated as that activity is, is a task that can only be performed with legitimacy by owners. Who should talk with companies about this if not their investors?

Hence, there is definitely a room for investor engagement when it comes to a large public policy issue such as climate change, and NBIM has indeed chosen dialogue with major carbon emitters about their lobbying strategies and goals vis-à-vis legislative authorities as a specific focus area within corporate governance.[15]

A similar step-by-step analysis can be made with regard to the international fight against corruption, not least in and around resource-rich countries with weak

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[14] For instance, former US Vice President Al Gore discusses public campaigning strategies by people linked to US carbon emitters in Gore (2006, 260–269).

[15] NBIM has chosen a total of six strategic focus areas so far, two of which are directly related to social and environmental issues. Company lobbying on environmental issues is one of these, children's rights and the fight against hazardous child labor is the other. See www.nbim.no, particularly the thematic articles in the 2006 and 2007 Annual Reports of NBIM, for more detailed information about the focus areas. See also www.nbim.no/Upload/NBIM/CG/Expectations%20childrens%20rights.pdf for NBIM's approach to the issue of child labor and children's rights.

governance.[16] Practices that are prone to corruption can, when seen in isolation, be beneficial to firms willing to play that game. But at the same time, such practices have huge negative external effects, represented by—in aggregate—increased cost and risk, lack of fair judicial treatment, inefficient contract awards, and decreased utility in resource allocation. Corruption and bad governance in many cases play a role in hampering economic development and prosperity. For a number of reasons, corruption, together with other factors, helps keep some countries poor, while idling resources, not least human resources. So, clearly, we are talking about market failure with severe negative impacts on wealth creation and business opportunity, and hence on the likely long-term equity returns of the widely diversified investor.

Having passed the materiality test, we should, as we did with the climate risk issue, turn to the question of whether investors can do anything useful, given the fact that they have limited resources. There are, of course, several aspects of corruption that investors cannot directly and immediately change. For example, practices seen as corrupt by one party may by another party be seen as so ingrained in a culture that there seems to be neither need nor realistic opportunity for change overnight. Indeed, in some cases what are seen as deplorable practices in one cultural context can be seen as absolutely required in another.

However, we can easily presume that many of the investee companies on a daily basis face the dilemma of how to tackle weak governance and corruption risk in societies where they operate, since they quite simply lose money because of the practices involved. Investees in the portfolios of international institutional owners tend to be larger corporations, often multinationals. The individual behavior of these companies may have direct impact on—and their collective conduct must be suspected over time to play a role in—the development of a nation's culture with respect to corruption. By, for instance, forming and adhering to industry norms on anticorruption behavior, groups of companies can indeed play a role. Such norms can be of mutual benefit to participating firms, given, of course, that outsider firms cannot easily get advantageous treatment by not adhering to the standards.

A corporation's attitude to, for instance, bribery will in many cases be part of the overall culture of the organization. Some of the really hard dilemmas, involving large projects or high-value assets, will normally be brought up to a high level of management for explicit or implicit decision-making. Thus, the top management and/or board will very likely be aware of the firm's overall tactic towards the risk of complicity in corruption. Since the main contact point of investors with companies is top management or board directors, they can meet with people who know the attitude of the company on corruption, and who are in a position to influence it. *Inter alia*, investors can ask investees to support and implement relevant anticorruption norms, to ensure that they have sufficient internal controls, and to demand business partners to apply equal standards. It is clearly an advantage in such a process that the well-diversified investor

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[16] An initiative that focuses on this issue, including investor strategies for fighting corruption in resource-rich countries, is the Extractive Industries Transparency Initiative (EITI). NBIM is a signatory to the Investors' Statement of the EITI. (See http://www.eitransparency.org/.)

is likely to own shares in a majority of the competitors within each industry, so it can express the same expectation across the market, regardless of differences as to the firm's legal nationality, listing, or company structure.

Because of their global reach, large institutional investors can thus engage universally in a way that few other players can, and the best way to do this is by acting together with similar institutions, creating more force behind the initiatives, and further supporting the universality of the actions.

It is against the background of these two examples that we now turn to public health. Public health issues clearly have many of the same features as the examples used from environment and corruption. (Indeed, some significant public health challenges today are linked to environmental problems such as water shortages, climate change, and changing weather patterns.) For example, deteriorating health and accompanying poorer quality of workforce resources due to rising levels of Diabetes 2 disabilities in industrialized countries could contribute negatively to the functionality of the affected markets, through rising health costs and more disabled workers facing early retirement or death. Large-scale disabilities and mortality due to AIDS in several developing countries are of a nature that also cripple the financial performance of the affected markets, and that can drive them to a virtual standstill lasting for decades. Universal owners are directly and critically exposed to such risks, and cannot regard them merely as elements in a cynical zero-sum game, but rather as factors working against the long-term financial interests of the portfolio.

But the second challenge remains: What can investment funds and their managers do, realistically speaking, to influence markets on public health issues?

To answer this, several lessons should be drawn from the aforementioned examples. Firstly, investors can monitor and attempt to influence the lobbying activities of companies. Companies will often, with their immediate financial return in mind, lobby against measures designed to address public health issues, such as sugar or tobacco consumption. While investors can hardly persuade companies to lobby directly against their own financial interest—by, for instance, joining in campaigns to ban the very product they are manufacturing—the investor can certainly dialogue with the companies about the strategy and legality of their lobbying aims, seen in the light of widely acknowledged public health concerns.

Secondly, investors can target specific sectors about their impact on public health by addressing the way in which they manufacture their products or make them available. A natural example would be the pharmaceutical industry, which could be challenged—sometimes on a sector level, at other times on an individual company level—to clarify how they can help make life-saving medicines available to wider segments of a population, in order to help address public health concerns. While, admittedly, achieving wider access to medicines must primarily be the task of regulators, not least through patent regimes and taxation policies, companies and trade associations can be targeted by investors in order to clarify their policies and show how they live up to their oftentimes lofty company aspirations. Through increased transparency about how these companies impact on public health, society at large can more effectively assess and influence their actual policies.

It is important to note here that transparency and proper reporting are tools very much at the investor's disposal, since better reporting is often the result of investors asking for specific information, for instance, in connection with the annual general meetings of companies. While legal regulations drive some of the public reporting of companies, investor concerns and pressures are often equally important to the actual quality and contents of corporate reporting.

Finally, investors can help each other single out companies that significantly harm public health through their operations, and recommend such companies for active ownership campaigns or, in the most egregious cases, disinvestment. Large institutional investors increasingly come together in international forums and networks to share strategies and concerns. Increasing the level and intensity of debate among financial investors about public health issues could help make those questions part of the mainstream. The United Nations Principles of Responsible Investment (UN-PRI) launched in 2006 could be a vehicle for such debates among investors, helping identify issues, sectors, and companies that ought to worry investors with a long-term, wide market exposure.[17]

Being a Political Actor Rather Than an Investor?

However, there are also some potential problems when investors take on public health and similar public policy issues from a universal owner perspective. Let us briefly address two of them:

Whether activist funds are—and should be—acting "politically" is a contentious issue. In this chapter, I have discussed how the idea and practice of universal ownership can provide insights that can be of value for financially motivated investors. At the same time, we should be aware that some players in the fund management world can find it tempting to argue along universal ownership lines in order to make room for engagement that is motivated more out of societal beliefs than financial need. While this is not wrong or illegitimate in itself, it is a possible trap for a fund that wants *qua investor* to gain access to—and have real influence on—the top levels of the targeted corporations, and it even represents a potential breach of the fiduciary duty of investors. It is arguably the strong business case that makes the investor

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[17] See www.unpri.org for the United Nations Principles of Responsible Investment. See Waygood et al. (2006) for an illustrative example of public health concerns integrated from an investment perspective. The latter case study, from the UK, shows how investors can successfully encourage companies to adopt better health and safety standards. I should add here (cf. footnote 15 above) that public health is not a special focus area of the Norwegian Government Pension Fund (or of NBIM as the fund's manager) as of today, since other issues have been focused on more explicitly in the 2007–2010 strategy (see www.nbim.no). However, public health concerns are often addressed more indirectly through voting on resolutions that raise such issues, and NBIM is also an active part of an investment community that increasingly discusses and raises issues of relevance to public health. Furthermore, NBIM's engagements on child labor and children's rights often touch on important public health issues in developing countries.

heard in the community of corporations and fellow investors, and raising issues that are political in nature, without any clear link to a business case (for either the investor or the company, or both) is likely to reduce the impact that an investor can have. Furthermore, we could speculate that such potential "abuse" (or at least different use) of the universal-owner argument may prove destructive to the long-term viability of the concept, since the issues raised will no longer be linked to the actual ownership interest, but rather to other concerns and interests. There is a particular danger here for a so-called sovereign wealth fund, such as the Norwegian Government Pension Fund, which invests money on behalf of a national owner. If such an investor is seen to be an overtly political rather than a business-minded actor, suspicions about the investor's ultimate goals will abound, and regulations to hinder it from having influence are likely to be introduced.

Admittedly, there is a possibility that truly fiduciary universal-owner strategies will sometimes be *interpreted* as political, even when this is unwarranted. This is likely to happen partly because such investors will sometimes argue within the field of political debate (both climate change and public health are obvious examples of this), and partly because the arguments conflict with conventional wisdom that holds that each investment should be assessed in isolation. This should not scare investors that are well prepared and have thought their arguments well through, but the problem must nonetheless be kept in mind.

At the same time, we should note the basic and commonsense point that having more than only *one* motivation for one's actions is not in itself wrong. If a company or an investor finds that a business strategy also fulfils other ideals or aims, including political or ethical ones, such motivational overlap can create extra incentives and even usefully broaden one's business concept. Hence, my point here is not that investors and their investee companies should be motivated *exclusively* by business or financial considerations when addressing public policy issues, but rather that it is important to be clear and honest about one's task and role as a business actor. This task and role may very well encompass a host of crucial ethical issues, and having a strong moral voice is rarely a disadvantage. But if it seems that a more purely *political* agenda lies behind or even overshadows one's business case, that could lead to ethical dilemmas (related to one's fiduciary duty) and also real problems in being listened to and taken seriously as an investor.[18]

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[18] Admittedly, the distinction I am hinting at here between "political agendas" and "ethical issues" is not crystal clear. What I am trying to point to is the difference between (1) particular agendas that include goals that are neither business-oriented nor necessarily oriented towards the common good or of those most in need of protection, and (2) agendas or issues that truly speak to the common good or to the needs of the weakest parties involved, while also encompassing the business case. The former will, negatively speaking, easily be labeled "political" (and thus self-interested in a nonbusiness-related way), whereas the latter will more positively be understood as "ethical" in a way that does not conflict with the investor's financial mandate and interest. There is clearly a grey area and much overlap here. For a useful contribution to the debate on constructively integrating the "ethics case" and the "business case" in active ownership and corporate governance, see Solomon and Solomon (2004, 23–29, 187–212); for NBIM's approach to integrating ethics into corporate governance, see Dramer and Syse (2006), and Norges Bank Investment Management (2006).

Do Portfolio Arguments Work in Company Engagement?

The other problem to be discussed in conjunction with universal owner arguments is the following:

The purpose of companies is to set capital to work. What investors, as owners, ask company management to do is to obtain the highest return possible on the capital. This is the simple, yet powerful, mission of investment. This does not capture external effects, and investors may therefore engage with management—boards can in this respect be seen as part of the management—to try to persuade the company to take into account not only the return on capital in that company, but also more complex investor interests, as outlined in this chapter.

But is such engagement credible? I have several times heard of management complaints that one has to listen to lofty ideals and demands made by investor representatives, about whom the management harbors doubts that they have any authority even within their own investment organization. Are corporate governance activists within investment organizations merely do-gooders who do their bit to keep up a nice façade, while others—the investment professionals—do the real, money-making work? More generally, investors must ask themselves whether they have much persuasive power when on the one hand they hold management responsible for achieving the required rate of return, and on the other hand challenge them to forgo profitable opportunities for the sake of something the investor, in a discretionary way, characterizes as "portfolio interests."

Again, we are in a territory of little empirical evidence, but we know that some active investors hold as a rule that engagement in order to be effective must to a reasonable extent be cooperative towards management. Hence, asking management to divert from profit maximization in order to pursue a portfolio interest of the investor will be difficult, especially when universal owner arguments are still the exception rather than the rule.

Being in a company-by-company profit maximization paradigm does not, however, render the universal owner thinking useless. Diversified owners may still do their internal analysis and prioritization on the premise that externalities do in several instances count. Building on this, they can as diversified owners work to create similar expectations and demands for all the corporate actors within the sector, field, or area, thus helping create a level playing field that does not demand sacrifices of some to the advantage of others.[19] As investors, they may also define consistency and sustainability in the value-creating mandates of company management as a constraint in the search for feasible investment and engagement targets. Finally, if the investor cannot find strong business arguments vis-à-vis each individual company for a case derived from portfolio interests, it may be better to explore alternative strategies. Surely, pure business arguments are not the only arguments that can work. When the case is clear, stand-alone ethical arguments can be forceful as such.

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[19] For a strong argument in favor of universal standards and a level playing field in international business, see Smeltzer and Jennings (2001).

When it comes to public health, the main theme of this book, this is certainly the case: appealing to one's moral concern for the preservation of human life or for increased welfare—not *against* one's investor interest but as part of it, and at the same time as a stand-alone ethical concern, in line with widely accepted international norms—can undoubtedly be part of a viable engagement tactic.

Conclusion

This chapter has aimed to show the relevance and possible use of the universal owner concept as well as some of its limitations, highlighting the arena of public health as one of several possible areas for fruitful investor engagement. The chapter is based on a positive belief in the role that institutional investors can and should play in influencing corporate governance. This potential has just recently been fully understood. Indeed, pre-Enron, most investors with widely dispersed investments did not think much about their role as corporate governance actors. Today, when more than 60% of the US stock market (according to 2005 figures from the Conference Board, a US business research group) is owned by institutional investors such as pension funds, many of them with truly long time horizons for their investments, this avenue of influence must be investigated–and used.

In conclusion we should, first, stress that investors have at least two potential avenues for exerting influence: company engagement on the one hand, and dialogue with standard setters such as regulators, stock exchanges, and accounting bodies on the other. In other words, it is not all about *company* engagement, but rather engagement on a wider field.

Second, we should note that there prevails—and should prevail—a division of labor. Investors do not have to act on everything that affects them, as governments and supranational bodies can be assumed to perform many tasks better and more naturally. Investors can, however, on certain occasions find it useful to voice core interests that normally pertain to the realm of governments or public policy, in order to gather extra momentum for change on issues important to investors.

Third, investors can strengthen their business case through collaborative efforts. Acting on universal owner insights (e.g., by forging better governance or by addressing concerns about deteriorating public health) will be beneficial to most diversified investors. By acting together, investors can extend their reach *and* achieve more in each case. There is a possible pattern emerging here: Policy campaigns that are relatively uncontroversial among investors are being executed increasingly well through broad, inclusive networks, such as the International Corporate Governance Network (ICGN) and, in the US, the Council of Institutional Investors (CII). More cutting-edge and slightly less consensus-oriented initiatives are being run through single-purpose bodies such as the United Nations Principles for Responsible Investment. As a third category, investors try increasingly to form informal and more intimate collaboration platforms that can be better suited for engagement at the single-company level. Such collaborations focused around company engagement are finding varying forms, from commercially offered overlay services to common efforts and various coordination activities. Given the "common goods" nature of many aspects of active ownership, investors are likely to continue to explore ways of pooling resources in search of increased efficacy.

Although I have in this chapter also discussed a few of the difficulties with the universal owner argument, I have hopefully shown that the argument can provide valuable insights and good starting points for an analysis of investor ownership policies. Actors concerned about public health, or about the relationship between financial markets and social issues more generally, would do well to factor in the influence and potential power of serious, long-term investors.

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Part III
Medical Need and Response

Toward Control of Infectious Disease: Ethical Challenges for a Global Effort

Margaret P. Battin, Charles B. Smith, Leslie P. Francis, and Jay A. Jacobson

Abstract Despite the devastating pandemic of HIV/AIDS that erupted in the early 1980s, despite the failure to eradicate polio and the emergence of resistant forms of tuberculosis that came into focus in the 1990s, and despite newly emerging diseases like Severe Acute Respiratory Syndrome (SARS) in 2003 and the fearsome prospect of human-to-human avian flu, it is nevertheless a time of some excitement over prospects for effective control of much of infectious disease. Funded by national and international governmental and nongovernmental organizations (NGOs), private foundations, and even popular entertainers, large-scale new efforts are under way to address global killers like AIDS, tuberculosis, and malaria, among others. This "marvelous momentum" can be seen as part of a continuing effort from the time of Jenner onward. Extrapolating from this, we explore the notion of a "*comprehensive global effort for the eradication, elimination or control of infectious disease*," with particular attention to the ethical issues that arise. This is to "think big" about disease-control efforts that are now often done in piecemeal ways. This chapter identifies five tracks along which such efforts need to be pursued: (1) national and international organizations and the development of collective will; (2) epidemiological and health care infrastructure; (3) scientific development; (4) religious, social, and cultural considerations; (5) legal and social protections for individuals and groups. Each of these poses significant ethical issues which, we argue, should be viewed in a comprehensive way, to ensure that practice, research, and policy in each of these areas understands the person with communicable infectious disease as both victim and (potential) vector.

Keywords Bioethics, infectious disease, communicability, victim, vector, AIDS, tuberculosis, malaria, global health, developing world

Introduction

Despite the devastating pandemic of HIV/AIDS that erupted in the early 1980s, despite the failure to eradicate polio and the emergence of resistant forms of tuberculosis that came into focus in the 1990s, and despite newly emerging diseases like

M. Boylan (ed.) *International Public Health Policy and Ethics*,

SARS in 2003 and the fearsome prospect of human-to-human avian flu, it is nevertheless a time of some excitement over prospects for effective control of much of infectious disease. Funded by national and international governmental and nongovernmental organizations, private foundations, and even popular entertainers, large-scale new efforts are under way to address global killers like AIDS, tuberculosis, and malaria, among others. Legal standoffs over patent rights to antiretrovirals and other drugs have to some extent been resolved, and pressure is being exerted for the improvement of infrastructure issues, like clean water and improved sanitation. Research in the identification of pathogens, as well as in the prevention, diagnosis, and treatment of infectious diseases, has made very great progress in some areas, especially in vaccine development and the development of rapid tests, in pandemic forecasting, and in the establishment of globally coordinated disease outbreak surveillance networks. At last, attention is being focused on orphan infectious diseases and the so-called neglected tropical diseases. It is, we think, a moment of growing optimism. Finally, after what has seemed like a long hiatus—roughly since the late 1960s and early 1970s when the then surgeon general was apparently saying that it was time to “close the book on infectious disease,” and concern over infectious disease was slipping out of public view, at least in the developed world—broad and publicly visible efforts at control are now again being made as a central part of the new concern for global health. Progress, it seems, is in the air.

A “Marvelous Momentum” for the Control of Infectious Disease

It is important to understand how very recent the new optimism is—as we write this, it is only about seven or eight years old. In 1999, the Gates Foundation announced that it would contribute $25 million to the International AIDS Vaccine Initiative (IAVI) to further the development of an AIDS vaccine, and the following year dedicated $90 million towards control of HIV/AIDS in Africa, especially to decrease the rates of new infections and maternal–child transmission, and provide resources and training in palliative care to children orphaned by AIDS (Bill & Melinda Gates Foundation 2008). The impressive size of the Gates’ contributions, together with the fact that they came from a private entity rather than a governmental organization, contributed to a new optimism that at last something could be done to try to bring under control one of the world’s most devastating pandemics, one that echoes the plagues of the middle ages and the 1918 influenza.

In the perception of both the public and of many professionals, this infusion of money and energy served as the turning point (Cohen 2006, 162–167) after years in which many institutions and governments, including that of the United States, had done little or nothing to try to stop the AIDS pandemic as a global phenomenon—even after effective drugs had been developed. The wealthy nations, especially the United States, had been attentive to issues of HIV treatment in their own populations and patent protections for their own pharmaceutical industries, but were seemingly oblivious to the skyrocketing death rate in the developing world and the devastation of an entire continent. HIV control on a global scale seemed impossible. However, galvanized perhaps by the infusion of both optimism and cash from the Gates Foundation, within the past decade governments, NGOs, public/private partnerships, multinational corporations, religious groups, and entertainers have rushed to contribute to a far more concerted effort to reduce the global burden of AIDS and with it other infectious diseases as well.

In fact, considerable progress toward the control of infectious disease had been being made during the decades of the 1970s and 1980s in the development of vaccines, anti-infectives, and methods for disease prevention and treatment. With the emergence of HIV/AIDS on a global scale, the public awakened as well. The World Health Organization (WHO) had been making tireless efforts over the years, culminating in the ambitious 3 by 5 program to have three million HIV patients receiving antiretroviral therapy by 2005. Other foundations as well as Gates had been concerned with global health, like the Rockefeller Foundation; so were many national and international governmental institutions. Evolving market forces and improved education also played some role. But the Gates Foundation's immense contribution of private funding to fight AIDS has served as a catalyst, giving focus to many other efforts, both those initiated beforehand and especially those introduced afterwards. Governments of affluent countries have become major donors to efforts to improve global health: the United States, France, Italy, the United Kingdom, Canada, Germany, the Netherlands, Sweden, Spain, Norway, Denmark, and Russia, ranked by size of contribution to the Global Fund as of early 2008, but less affluent countries have also been donors: Romania, Brazil, Mexico, Slovenia, Poland, and Hungary (The Global Fund, 2008). Funds have poured in from multiple sources—a total of some $35 billion, by one estimate, as of January 2006 (Cohen 2006, 162–167). Laurie Garrett, seconded by Paul Farmer, calls this "a marvelous momentum" (Garrett 2007) (Farmer and Garrett 2007) towards assistance in global health.

To be sure, this picture of progress and emerging comprehensive global efforts toward the improvement of global health, and with it the control of infectious disease, is hardly a fully coordinated or integrated one: efforts by one foundation or NGO sometimes reduplicate efforts by another, and related but not-quite-parallel research programs leave gaps where articulation of related efforts might be much closer. Competition between entities, international tensions, commercial agendas, and very different styles of research funding and priority-setting make the picture far from seamlessly smooth. Political agendas sometimes undercut research; research sometimes violates local custom or understandings of fairness; popular misunderstandings sometimes block immunization drives and other efforts to control the transmission of disease. Officials at one organization complain of dominance by another (McNeil 2008). There have been disappointments and failures: the 3 by 5 program for AIDS and Roll Back Malaria, for example, did not meet their ambitious initial goals. Only one million rather than three million people were receiving combination antiretroviral therapy for HIV/AIDS in developing countries by June 2005 (WHO/UNAIDS 2005). Roll Back Malaria's clear pledge in 1998 to cut deaths from malaria in half by 2010 was labeled a failure, its principal contributors admitting that it was "acting against a background of increasing malaria burden"—that is, that malaria deaths were going up, not down. (Yamey 2004, 1086–1087).

Furthermore, attention to infectious disease has been patchwork in character, focusing on some high-profile diseases while ignoring others that cost far more lives. While AIDS, Ebola, and avian flu fuel widespread fear, some ongoing endemic killers, such as infantile diarrhea and childhood acute respiratory tract infections, receive little press and correspondingly little funding or policy attention. Indeed, Solomon Benatar laments the “siloed” character of approaches to infectious disease (Benatar 2005), one disease at a time. Laurie Garrett despairs of “stovepipe” funding: aid that is piped down narrow channels relating to a particular program or disease, ignoring broader needs and concerns: she cites as an example the case in which a government receives considerable support for an antiretroviral distribution program for mothers and children in a specific area, but nothing else. The consequence: mothers who are HIV+ receive drugs for their own infection and to prevent maternal/infant transmission at delivery, but they cannot obtain obstetric and gynecological care or infant immunizations (Garrett 2007, 22–23). Attention to specific diseases has seemed to be quite unequal: while massive research efforts have been directed towards development of a vaccine against HIV, with more than 30 candidates currently in the pipeline, no new tuberculosis vaccine has been developed since 1921, even though the TB bacillus is a technically easier target than the human immunodeficiency virus. In most developing countries the method of diagnosing TB is still the same as that used in 1847.

Yet even if not fully coordinated and sometimes seeming to undercut each other, these disease-by-disease, program-by-program efforts all focus directly or indirectly on a common goal, the reduction of the global burden of infectious disease. Thus these varied efforts can all be seen as a sort of mosaic or kaleidoscope of specific efforts that perhaps all form part of a broader one, coming incrementally into being. The many programs of research in vaccines and antimicrobials, the various water purification and public sanitation projects, the various initiatives for the control of diseases from AIDS to human papillomavirus (HPV)-caused cervical cancer to river blindness, and the multiple legal and social programs like model statutes and pandemic prioritization policies contribute to these emerging, newly coalescing global efforts towards the ultimate goal of control of infectious disease, the details of which are being continuously filled in and modified as the various individual projects are developed and become more fully integrated. We can think of it as a projection forward of current efforts and an anticipation of future ones, an ongoing, overall project under continuous development. Call this still-emerging set of efforts by a unifying name: a *Comprehensive Global Effort for the Eradication, Elimination, or Control of Infectious Disease*.

A Vision for 2020–2030? A *Comprehensive Global Effort for the Control of Infectious Disease*

We want to take advantage of this forward-looking, unifying, optimistic picture of new progress and reenergized enthusiasm over the last seven or eight years to examine the ethical questions a genuinely global effort would raise. After all, practical success as the various components of this overall effort move forward does not entail ethical success, either in their mosaic diversity or as a comprehensive whole.

One way to give the notion of an emerging *Comprehensive Global Effort* concreteness and urgency is to think about what would need to happen if we were to try to bring these various efforts to fruition within a given decade—for example, to imagine implementing it fully within, say, the decade 2020–2030. A clearly defined *Comprehensive Global Effort* imagined as just far enough away to give some time for coordination and preparation would nevertheless be close enough to make a real difference to the world today. This is a somewhat visionary approach, but not just fantasy—rather, it is an approach that looks ahead to a future we can reasonably foresee.

To the degree that such an approach involves extrapolating into the future from current trends, we can hardly be sure what the conditions and events even in the future will be, or whether a *Comprehensive Global Effort* could or will succeed or even partly succeed. It might work; it might not; or it might be only a partial success.

Elsewhere, we have described what we call the "patient-as-victim-and-vector view," or *PVV* for short, as a way to think about issues of policy and practice. It begins with an account of the patient—the person, indeed any person—as physically "embedded" in a web of disease, a "way-station self" who is breeding ground and launching pad for literally trillions of microorganisms, many of which are benign or crucial to human functioning but some of which are dangerous or lethal, and involves three intertwined perspectives through which to take account of the phenomenon of transmissibility of disease: self-views, population-level views, and hypothetical, Rawlsian-like views (Battin et al. 2008). The normative conclusion of the PVV view can be stated simply:

> *Ethical problems in infectious disease should be analyzed, and clinical practices, research agendas, and public policies developed that always take into account the possibility that a person with communicable infectious disease is both victim and vector at one and the same time.*

Using this view of the patient as both victim and vector, we can reasonably foresee something about the ethical challenges that can be expected to arise along the way as the *Comprehensive Global Effort* proceeds, and it is these challenges we wish to explore here.

A more pessimistic version of the same projection of a *Comprehensive Global Effort* despairs of the possibility of ever achieving control of infectious disease or doing so within a specific period of time. It asks instead what are the crucial features in delay—what factors are operating now or might operate in the future to make such a goal unattainable? Could the fearsome prospect of virtually total collapse of public health portrayed so effectively by Laurie Garrett in *Betrayal of Trust* (Garrett 2001) be inevitable? Could the effects of climate change and global warming destroy advances in environmental preventatives like vector control, or could the expansion of warfare and ethnic cleansing, especially that which employs deliberate tactics for spreading infectious disease, undercut any progress in disease-control programs? And what ethical failures in disease control are becoming increasingly evident, and what ethical objections might be so strong that they would be sufficient to warrant blocking of any attempt to undertake comprehensive global efforts?

Leaving these concerns aside for the moment, the optimistic picture we explore here of an emerging *Comprehensive Global Effort for the Control of Infectious Disease* is in one sense an elaboration and expansion of a comparatively simple thought-experiment about airport surveillance for infectious disease, a way of considering what constraints would be acceptable in the effort to eradicate, eliminate, or control the serious human infectious diseases. This thought experiment considered the possibility that rapid testing (and treatment) were available for all the major infectious diseases—and asked whether it would be permissible to require such testing of everyone before they boarded an airplane. The inconvenience would be limited—just a cheek swab, a short delay (perhaps 20 minutes, perhaps as short as 120 seconds), and of course a longer delay with treatment if necessary—but the possibility of reducing the global burden of infectious disease would be immense (Battin et al. 2008, chapter 15). In another sense, it is a projection of the overall direction we discern in the many somewhat disparate enterprises already under way, a description of an overall project on which many organizations around the globe have already embarked. And in yet another sense, casting a *Global Effort* as highly time-focused, pursued within the specific decade 2020–2030, looks very much like a plan, something we are already embarked upon and should continue pursuing.

This essay's account of a *Comprehensive Global Effort* can thus be read in at least three not fully distinct ways. It lies somewhere between a sheer thought-experiment ("What if the serious human infectious diseases could be brought under control?"); a factual account of events that are now taking place ("Look at all the remarkable progress that is going on!"); and a practical proposal with a concrete, dated plan ("What would it take to bring the serious human infectious diseases under control, and to do so—this is the visionary part—*by the end of the decade 2020–2030*?"). The power of a thought experiment is to help identify moral fault lines (as in our airport thought experiment), and the importance of a factual account of what is actually going on is to remind ourselves of the very substantial progress, as well as backsliding, that has been made so far. And the heuristic device of a time-pressured feature, of imagining the culmination of this *Effort* in a fast-approaching, specific, and limited period of time—the decade 2020–2030—emphasizes the real-world challenges of global coordination and cooperation, if that is what would be necessary to bring the serious human communicable diseases under control. But most important for our concerns here, this chapter's broader and far more realistic exploration of what is afoot in the new "marvelous momentum" of efforts to reduce the global burden of disease also involves exploring concrete moral claims about what would be required to make this immense global effort go *ethically* well.

Some authors suggest that the moment for such a project is already past. Robert Baker, for instance, contends that humankind has "squandered" the opportunity to usher in a "Golden Age of protection from disease" (Baker 2007). But that does not preclude a renewed, reinvigorated, and better-orchestrated effort as a revitalized attempt, something we see as again under way.

Other global efforts are also beginning to attract at least some measure of global cooperation—for example, controlling global warming; rescuing endangered species; securing equitable access to water or establishing water justice; developing alternative energy sources; managing immigration; controlling drugs; and eliminating terrorism, ethnic cleansing, and war. But a common goal of the eradication, elimination, or full control of serious, human-affecting infectious disease may be, as we will consider later on, both more practicable and less controversial than these others, even though like them it may involve quite controversial policy initiatives.

In a *Comprehensive Global Effort*, coordination of effort or at least simultaneous effort on many different fronts is crucial, since many of the factors that need to be addressed are highly interrelated with others. Scientific advances accomplish little without infrastructure improvement, for example, or environmental control. Institutional cooperation and legal protections are inadequate in the face of cultural and religious attitudes that vilify carriers of infectious disease as sinful individuals, or characterize outbreaks of infectious disease as an appropriate scourge for sinful populations. To think about an emerging, overall, coordinated globe-wide project is to "think big" about all the factors across the board that affect how we might address a challenge to human well-being that had almost disappeared from ethical dialogue in the late 1960s and early 1970s, before renewed ethical debate with the emergence of HIV, even though advances like the development of new antimicrobials and the eradication of smallpox were proceeding apace. It is such an ongoing project that has now come into view again with real force, reenergized and far more publicly visible in the last seven or eight years, and that makes it imperative to "think big."

"Thinking Big," Both Practically and Ethically

A number of "think big" efforts toward reducing the global burden of infectious disease are already under way, practical efforts of a variety of sorts focusing on social realities and scientific gains. The United Nations Millennium Development Goals (MDG), for example, represent an effort to think globally about health and related problems (United Nations 2008). The Gates Foundation's Grand Challenges in Global Health Initiative is also global in scale: it seeks to achieve scientific breakthroughs against diseases that disproportionately affect the two billion poorest people on earth, though of course diseases like AIDS and tuberculosis can affect people everywhere. The Council of Science Editors has organized a global theme issue on poverty and human development involving more than 230 science and biomedical journals, focusing among other things on interventions to improve health among the poor (Flanagin and Winker 2007). These are all invaluable efforts involving the many, many parts of the overall picture, and they all "think big."

At the same time that practical efforts are converging in the effort to control infectious disease, there is an efflorescence of efforts to consider the ethical issues involved. With the exception of those directed to HIV/AIDS, most date from 1999 or later, and recent attention to the ethics issues in pandemic influenza planning has been particularly extensive. Documents like that from WHO by Coleman, Reis, and Croisier (Coleman et al. 2007) articulate policies; others, like the American Civil Liberties Union (ACLU) document authored by Annas, Mariner, and Parmet (Annas et al. 2008), vigorously critique policies already developed on the basis of ethical inadequacies. And a major effort has been mounted by the Bill & Melinda Gates Foundation to look specifically at the ethical issues in the emerging concern with global health: this is the ethical, social, and cultural program that is funded under the Grand Challenges in Global Health Initiative, designed to use bioethics considerations to assess the specific Grand Challenges projects that are planned or are currently under way (Singer et al. 2008). Elsewhere we document how infectious disease had been left out of bioethics during that new field's formative years (Battin et al. 2008, chapter 4); now it is moving back in, so to speak, with extraordinary rapidity, making up for a couple of decades of lost time.

However, much of the burgeoning new work in the ethics of infectious disease employs the conceptual categories of traditional bioethics that were developed without specific attention to the moral issues in transmissibility. To be sure, this may be perfectly adequate in addressing issues like caged field trials of genetically modified mosquitoes, as is the subject of one of the current projects under the Gates Foundation's Grand Challenges program, but the traditional approaches of bioethics' usual ethical framework within which projects are assessed needs, as we argued there, to be augmented and expanded.

Of course, many writers and theorists already instinctively appeal to both victim-related and vector-related concerns, but as far as we are aware none have done this explicitly or systematically in a way that would *guarantee* that both concerns would be addressed in any given issue. This is what we have sought to do with our PVV view. Hence, we like to think of our objective here in exploring the notion of a comprehensive global project as in concert with, and indeed admiring of, the many efforts now afoot to explore the ethical issues in infectious disease, but pushing them a good step further—a step we believe necessary for morally adequate reflection on a very broad scale.

What, then, would be involved in a *Comprehensive Global Effort for the Years 2020–2030 for the Eradication, Elimination, or Control of Infectious Disease*? We point to both practical and ethical issues that would arise along at least five different though interrelated "tracks": (1) What would be desirable in the spheres of national and international policy? (2) What would we need to bring about in terms of epidemiological and health care infrastructure? (3) What are the most crucial lines of pursuit in scientific development? (4) What would need to be thought about in light of religious, social, and cultural considerations? and 5) What would need to be developed as legal and social protections for individuals? These five are all critical areas for research and policy development, most of them interdependent upon each other, and all raising substantial ethical issues we will sketch here.

This *Global Effort* is not to be imagined as starting from zero. On the contrary, many of the critical areas in Tracks 1–5 are already well known to participants in current efforts to address infectious disease across the globe, from researchers and clinical health care providers to immense organizations concerned with global health. Indeed, everyone and every organization working in infectious disease participates in some part of the global project explored here, whether aware of the emerging comprehensive effort or not. It is already in progress—indeed, in full swing.

Global Efforts: Results So Far

Can we even imagine a *Comprehensive Global Effort for the Eradication, Elimination, or Control of Infectious Disease?* Indeed, in many respects the world is already halfway there, at least in developed countries. It is important to remember as we entertain the notion of a *Global Effort* the impressive list of infectious diseases affecting humans for which effective vaccines, treatments, or preventive measures have been developed. Some of these diseases have already been eradicated, eliminated, or brought under control in the wild, though for many methods for prevention and treatment are known but not available in much of the developing world.

Here is a snapshot taken at the current moment in history of our progress so far in bringing the serious human infectious diseases under control: it is a shifting picture and highly variable from one area to another, but a picture of extraordinary achievement just the same. Some is due to the development of effective vaccines or drugs, some due to quality-of-life improvements and infrastructure development, some due to effective preventative measures, and some due to accidents of geography or environmental change, as with alterations in the ranges of animal or insect vectors.

Here is a partial list of human diseases that have been eradicated, eliminated, or can be well controlled by vaccines or effective therapies. Among these are:

- Smallpox
- Leprosy
- Plague
- Yellow fever
- Pertussis (whooping cough)
- Syphilis
- Diphtheria
- Tetanus
- Rabies
- Measles
- Mumps
- Polio
- Varicella (chickenpox)
- Rubella (German measles)
- Invasive pneumococcal disease

- *Hemophilus influenzae* type B
- Hepatitis A and B
- Meningococcal meningitis
- Japanese encephalitis
- Seasonal influenza

Other infectious diseases, particularly those common in developing countries, have effective therapies or methods for control, but these controls have not been widely implemented. They include:

- Tuberculosis
- Malaria
- Trypanosomiasis (sleeping sickness, Chagas disease)
- Cholera
- The "neglected tropical diseases" for which effective oral treatments are already known (Reddy et al. 2008, 1911–1924):
  - Roundworm
  - Whipworm
  - Hookworm
  - Schistosomiasis (snail fever or bilharzias)
  - Elephantiasis
  - Trachoma
  - River blindness

Still other infectious diseases remain essentially uncontrolled or currently lack any effective vaccines or therapies, among them:

- Ebola
- Marburg
- HIV
- Dengue fever and dengue hemorrhagic fever
- West Nile virus
- Hantavirus
- SARS viruses
- Leishmaniasis (sandfly fever)
- Creuztfelt-Jakob Disease and variant Creutzfeldt-Jakob Disease
- Food-borne toxigenic E. coli
- Evolving highly antimicrobial-resistant strains of tuberculosis
- Influenza type A

So far, successes in reducing the burden of disease in the developed world have been remarkable. In the United States, the death rates for smallpox, diphtheria, and polio have declined by 100% since vaccines were approved; for another nine diseases, they have declined by 90% (McNeil 2007). To be sure, there have been major setbacks (like the reemergence of tuberculosis, polio, yellow fever, even plague), but in general progress towards the full control of infectious disease is astonishing—at least where it is fully implemented, as in the wealthy parts of the world. In contemplating the possibility of eradication, elimination, or control of the serious human infectious diseases, it might be said, we are halfway there, at least in the developed world.

Human Health in Epidemiological Perspective

The already impressive successes of an emerging *Comprehensive Global Effort*, if we can think of them as part of a long-term effort, are after all evident in the history of demographic shifts in causes of human mortality. Up through the middle of the 19th century, everywhere in the world, parasitic and infectious diseases were the principal cause of human mortality (Olshansky and Ault 1987, 207–217). With the development of clean water, public sanitation, immunization, the germ theory of disease, hand washing by physicians, antibiotics, and many other factors, infectious disease (with the single exception of pneumonia) is not even on the standard list of the top ten causes of death in the developed world. At the same time, infectious diseases remain a major factor in the developing world, where death rates particularly for children remain high. Just a century or two ago, infectious and parasitic diseases were the way most people everywhere in the world died; in the developed world, they are a much reduced threat, and where they do kill, kill mainly the old. Infectious disease mortality in the United States has declined remarkably in the past century, and now represents a small percentage (<5%) of disability-adjusted life-years lost (Armstrong et al. 1999). The stark differences in life expectancy around the world, ranging roughly from a high of between 75 and 86 years for both sexes in Japan, Australia, Iceland, Canada, the Netherlands, Cuba, and the United Kingdom at the top end of the range, downward to 40–60 years in the poorer, developing nations, and in some countries, like Malawi, Mozambique, Zimbabwe, Zambia, still lower, to Sierra Leone, with a low of 37–40 years, is not just a matter of disparate human development indices but differential death rates from infectious disease (World Health Organization, data for 2005). A *Comprehensive Global Effort*, it is painfully obvious, has already been very largely successful in the developed world—this may be part of what has allowed the developed world to become developed—but has a long, long way to go in those countries left behind.

Is a *Comprehensive Global Effort* Realistic? On Eradication, Elimination, and Control

It is crucial in understanding any *Global Effort* to recognize the differences between eradication, elimination, and control. Complete eradication by eliminating entirely the pathogen which causes disease is realistic in only a small proportion of cases, those which involve human vectors only and no intermediate stages: e.g., smallpox, polio, measles, and tuberculosis. The eradication of all human infectious disease—that is, completely ridding the world of all disease-causing pathogens in the wild—is not a realistic goal, since many human-affecting infectious diseases also have nonhuman vectors or reservoirs. Tetanus, for example, lives in the soil; so do the spores of coccidioidomycosis, a fungal infection responsible for valley fever (McKinley 2008). Malaria involves a transmission stage in mosquitoes; so do yellow fever, dengue fever, and many other arthropod-borne infectious diseases. Other common infections—such as staphylococcal skin infections, or peritonitis due to ruptured bowel—are due to organisms that we normally carry on our skin or in our gastrointestinal tracts, and attempts to eliminate one pathogen would be foiled by the rapid appearance of other potential pathogens to refill the microbial niche in the skin or gastrointestinal (GI) tract.

Furthermore, many pathogenic organisms do not require humans for their perpetuation and are not acquired from other humans. Elimination of these organisms in humans, for instance by means of universal immunization or effective treatment, would still not eliminate these organisms, and the diseases they cause will remain a continuing threat. Some human-affecting diseases also affect animals and are carried by animals—Rift Valley fever, for example—and unless contact between these animals and humans were completely interrupted, control of these diseases in humans could not be complete without achieving control in the animal population as well. Some pathogens affect both people and plants, like the bacterium *Burkholderia cepacia* (people and onions), which can be lethal for people with cystic fibrosis, or *Serratia marcescens* (people and squash plants), which reaches immunocompromised hospital patients through floral arrangements, salads, and intravenous tubes (Milius 2007, 251); it is hard to see how these pathogens could be entirely eradicated. And some infectious diseases, such as influenza and HIV, reappear in modified form and potentially require ongoing prevention or treatment in generation after generation. At this point in the human history of infectious disease, there is just one extant example of complete eradication: smallpox. But there are many examples of elimination, that is, reduction to a very low level, like leprosy, plague, and polio, the latter on the verge of eradication despite recent outbreaks. And there are many examples of full or nearly full control, at least in the developed world, where disease is preventable, treatable, or curable by means of immunization, antimicrobials, sanitation measures (e.g., clean water), or other effective prevention or treatment.

Of course, there is an immense gap between diseases which can be eliminated and diseases which are in fact eliminated. Leprosy, for example, falls in this category, as do many of the so-called neglected tropical diseases for which effective treatment is known but not widely available: here the gulf between the developed world and the developing world is at its greatest. It is already possible in principle, despite enormous practical obstacles, to reduce dramatically much of the huge burden of disease suffered by those in poorest parts of the globe, and as new diagnostic technologies, vaccines, and treatment modalities are developed, so does the likelihood of elimination or full control for many additional diseases.

Obviously, even in the developed world control of infectious disease will never be complete. There will always be newly emerging diseases: in recent years, some

39 new communicable diseases with the potential to become pandemic have jumped species, including SARS, monkeypox, and bird flu (Rubin 2008). The prospect of newly designed or already known pathogens used as bioweapons cannot be ruled out (Selgelid 2007; Zilinskas 2007). Climate change, settlement of newly cleared land, and warfare and its dislocations can also play a role in the emergence or evolution of disease.

Some theorists might argue that certain serious diseases should not be eliminated because they are useful in other respects, as when pneumonia serves as the "old man's friend," a bringer of death more easeful than that from other human maladies. Others might point to research suggesting that exposure to infectious disease has played a major role in mammalian evolution, resulting among other things in the development of the amniotic sac and other adaptive advantages (Zuk 2007), and thus argue that continuing exposure should not be eliminated, lest further evolutionary gains be lost. Still others claim that the overuse of antibacterial soaps and other "germ-proofing" methods results in higher rates of asthma and allergies. A *Comprehensive Global Effort* certainly would not seek to exterminate all parasites, fungi, bacteria, viruses, and prions (the microorganisms that affect human beings), since many are essential for human health, but only the pathogenic ones that do not have beneficial functions and are responsible for extensive human morbidity and mortality. It is this process of overcoming *disease* that we see as already well under way in any long-term *Comprehensive Global Effort*.

We may ask, then, phrasing the question in three ways that correspond to seeing a *Comprehensive Global Effort*—as a thought experiment, as a report of current activity, or as a plan—what would it be like if, what is happening that, or what do we need to do to try to achieve the eradication, elimination, or full control of serious human-affecting infectious disease, say within the decade 2020–2030, around the globe? The question, in each of these forms, is not just about what practical projects of research, policy development, or implementation would be most urgent, but also about what ethical issues most urgently require attention as a *Global Effort* proceeds.

We suggest five tracks along which to consider these questions.

Track 1: National and International Organizations and the Development of Collective Will

If a *Comprehensive Global Effort* is to succeed fully, it would be important to foster the cooperation of institutions and players of all sorts, public and private. Many are already committed—but not all. Thus a first part is to consider what sorts of institutions are critical to infectious disease control, which are helpful, which are problematic—and how the support of such institutions could be enlisted and maintained, or modified where it has been counterproductive. This is to seek to establish and maintain the collective, global will to try to reduce the global burden of infectious disease as low a level as possible. The practical challenge is to develop the global political will to try to work together to bring infectious disease under control in the first place, and it is a substantial challenge. If the many sorts of institutions are all to cooperate, it would require laying aside infighting, reducing political competition, avoiding distraction by shifting from one to another "short-term numerical target" (Farmer and Garrett 2007), avoiding turf wars, and other things that could derail progress (Cohen 2006, 162–167). Could all these institutions contribute cooperatively in their myriad ways to a common project, even for just a decade? How such matters should be addressed is a crucial issue for reflection in the development of this track of a *Global Effort to Close the Book on Infectious Disease*. After all, the *Effort* cannot succeed, or succeed quickly, if some institutions undercut the efforts of the whole.

Track 2: Epidemiologic and Health Care Infrastructure

Track 2, epidemiologic and health care infrastructure, is widely recognized as indispensable in the control of infectious disease. The absence of adequate health care infrastructure, including the absence of adequate diagnostic and surveillance measures as well as adequate immunization and treatment measures, can contribute dramatically to the unchecked spread of infectious disease. An outbreak unnoticed (or ignored) can have an immense amplification effect down the road; the "stitch in time" approach to infectious disease is key to prevention, in that it is almost always easier to stop one case now than ten cases down the road—or a hundred, or a hundred thousand. Poverty and war have crucial amplifying effects: diseases that might be mild or resisted altogether by individuals who are healthy and well nourished may spread rapidly in disrupted conditions where people endure malnourishment, parasites, and chronic illness. Natural disasters can also produce similar effects, if populations are cut off from care, and if the conditions of the disaster—standing water after a flood, for instance—create risks of disease. Economic practices can also affect disease transmission: for example, the practice common in many developing countries that physicians see private patients rather than poor, charity ones, exacerbates disease transmission, since it is poor, charity patients who are most likely to be afflicted because of their crowded living conditions and lack of access to clean water and adequate sanitation.

Poverty, war, and natural disaster are also typically associated with inadequate infrastructure: for those who do become ill, health care is hardly available; clinics, if there are any, are overcrowded; personnel are inadequately trained and hopelessly stressed; medications are outmoded or unavailable. Poverty and war are often closely intertwined: northeast Kenya, for example, has a million refugees from Somalia, people for whom the risks of infectious disease are compounded over the already difficult lives they had previously led. Another 300,000 have been internally displaced following the postelection violence in early 2008, and the chief among the many health risks they face is cholera (Harvard World Health News 2008). Life in refugee camps or urban slums, often without adequate sanitation facilities, is, as our PVV view might describe it, life most fully "enmeshed in the web of disease," life in which people are most obviously "way-station selves" as microorganisms travel unchecked among them. Thus, in seeking greater control of infectious disease, attention to social and sanitary infrastructure issues is crucial:

- Clean water
- Sanitation
- Waste disposal
- Control of insect and animal vectors (mosquitoes, fleas, rats, etc.)
- Control of environmental toxins
- Health-related transportation, including roads or airlifts and other ways of bring health care to people in remote or disrupted communities
- Enhancement of health care delivery systems, especially vaccine delivery systems, treatment facilities, and easy-access clinics
- Encouragement of use of low-tech, low-cost modalities for infectious-disease prevention: bed nets (Bradley 2007), water filters, "drinking straws," and pond attendants, etc.
- Development of novel health care delivery modalities, e.g., *accompagnateurs* (Farmer and Garrett 2007) as Partners in Health has utilized in HIV/TB treatment in Haiti
- Attention to the causes of poverty associated with infectious disease, particularly those associated with the neglected tropical diseases and with disease outbreaks among dislocated populations like refugees
- Attention to the causes of war, civil conflict, guerilla actions, and related hostilities that exacerbate the risks of infectious disease
- Rapid response to natural disasters, with particular attention to special characteristics of a disaster that might encourage the spread of disease

Ethical questions associated with this enormous variety of concerns might range from consideration of who should receive how many bed nets and what they may or may not do with them, to requiring contributions or labor for the installation of sanitary systems, to the very substantial privacy and confidentiality issues that arise with local and global surveillance systems. Modeling methods used in planning, whether for endemic disease in poverty and war or for outbreaks associated with pandemics of newly emerging diseases or in natural disasters, are of particular ethical significance under the PVV view, since they often incorporate assumptions about what levels of disease can be tolerated; the PVV view warns against cavalier acceptance of leaving a significant proportion—indeed, any proportion—of a population still subject to preventable or treatable disease, since that is to ignore the fact that those who suffer disease are indeed victims.

Particularly important under the PVV view is attention to how large-scale programs are formulated. Classic epidemiology tracks disease movement through populations. Research agendas focus on issues of particular salience in specific populations but leave aside others. Treatment programs often target just those populations or population subgroups at highest risk of contracting and transmitting disease. There are obvious advantages of design and efficiency here, but at some moral cost. Our PVV view insists that those left outside these categories—people not in high-risk groups who nevertheless contract disease, people whose groups are not the focus of research efforts, and sufferers from "orphan diseases"—be recognized too, both in their own roles as vectors but especially as victims.

Track 3: Scientific Development

Effective control of human infectious disease cannot be possible without continuing scientific development. Examples of scientific efforts—many already well under way—that would be essential to achieving any measure of success involve better diagnosis, better treatment, better mechanisms for prevention, and better background science in the understanding microbial pathogenesis, defense mechanisms in humans, and evolutionary, genetic and other factors relevant to human vulnerability to infectious disease. The Gates Foundation's handsomely funded Grand Challenges in Global Health program already includes some 14 research incentives which serve seven long-term goals in global health: improving childhood vaccines, creating new vaccines, controlling insects that transmit agents of disease, improving nutrition to promote health, improving drug treatment of infectious diseases, curing latent and chronic infection, and measuring health status accurately and economically in developing countries (Singer et al. 2007). These are immense important goals; many others are in progress or remain to be developed. A group of comparatively realistic research goals would include:

- Improvement or development of rapid, reliable tests for all infectious diseases, based on PCR, proteomic, or nanotechnology methods:
  - Goal: 100% specificity, 100% sensitivity: 0 false positives, 0 false negatives, including field-usable tests available at point-of-care
  - Goal: rapid speed of identification, in minutes or seconds
  - Goal: low cost, easy use
- Improvement of genetic identification methods for pathogens and other means for transmission tracking
  - In humans
  - In animal vectors
- Development of improved methods of rapid identification of emerging diseases

Pathogen identification and disease diagnosis are crucial in prevention, and central to a *Global Effort* already under way. Particularly challenging scientific goals include treatment as well, especially since treatment possibilities change with the rapid replication rate of many infectious organisms, with the development of drug resistance, and other factors. A drug that may have worked in one context, like chloroquine for malaria, for example, may not work in other contexts or with the same disease in other regions (Bradley 2007); developing effective prevention and treatment is an ongoing challenge. Other obviously crucial scientific goals include:

- Development of improved vaccines and vaccine administration and storage methods
- Development of improved antimicrobials and other treatment methods
- Development of safer insecticides and vector controls

The PVV view also urges that governments and entities recognize the hypothetical as well as actual reasons for support of scientific research and cooperation in a *Comprehensive Global Effort*: although epidemics may at the current historical moment seem particularly likely to afflict some countries or continents rather than others, when it comes to globally transmissible disease, it could be otherwise. After all, dengue may be spreading to areas that, it is claimed, are warming with global climate change, but influenza flourishes in colder weather, and we may be quite unable to predict the ranges of future, not-as-yet emerging diseases.

Track 4: Religious, Social, and Cultural Considerations

Track 1's concern with developing cooperation among the various major institutions of the world—governmental, corporate, private, intergovernmental, and so on—also included religious institutions. Inasmuch as religious traditions and their institutions influence much of what people in every part of the globe think about disease and also govern their disease-transmission behavior, from hand washing before meals to sexual contact, the participation of religious institutions is crucial to the success of a *Global Effort*. However, some religious traditions preserve scriptural or traditional characterizations of infectious disease as "scourge," as "punishment" that is divinely ordained, or as the product of wrong behavior in this or previous lives. Addressing these often archaic characterizations of infectious disease is of consummate importance in securing the cooperation of people and their religious institutions, often enormously powerful, around the globe.

Consider the various portrayals of leprosy or plague or other infectious diseases in the scriptures of religious traditions. In the Hebrew/Christian Bible, for example, God allows Satan to test the loyal Job with any hardship that is short of fatal, and Satan begins with infectious disease (perhaps leprosy or a staph infection?): Satan "smote Job with running sores from head to foot, so that he took a piece of broken pot to scratch himself as he sat among the ashes" (Job 2:7–9, New English Bible translation). In the Muslim *Hadith*, plague is described as "a means of torture which Allah used to send upon whomsoever He wished, but He made it a source of mercy for the believers, for anyone who is residing in a town in which this disease is present, and remains there and does not leave that town, but has patience and hopes for Allah's reward, and knows that nothing will befall him except what Allah has written for him, then he will get such reward as that of a martyr"—in other words, plague is a punishment, though it can also become a blessing for those who believe (al-Bukhari 1959).

In many religious traditions, the implication is that people or groups afflicted by disease deserve it in one way or another, and that such illnesses are a product of divine wrath visited upon them or perhaps an opportunity for spiritual growth.

Attitudes about HIV/AIDS or other STDs expressed in some contemporary religious groups sometimes construe contracting the disease as punishment for homosexuality, infidelity, promiscuity, or other sinful behavior, either of individuals or of groups. Fatalism may also be associated with religious views, as when it is held that the visitation of infectious disease is God's will and hence that nothing can be done about it. Both religious and cultural attitudes may be involved in ancient practices like belling lepers or shunning victims with pocks, boils, open sores, or other visible evidence of disease. In some traditions, such attitudes may include views that the afflicted not only deserve it but are "not our problem," that justice is being done and others have either no obligation to intervene, or no intervention is appropriate. Some religious groups appear to fear that attempts to reduce infectious disease transmission, especially of sexually transmitted diseases like HIV, might interfere with teachings prohibiting homosexuality or encouraging chastity. And some religious traditions value the contingency of human life *per se*, appearing to hold that efforts to forestall illness or delay death are contrary to divine plan.

Religious beliefs and attitudes can of course play a strongly positive role in encouraging cooperation with a societal project to protect the life and health of human beings. Religious commandments like "do not kill" and "respect life" speak in favor of bringing potential lethal infectious disease under control. Traditions which stress compassion and the relief of suffering would presumably also support the underlying concern of a *Global Effort*, to extricate humankind from the web of disease within which it is enmeshed. Some religious traditions stress the unity of human beings in divine creation; some stress stewardship of the environment and with it, concern for human health; some emphasize attitudes of caring, concern, and compassion for those who are ill. And many stress the value of sacrifice and dedicated work for the good of the community, a commitment believed to be viewed favorably by the divine or rewarded well in the next life. These are all attitudes that suggest that religious institutions might play a powerful role in engendering cooperation with a *Global Effort* by the world's faithful who subscribe to these views.

But not all religious views concerning infectious disease favor constructive cooperation. To challenge entrenched social or religious beliefs is never easy, and rarely fully successful. This is the issue our PVV view expects us to put on the table: that entrenched beliefs and practices may fail to regard people, both as individuals and in groups or populations, as both victim and vector at one and the same time, in ways that work to the detriment of all.

Track 5: Legal and Social Protections for Individuals and Groups

Our PVV view here also recognizes that a *Global Effort* for the control of infectious disease cannot satisfy the conditions of this view unless it attends to legal and social protections for individuals and groups, to ensure that neither individuals nor groups are victimized by institutional measures, scientific research programs, infrastructure changes, or other matters that are part of the *Global Effort*. This is to recognize that, under our PVV view, "victimhood" can have a dual sense: a person or group, or entire population, may be the victim of a disease—this is the primary sense of "victim" in the PVV view—but may also be the victim, so to speak, of policies, programs, prejudices, and other matters associated with disease, or both.

Legal and social protections for individuals, groups, and populations, under our PVV view, should include at least:

- Development of rigorous local, national, and international protections for privacy and confidentiality of individual information in surveillance systems
    - In reporting of data
    - In contact tracing and transmission tracking
    - In follow-up for health care
- Development of policies concerning rights to privacy and/or confidentiality for information that poses a risk to other people, or a right to privacy in a public place
- Development of protections and systems for maximum communication among families and social groups during isolation, quarantine, home quarantine, or other restrictions in epidemics
- Development of protections for things that matter to people, e.g., pets and property
- Attention to animal rights and animal-welfare issues
- Erection of special protections for the least well-off (and most likely to be affected by infectious disease):
    - Refugees
    - Prisoners
    - The institutionalized, including those in mental institutions
    - The homeless
    - The elderly
    - Infants and children
    - People with disabilities, poor health, or compromised immune systems

As Michael Parker puts it, echoing the British pandemic plan, "Everyone matters" (Parker 2007). This notion is essential to our PVV view: while it recognizes that trade-offs between concerns like privacy and surveillance or confidentiality and interruption of transmission must sometimes be made, it still insists that policies not victimize or exempt those whom they affect.

A further area of concern about legal and social protections for individuals and groups involves attention to micro- and macroeconomic issues. What will be the impact of a *Global Effort* on all parties? Some concerns might involve those whose current income depends on treatment of infectious disease. After all, if a *Global Effort* were to succeed and the global burden of infectious disease dramatically reduced, this income would be eliminated. Who will be out of a job? Larger economic concerns might focus for instance on the impact of higher rates of infant and child survival on domestic and social situations where poverty is severe, or on changed patterns of survival—reflecting the success of a *Global Effort* in reducing death rates—on economies around the world. There would presumably be relatively little effect on economies in the advanced industrial nations where infectious disease is already largely under control, but there could be dramatic effect in the worst-off nations of the world. Like everything else associated with it, a *Comprehensive Global Effort* should be subjected to adequate scrutiny in the decades prior to and during the culminating phase itself, with of course an eye to mitigating economic damage where it threatens to occur and but reaping the economic benefits of effective disease control as well.

A *Comprehensive Global Effort:* From Thought Experiment to Plan

Attempts to control infectious disease are already going on in many areas—indeed, in all five practical and policy tracks considered above—and they all raise important ethical issues. A *Comprehensive Global Effort for the Control of Infectious Disease*, incompletely developed as it is, is already well under way, whether we see it as a thought experiment, a description of current events, or a plan. Whichever way we interpret it, it requires us to consider the importance of not only global coordination and cooperation, but also the importance of coordinated, across-the-board *ethical* reflection. This ranges from reflection on comparatively focused issues like how to balance considerations of confidentiality versus public interest, how to weigh the impact of mandated treatment, or how to prioritize access to prevention and care in epidemics, to the deeper but at the moment more diffuse sorts of philosophical issues, such as whether attempts to control infectious disease should be given priority over attempts to control cancer or whether bioweaponry is intrinsically worse than conventional arms. In part because attention to the full control of infectious disease on a global scale has not so far been unified, the ethical issues each distinct effort raises have not been unified either, and have to a considerable extent been treated in comparatively isolated, discrete, "siloed" ways, even now that they are finally coming to be discussed at all in bioethics and other fields. This is not to say that ethical issues are to be viewed in a monolithic way, but rather that reflection on them must include understanding them in the larger context of a world in which we are "all in this together," all potentially victims and vectors of transmissible infectious disease.

No writer, as far as we are aware, is currently advocating the kind of universal surveillance or mandated treatment imagined in our airport thought-experiment, and no writer is advocating a decade of intense dedication to infectious disease control. But part of the point of a thought experiment like that is to test the ethical challenges to be faced in the real world, not just in a fictional one, and hence the challenges that would and do arise in what we see as an already-emerging

Comprehensive Global Effort. Ethical reflection in the context of infectious disease, we have been arguing all along, must be far broader than it has been, even during the efflorescence of the last seven or eight years—that is why we appeal not only to a limited thought-experiment about airport surveillance but to the much broader constellation of developments we have called an emerging *Comprehensive Global Effort for the Control of Infectious Disease*.

If a *Global Effort* as imagined here seems too grand—an overly far-fetched thought experiment, a misdescription of current reality, or an unworkable concrete plan—imagine what is involved in trying to extricate the globe from any *one* of the particularly serious diseases that are currently widespread—say, HIV/AIDS, or tuberculosis, or malaria. These are all recognized as devastating. AIDS has already killed 19 million people and, as of 2007, another 33.2 million are infected with the HIV virus. Tuberculosis infects or has infected an estimated 30% of the global population and kills about 2 million people a year. Worldwide, malaria infects between 350 and 500 million people every year, and between 2 to 3 million die from it—90% in Africa, where it is estimated that one child dies from malaria every 30 seconds (Packard 2007, xvi). The new movement for global health, building on the steady work of the WHO and others over many years and galvanized less than a decade ago by the remarkable private contribution of the Gates Foundation, is already committed to the elimination of these diseases; it has become a top global priority. Yet—here is the key to our project in this "think big" essay—eliminating any one of these diseases will raise virtually *all* the issues we have posed in the five tracks outlined above. So would eliminating all three. Indeed, for any disease or group of diseases for which we might consider trying to achieve global or even local eradication, elimination, or control, issues about institutional cooperation, infrastructure improvement, scientific development, religious and cultural attitudes, and social and legal protections are all relevant. Comprehensive ethical reflection is crucial in such an enterprise as well: while it is important to be sensitive to the specific, factual features of any given case, we cannot do ethics piecemeal, as an iterated effort one disease after another for the indefinite future, or in response to one new technology, or one political challenge, or one scientific development at a time, without a larger picture of human embeddedness in webs of mutual disease transmission, within which they occur.

"Think Big" thought experiments are unlimited in scope, in this case fueled by an elective optimism and bounded only by the limits of plausibility in assembling the resources of the world to confront one of its most pervasive problems. We can imagine, as we have said, other *Global Efforts* directed towards other global problems—climate change and global warming, endangered species rescue, water justice, immigration management, global drug control, and so on. But the vision of a *Comprehensive Global Effort for the Years 2020–2030 for the Eradication, Elimination, or Control of Infectious Disease* may be, in contrast, simpler: its overall purpose of reducing the burden of infectious disease may be less controversial; its methods are not technically impossible; its science is reasonably well understood; and it does not require the change of institutions, only coordination and cooperation. Imagining such a project is of course to "think big," but we can certainly imagine what this project would take, as the culmination of the efforts of several centuries, to achieve within a single decade a goal with which the fate of humankind might be dramatically improved. There is no way to guarantee that it would succeed. But it is a project already well under way, since the time of Jenner and with the best efforts of dedicated researchers, clinicians, and workers in public health. There is no practical or moral reason not to undertake this project, though plenty of reason to be cautious about how to do so—that is what we have tried to explore.

There is another, darker reason for exploring the practical and ethical issues in the *Global Effort* in this comprehensive way. A *Global Effort*, or even just continuing ordinary efforts to control infectious disease, might contain repressive, biased, insensitive, or otherwise morally indefensible elements, particularly if it were pursued under a tight time schedule by zealous institutions or highly competitive players. That there is a current efflorescence of ethical reflection does not entail that the various components of the overall global effort will go ethically well, and ethical reflection by itself will not prevent abuse. It is important to understand how even an admirable project with a highly desirable goal—extricating humankind from the web of infectious disease—could go wrong, that is, how it could be done, but not done well. It remains to look at a variety of policies of the sort that might be involved in a *Global Effort* to see what can go wrong with them as well as right, using our PVV view as a tool for examining actual, real-world policies as a way of thinking about larger aims.

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Shaping Ethical Guidelines for an Influenza Pandemic

Rosemarie Tong

Abstract This chapter describes the process of shaping ethical guidelines for an influenza pandemic by the North Carolina Institute of Medicine (NC IOM)/North Carolina Department of Public Health (NCDPH) Task Force. The author discusses the threat of a pandemic in the twenty-first century, comparing a potential pandemic with past flu pandemics as well as the Severe Acute Respiratory Syndrome (SARS) outbreak in Canada and parts of Asia. Also discussed are the ways in which influenza would spread, be treated, and hopefully contained. Addressed are the ways in which one becomes ethically prepared for an influenza pandemic, as well as the challenges to incorporating ethical guidelines in preparations. Tong also addresses the role of a duty/obligation/responsibility to work by health care personnel, the role of volunteers, and when health care personnel may refuse to treat someone. Also taken into consideration are such issues as the distribution of food and vaccines, quarantines, work stoppage, both physical and social infrastructure, the role of military and police forces, and the effect of a pandemic, isolation, and quarantine on various industries. Tong shows the complicated nature of working on a task force and the complexity of incorporating ethics into logistical planning.

Keywords Influenza pandemic, Avian flu, flu vaccine, health care personnel, bioethics, obligation, responsibility, ethics of care, quarantine, North Carolina Public Health, international public health

Introduction

When the North Carolina Institute of Medicine (NC IOM) and the North Carolina Department of Public Health (NCDPH) asked me to join a 37-member statewide North Carolina Institute of Medicine/Department of Public Health Task Force to develop ethical guidelines for an influenza pandemic, I thought they had dialed the wrong number mistakenly. I told the NC IOM administrator who contacted me I knew next to nothing about influenza pandemics, including the Avian Flu. She said that my infectious-disease ignorance was of little concern to her; the NC IOM/DPH

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Task Force would have among its members many public health and safety experts. In addition, there would be representatives from government agencies, health care organizations, businesses, industries, faith communities, and advocacy groups. What the Task Force lacked were ethicists. Specifically, it needed an ethicist to serve as co-Chair together with the Director of the North Carolina Department of Public Health, and I had been identified as a likely candidate for this role.

Intrigued by the NC IOM administrator's request, I asked her to be honest. Would the NC IOM/DPH Task Force really be serious about ethics? Or would it simply want to use ethics as a sweet frosting to lather over a cake of political deals made between special-interests' lobbies? She responded: "Come to the first meeting. If you do not like the way it goes, you never have to come to another meeting." I went to the first meeting of the Task Force; I was very impressed by the sincerity and genuine ethical concern of its members. After that meeting, I agreed to co-Chair the Task Force. During the months that followed, I learned how alternately heartening and disheartening the process of producing a set of guidelines that merit the descriptor "ethical" can be. It is not easy to get 37 diverse people to develop and endorse a set of ethical guidelines. On the contrary, it is very hard work!

The Threat of an Influenza Pandemic in the Twenty-First Century

Influenza pandemics constitute a public health threat of global proportions. Although people in the United States may think that such disease outbreaks are confined mainly to their television screens and disaster films, history teaches that influenza pandemics typically occur three times in a century. In the twentieth century, the three influenza pandemics were the 1918 Spanish Flu, the 1957 Asian Flu, and the 1968 Hong Kong Flu (NC IOM/DPH Task Force 2007, 21). All were of avian (bird) origin, and the worst of them was the Spanish Flu; worldwide, 50 million people died. In the United States the death toll was 675,000 (Berlinger 2006). A particularly vexing feature of the Spanish Flu was that it did not strike the populations that annual flus generally hit hardest: the very young and the very old. Instead it targeted people in their twenties and thirties (Engel 2007, 32). The other two twentieth-century influenza pandemics (the Asian Flu and the Hong Kong Flu), though not as devastating, were no small matter. The Asian Flu killed 2 million people worldwide, 70,000 of them in the United States; and the Hong Kong Flu killed 700,000 people worldwide, 34,000 of them in the United States (Garloch 2006, A1).

Because the Avian Flu has yet to reach US shores, the US population has moved on to worrying about other problems, the war in Iraq and the economy to name two. But just because the Avian Flu has not visited the United States during the first eight years of the twenty-first century, does not mean it will not. The first human cases were reported in China and Vietnam in 2003. They were four in number, and all were fatal. In 2004, 46 cases were reported in Vietnam and Thailand; of these, 32 were fatal. In 2005, 97 cases were reported in Vietnam, Thailand, China, Cambodia, and Indonesia; 42 were fatal. In 2006, 116 cases were reported in a large range of countries: Azerbaijan, Cambodia, China, Djibouti, Egypt, Indonesia, Iraq, Thailand, and Turkey. Of these, 80 were fatal (Engel 2007, 34). To be sure, the Avian Flu has not killed many people to date, and no US citizen has succumbed to its horrors. Yet, according to public health authorities, we are closer now to an influenza pandemic than at anytime since the Asian Flu outbreak in 1968–1969 (World Health Organization 2007). When the first influenza pandemic of the 2000s hits it will kill somewhere between 209,000 to 1,903,000 members of the US population (Department of Health and Human Services 2006).

Although both pandemic flu and regular seasonal flu are similar in that they spread easily between people by coughs and sneezes, they are quite different in several other ways. With respect to regular seasonal flu, outbreaks typically occur in the wintertime; the same type of flu virus occurs each year; and vaccine is generally available, with shortages being the exception rather than the rule. The situation is quite different with respect to an influenza pandemic, however. Outbreaks can occur any time; the type of flu virus is novel; and an *effective* vaccine takes months to identify, develop, and get to market in large enough supplies to meet the demand (Adler 2005, 44).

More than likely, an influenza pandemic will begin in a developing nation where animal-to-human contact is close and public health systems are either nonexistent or very fragile. An international traveler probably will bring the disease to US shores, having exposed at least some of his or her traveling companions to the virus. Infected patients will start trickling in to primary care offices, urgent care clinics, and hospital emergency rooms. Regrettably, health care personnel may not have much in their medical arsenal, over and beyond the antiviral Tamiflu, to treat the initial wave of infected patients. Worse, before too long, health care personnel may find themselves drowning in a sea of infected patients, unable to assist but a small fraction of them.

In North Carolina, public health officials know there is no way to be totally prepared for a severe influenza pandemic. As they see it, even a *mild* or *moderate* influenza pandemic would probably last eight weeks and result in 1.6 million physician visits, 35,000 hospital admissions, and 7,900 deaths statewide (McGorty et al. 2007, 39). Nonetheless, despite their realization that their best preparedness efforts may not be enough to meet North Carolinians' needs during an influenza pandemic, NC public health officials are determined to prepare as much as they can.

Laying the Foundation for an Ethical Preparedness Plan for an Influenza Pandemic

To their credit, NC public health officials think North Carolinians need to be *ethically* as well as medically prepared for an Avian Flu attack. As difficult as it is to get medical systems of command and control, surveillance, vaccine and antiviral production, and health care delivery prepared for a deadly pandemic, it is even more difficult to get ethical codes and guidelines prepared for it. Experience teaches that once an influenza pandemic hits full force, it is too late to formulate ethical codes and guidelines to help citizens meet its distinctive ethical challenges. Accustomed to using ethical guidelines that work well enough in the clinical context, people may discover that the principles of autonomy, beneficence, nonmaleficence, and justice need to be interpreted and/or prioritized differently in the public health context. In addition, they may discover that these principles need to be supplemented by ethical principles they rarely, if ever, invoke in the clinical context. For example, individual freedom may have to give way to the public good.

Interestingly, the prime movers behind the NC IOM/DPH Task Force on which I served were very much influenced by the work of the University of Toronto Joint Center for Bioethics. In the aftermath of the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak in Canada and several Asian nations, members of Toronto's Joint Center for Bioethics drafted a document entitled "Stand on Guard for Thee: Ethical Considerations for Pandemic Preparedness Planning" (University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group 2005). The phrase "stand on guard for thee" occurs in the Canadian national anthem. It signals to Canadians their obligation to be on the lookout for each other's best interests. Whatever befalls one Canadian potentially affects all Canadians. Although Canadians behaved well enough during the SARS crisis, manifesting their traditional communitarian spirit, the drafters of the Stand-on-Guard-for-Thee document felt Canadians would have acted even better had they been *ethically* as well as medically prepared for SARS. Among the things that went wrong ethically during Canada's SARS experience were: (1) some health care personnel refused to care for people infected with SARS and were subsequently dismissed for failing to report for duty; (2) other health care personnel were socially ostracized or stigmatized because they willingly cared for infected patients (Rhyne 2007, 51); (3) some physicians and nurses left their respective professions voluntarily because they did not want to continue in what they had come to regard as a truly life-threatening job (Rhyne 2007, 51); (4) some Canadians infected by or exposed to SARS did not comply or fully comply with quarantine restrictions (University of Toronto Joint Centre for Bioethics 2005, 12–13); and (5) some Canadians boycotted all Chinese businesses everywhere in Toronto just because the initial case of SARS was linked to an international traveler from China (Yount 2005, 21).

Wanting to avoid SARS-like mistakes in the event that an influenza pandemic hit the United States, the leaders of the NC IOM/DPH Task Force invited Alison Thompson, PhD, to discuss the reasoning process behind Toronto's Joint Center for Bioethics document. The Task Force wanted to explore with her whether the ethical values guiding the Canadian document were exportable to the United States. Dr. Thompson stressed that two interrelated but nonetheless distinct sets of values, one *procedural* and the other *substantive*, were embedded in the Stand-on-Guard-for-Thee document. She then identified the procedural values as: (1) reasonability, (2) openness, (3) inclusiveness, (4) responsiveness, and (5) accountability; and the substantive values as: (1) individual liberty, (2) protection of the public from harm, (3) proportionality, (4) privacy, (5) equity, (6) duty to provide care, (7) reciprocity, (8) trust, (9) solidarity, and (10) stewardship (University of Toronto Joint Centre for Bioethics 2005, 6–7).

No one on the NC IOM/DPH Task Force had a problem with the Toronto team's procedural values, but several members of the Task Force questioned Dr. Thompson about the Toronto team's definitions for the substantive values of solidarity, stewardship, and reciprocity, respectively. In addition, they interrogated her about the Toronto team's views on the duty to care as it applied to licensed health care professionals in particular, but to others as well. Did licensed health care professionals really have a duty to risk their own lives in order to serve infected patients? Was this duty professional, contractual, legal, or moral? Did nonlicensed health care professionals have the same or different duties as licensed health care professionals? Did other professionals have the same or different duties as health care professionals? Did families have either a legal or a moral duty to take care of their infected relatives? Was a duty the same as an obligation? A responsibility? Was there a difference between a *moral* duty/obligation/responsibility and an *ethical* duty/obligation/responsibility?

After Dr. Thompson's visit and nearly two months of sometimes heated, but always careful, discussions the NC IOM/DPH Task Force decided not to embrace the substantive values of solidarity and stewardship. Because some Task Force members associated the substantive value of solidarity with unions and/or socialism/communism, the Task Force as a whole decided to forsake this value as too politically charged. Solidarity does not play as well on North Carolina soil as on Canadian ground. Americans are, on the average, more individualistic and less communal than Canadians; and solidarity with fellow citizens is not as important to Americans as being able to chart the course of their own individual destinies.

NC IOM/DPH Task Force members' reasons for rejecting the substantive value of stewardship ranged from very serious ones to fairly comical ones. One Task Force member objected to the substantive value of stewardship because he feared it connoted heavy fiduciary burdens. Another Task Force member stated the term "stewardship" had too many religious connotations. Yet another Task Force member could not disassociate the term "stewardship" from memories of the stewards who had served him on a recent ocean cruise. Realizing that stewardship was a substantive value without which the Task Force could still accomplish its mission, I suggested that, on balance, it was one we need not embrace.

Thinking that the IOM/DPH Task Force also would dismiss the substantive value of reciprocity as yet another unpalatable Canadian import, I was surprised when the entire Task Force embraced the value of reciprocity as one of its premier substantive values. Apparently, most Task Force members reasoned it was only fair that those who performed their usual duties and/or accepted heavier/riskier new duties during an influenza epidemic should be reciprocated in some way during and/or after the outbreak. Although some Task Force members interpreted reciprocity in a way that suggested they had not progressed beyond Stage Two ("I'll scratch your back, if you scratch mine") on Lawrence Kohlberg's well-known six-stage trajectory for moral development (Kohlberg 1971, 164–165), other Task Force members interpreted the substantive value of reciprocity in quite demanding ways, such as requiring those who receive services in an influenza pandemic to feel duty-bound to give back something of at least equal value to those who rendered the services to them.

Health Care Personnel and the Duty/Obligation/Responsibility to Work During an Influenza Pandemic

As I indicated above, one of the most prolonged and uncomfortable NC IOM/DPH Task Force meetings centered on health care personnel's purported duty to care for infected patients during an influenza pandemic. Several Task Force members asserted the term "duty" was too strong. To them, the term implied that health care personnel had an *ethical* duty to care for infected patients. I responded that, as I saw it, at least *licensed* health care personnel (e.g., physicians and nurses) did indeed have an ethical duty to care for infected patients for three reasons. First, licensed health care professionals have a greater ability than any other segment of the public to provide medical care, a fact that increases their obligation to provide it. Second, licensed health care professionals have a contract with society, resulting from the privilege of self-regulation and self-licensure, that calls on them to be available in times of emergency. Third, licensed health care professionals, by freely choosing a profession devoted to caring for the ill, prima facie accept an ethical obligation to act in the best interests of the ill and to assume a proportional share of the risks to which their profession exposes them (NC IOM/DPH Task Force 2007, 28).

Within nanoseconds of my response, several vociferous objections were made to it. Some Task Force members claimed that individuals' professional ethics were separate from their personal ethics. As they saw it, a professional duty was less ethically binding than a personal duty. When I asked them why, they had no definite answer. However, I did find plausible the suggestion that because professional duties *typically* are less linked to one's central self-identity than to personal duties, they may be less ethically binding. Yet even though this suggestion made sense to me, it also made me want to run for cover. Suddenly, I realized the extent to which ethical theory has failed to clearly specify whether professional duties are "perfect" or "imperfect" in the Kantian sense of these terms. For Kant, a perfect duty is one "which admits of no exception in the interests of inclination" (Kant 1964, 96). In contrast, an imperfect duty is one that must be performed at least sometimes when the opportunity arises. Did licensed health care professionals always have a duty to treat infected patients during an influenza pandemic or could they, with clear conscience, balance their duty to care for infected patients against their duty not to infect others, including themselves under certain circumstances? In answer to my question, one Task Force member noted that the American Medical Association (AMA) Policy E-9.067 Physician Obligation in Disaster Preparedness and Response states:

> The physician workforce … is not an unlimited resource; therefore, when participating in disaster responses, physicians should balance immediate benefits to individual patients with ability to care for patients in the future. (Rhyne 2007, 52)

He then claimed that, at most, health care professionals had an imperfect duty to care for infected patients. Other members of the Task Force disagreed. They worried that unless health care professionals were exhorted to think they have a perfect duty to care for infected patients, they would always find a reason not to discharge their "imperfect" duty to care for infected patients.

The perfect/imperfect duty debate was never resolved. Rather it was shelved for future consideration. But not every uncomfortable debate was shelved. Sometimes the Task Force had the fortitude to resolve a moral disagreement relatively quickly. For example, when two Task Force members referred to Ayn Rand's *The Virtue of Selfishness* (Rand 1964), claiming that the only moral duty individuals had was the duty to maximize their own self-interest, they were immediately challenged by the majority of Task Force members who claimed either that individuals had moral duties to others or that it was in individuals' self-interest to serve the interests of others. Realizing there was major opposition on the Task Force to Ayn Rand's brand of ethical egoism, her two followers quickly decided it was probably in their own self-interest to soft-pedal their point of view. However, one of them suggested the Task Force reserve the term "duty" or "obligation" for (1) licensed health care personnel's *professional* obligation to care for infected patients; and (2) unlicensed as well as licensed health care personnel's *contractual* obligation to meet the terms of their respective employment agreements. He further suggested that a weaker term like "responsibility" be used to refer to everyone else's purported duty/obligation to assist each other in times of need. Although I was not certain I agreed with these two suggestions, I ultimately voted with the rest of the Task Force to accept them as verbal distinctions that probably would not make much of a substantive difference in the Task Force's final report.

Relieved to have the duty/obligation/responsibility "wordsmithing" session behind it, the NC IOM/DPH moved on to a matter more easy for it to understand and discuss; namely, what society "owed" to health care personnel willing to put their lives on the line for the sake of the common good. As it considered society's debt to those who serve it in times of crisis, the NC IOM/DPH Task Force repeatedly invoked the value of reciprocity. To its credit, the Task Force was alert to the fact that if health care personnel and other critical workers were asked to fulfill their duties/obligations/responsibilities to society, it was only fair that society express its gratitude to them. Thus, the Task Force insisted that frontline health care personnel and others at increased risk of infection should have priority for protective equipment, antiviral medications, vaccinations, counseling services, and adequate on-the-job training if necessary (NC IOM/DPH 2007, 29–32). In addition, most, if not all, of the Task Force members insisted that families of frontline health care personnel be given priority for preventive measures and/or curative treatments, so as to increase the likelihood of health care personnel reporting for duty. Finally, the Task Force urged government authorities to take measures such as the following three:

1. Establish liability immunity for good faith medical treatment and triage judgments.
2. Suspend Health Insurance Portability and Accountability ACT (HIPAA) regulations enforcement in cases of necessary and/or inadvertent violations in a crisis situation.
3. Provide a compensatory program modeled on workman's compensation for physicians who die or become disabled as a consequence of providing care in a pandemic (Rhyne 2007, 52).

Interestingly, the NC IOM/DPH Task Force considered, but ultimately rejected, the suggestion that health care personnel, nonlicensed as well as licensed, be paid extra for working during an influenza pandemic. Several Task Force members feared that extra pay might entice infected health care personnel to report for work. They had in mind relatively low-paid health care personnel such as nurse aides.

As much as I wanted to believe that most health care personnel would continue to work during an influenza pandemic, reciprocated or not, my inner skeptic chipped away at my inner optimist. My unease increased when several Task Force members recommended that we rely on *volunteers* during an influenza pandemic. The idea of relying on volunteers is, in the Southeast region of the United States, still enormously popular. The region is characterized by a particularly large number of charitable organizations, many of them church based. A remarkably high number of physicians and other health care personnel volunteer to work at free clinics, respond to medical crises whenever and wherever they occur, and serve desperately ill people in developing nations. Yet, in time of an influenza pandemic, there may be something wrong about relying on volunteers. I asked the Task Force if risk of death should not be distributed equally among all health care personnel, particularly the licensed ones. I noted that during the height of the HIV AIDS crisis, when a sizeable number of physicians and nurses refused to treat infected patients, Abigail Zuger, MD, argued that the American Medical Association (AMA) code of 1847 had it right when it stated: "When pestilence prevails, it is their duty to face the danger and to continue their labors for the alleviation of suffering, even at the jeopardy of their own lives" (Zuger 1987). The 1847 code imposed on *all* licensed health care professionals, and not merely the volunteers among them, the duty to care for infected patients during an influenza pandemic.

To be sure, there are times when a health care professional justifiably may refuse to treat an infected patient on the grounds that his or her attempt to do so would most probably (or nearly certainly) result in more harm than good for the patient. For example, the Task Force imagined the following scenario as one which might constitute a justification for a licensed health care professional, in this case a psychiatrist, not to treat an infected patient:

> A psychiatrist has been called in to help hospital personnel cope with the stresses of the influenza pandemic. Suddenly, while waiting to speak with emergency department physicians, a patient on a gurney begins to turn blue and struggle to breathe. All of the other physicians and healthcare personnel are busy with equally ill patients. The psychiatrist knows that she must intubate the patient (e.g., insert a breathing tube into the patient's airway) to help him breathe but has concerns because she has not intubated a patient since she was an intern 10 years ago. Should she intubate the patient? Is the risk of him dying greater than the risk of her injuring him while attempting to intubate him? What if something goes wrong? (NC IOM/DPH 2007, 32)

Still, even in this scenario, from a patient's point of view, he or she might reasonably prefer the help of a psychiatrist with rusty intubation skills to no help at all. If not the psychiatrist, then who? The health care ethicist on call? A food service employee?

Although the Task Force seemed particularly worried that not enough health care personnel would be willing to risk their lives for infected patients, the health care personnel on the Task Force all expressed the sentiment that if an influenza pandemic did hit US shores, *they* intended to report for duty. They felt personally, as well as professionally and contractually, bound to do so. However, one physician in this group, who described himself as a realist, said his and other health care personnel's good intentions might weaken or even disappear if a sizeable number of health care personnel died as a result of serving infected patients. He noted that during the three-century long pandemic of bubonic plague in Europe, each new outbreak provoked physicians to reconsider their duty to treat infected patients. I added that during this plague many physicians ultimately followed the advice they gave patients: namely "leave fast, go far and return slowly" (Jonsen 2000, 45).

Other Critical Workers and Duty/Obligation/Responsibility to Work During an Influenza Pandemic

Although the NC IOM/DPH Task Force spent considerable time addressing the concerns of health care personnel, throughout its deliberations it always was aware that health care personnel were only one among many types of workers *critical* to maintaining society during an influenza pandemic. Although there are significant differences between a medical crisis like an influenza pandemic on the one hand and a natural disaster like a hurricane, earthquake, or tsunami on the other, there are certain similarities. When the situation gets dire—and people find themselves in a survivor scenario, scrambling for water, food, shelter, and other necessities—morality's grip on people's minds and hearts is severely tested. To be sure, such disastrous states of affair often bring out the best in people; but sometimes they also bring out the worst. Therefore, the Task Force reasoned it would be incumbent upon government officials to get not only health care personnel but also other socially essential personnel to do their jobs.

In its deliberations about the degree to which workers in critical, nonhealth-related industries would have duties, obligations, and/or responsibilities to work during an influenza pandemic, the NC IOM/DPH Task Force struggled to draft a complete list of industries "critical" for social functioning. It found some helpful leads in the US Department of Homeland Security's (DHS) list of 17 critical industries that comprise the national infrastructure and would require protection in the event of a terrorist attack or other hazard: agriculture and food; energy; public health and health care; banking and finance; drinking waters and water treatment systems; information technology and telecommunications; postal and shipping; transportation systems including mass transit, aviation, maritime, ground or surface, and rail and pipelines systems; chemical; commercial facilities; government facilities, emergency services; dams; nuclear reactors, materials and waste; the defense industrial base; and national monuments and icons (NC IOM/DPH 2007, 35). Absent from this list (and rightly so because it is a list of *industries*) were two sets of critical workers whom the Task Force thought would be essential during an influenza pandemic: the police and the military.

No doubt, it was largely the memory of the aftermath of Hurricane Katrina in New Orleans that prompted the NC IOM/DPH Task Force to realize how much social order depends on a disciplined, fair, and humane police force and military to stay the course during times of civil unrest or even panic. In a *Newsweek* article written shortly after Katrina hit New Orleans, the reporter noted that within the space of days, the city was "on the verge of anarchy" and "policemen [sic], many of whom had lost their homes, were turning in their badges rather than face … looters for another day" (Thomas 2005, 47–48). The National Guard had to be called in. Eventually order was restored, in large measure because so many people had left New Orleans voluntarily or involuntarily. There were other places to go—safer places. But in a full-scale influenza pandemic there will be no safe places to which to flee. The Task Force theorized that although most workers in critical industries probably did not have the same degree of duties/obligations/responsibilities to work as, for example, licensed health care personnel had, the police and military probably did.

To the Task Force's relief, the police personnel Task Force members on it stated they viewed themselves (as well as the military) as having a professional as well as contractual duty/obligation/responsibility to do their job during an influenza pandemic. Police personnel had some concerns, however, about how to maintain order at pressure points such as grocery stores and pharmacies. They also were worried about the role they might be required to play in enforcing isolation, quarantine, and social-distancing regulations. Significantly, none of the Task Force members were official representatives of the military sector, a fact that concerned me. Given the role the National Guard had played in trying to restore and keep order in the aftermath of Katrina, for example, I thought it would be important for the Task Force to at least be informed about the NC National Guard's influenza pandemic plans. Do they exist? I felt we were largely avoiding discussions about a worse-case influenza pandemic during which police personnel and military personnel might need to resort to force (even deadly force) to maintain order.

Significantly, the police personnel on the NC IOM/DPH Task Force were not the only group of nonhealth critical workers who voiced more than a contractual obligation to work during times of crisis. The Task Force was most impressed by the influenza pandemic preparedness plans of North Carolina's energy industry. One representative of this industry spoke with particular eloquence about the *ethos* behind his company's preparedness plan. He said, "We know folks will need light and heat and we are determined not to leave them in a lurch during a crisis situation even if we take a major financial hit." The Task Force noted how sensitive the company in question was not only to its customers' needs but also to its employees' needs (Kerin 2007, 62–64). Indeed, the company put many health care institutions' preparedness plans to shame.

In contrast to the NC police force and the NC energy industry, the food industry seemed to be significantly unprepared for an influenza pandemic. No one was quite sure whether the food industry included only farms and groceries, or whether it also included restaurants; and Task Force members from the food industry confessed their companies had no explicit ethos about their duty/obligation/responsibility to feed the public in time of crisis. Most people who work in the grocery stores at which the public shops and the restaurants at which it eats are paid fairly minimal wages. During an influenza pandemic, food-industry employees may respond in dramatically different ways to “come-to-work” summons. Some may refuse to work for fear of being infected by customers or coworkers; others may insist on working for fear of having no income or being fired.

The more the NC IOM/DPH Task Force focused on the food industry, the more it realized that during an influenza pandemic, food might become a scarcer resource than medical treatment. How would food be delivered to isolated, quarantined, or socially distanced people? Who would deliver it? Who would pay for it? And so forth. I thought to myself: Does any ethicist I know have good answers to such everyday, but crucial, questions? What, if anything, do workers in the food industry owe the public; and what, if anything, does the public owe them? I was relieved when the Task Force decided to move on to another topic, largely because I realized that as much as ethicists like to talk about applied ethics, they rarely address issues such as whose obligation it is to feed the grumpy old man down the street who has a hard time walking and communicating and who seems to have no visitors.

Social Distancing, Isolation, and Quarantine

Unfortunately, the next major topic of discussion also proved to be a difficult one for the Task Force to address. During an influenza pandemic, some individuals’ rights would need to be temporarily suspended to protect the public from harm. For example, during a mild influenza pandemic (1 on a scale of 1 to 5), public health officials may require isolation of actually infected persons at home or in a secure environment. They may also require quarantine of individuals exposed to the virus, once again in their own homes or in a secure environment. The rest of the public could go about its usual business. In contrast, in a severe influenza pandemic (4 or 5 on the 1–5 scale), not only would isolation and quarantine measures be implemented, so too would social-distancing measures be implemented. Schools and day care centers might be asked or required to close (NC IOM/DPH Task Force 2007, 41–42). Large social gatherings including church services as well as sports and entertainment events might be discouraged or even prohibited. Moreover, in a worst-case scenario all nonessential businesses might be asked or required to close and/or all nonessential workers might be asked or required to stay at home (Ibid).

Although most of the Task Force wanted to believe that North Carolinians would *voluntarily* isolate, quarantine, and/or socially distance themselves in order to protect the public from harm, some members of the Task Force were more skeptical about North Carolinians’ behavior in an influenza pandemic. They noted that at each of the four public meetings the Task Force held, in the cities of Asheville, Charlotte, Greenville, and Raleigh, respectively, those assembled said most people’s economic situations would determine whether they stayed home from work voluntarily. If their workplace was open and they needed the money to pay their bills, people would drag themselves to work. Many members of the public suggested that the only sure ways to prevent this state of affairs would be to force workplaces to close or to pay workers to stay home. Of course, the wisdom of the state actually implementing either of these suggestions is highly questionable. The former suggestion might be financially devastating for many businesses, and the latter only marginally less so. Businesses could ask the government to provide them with funds to mitigate their major financial hits, but whether the government could do this without jeopardizing the economy as a whole is an open question. During the SARS pandemic in Canada—a very mild pandemic—about $2 billion was lost (Jha 2004). The bulk of these dollars was confined to the Toronto area, sparing the vast majority of Canada. In the case of an influenza pandemic, however, the economic impact would likely not respect any borders nor be limited to a single metropolitan area.

On the whole, the people who came to one of the Task Force's public meetings stated they were willing to forgo church services and other events, including entertainment and sports events, which sometimes seem as sacred to North Carolinians as church events. They also expressed willingness to keep their children home from school and to tend the sick in their own homes, provided their families' basic needs were met and they received adequate instructions and supplies for tending their infected loved ones and themselves. Once again, the NC IOM/DPH Task Force was sobered by the fact that during an influenza pandemic, so much would depend on society having well-developed systems to meet people's basic needs and on having adequate reservoirs of community goodwill and public service at hand. But did North Carolina have such systems and reservoirs? Was it realistic, for example, to expect family members to care for their infected relatives? Maybe. But studies indicate that many people would prefer their families not take care of them if they fall victim to an influenza pandemic. Should such studies prove to be true, who would take care of these people and where? Health care facilities would be without enough beds, and thoughts of housing infected people in Superdome-type quarters are frightening. Should people be housed in schools? In churches? In fitness centers? Who should staff these facilities? What about people for whom no one seems to care? As usual, I asked myself why is it that society creates task forces to meet all people's, but especially vulnerable people's, needs during an influenza pandemic or subsequent to a major natural disaster, when that same society ignores and/or neglects meeting vulnerable people's needs in relatively good times? Why is *care* reserved for moments of crisis? As much as I wanted to pose these fundamental questions to the Task Force, I knew they would serve only to sidetrack it. I held my tongue and focused on the Band-Aid at hand.

Allocation of Scarce Health Care Resources

The last major issue the NC IOM/DPH Task Force discussed was the allocation of scarce health care resources during an influenza pandemic. In an effort to avoid wasting time, the Task Force read the results of the Center for Disease Control's (CDC) 2005 Public Engagement Pilot Program on Pandemic Influenza (PEPPPI) project. The leaders of this project wanted to ascertain the general public's views on distributing scarce vaccine during an influenza pandemic. They asked citizens to rank order the following ethical guidelines for distributing scarce vaccine fairly: (1) Save those most at risk; (2) put children and younger people first; (3) limit the larger effects in society; (4) use a lottery system; and (5) use the principle of "first come, first served." After much discussion, the consulted citizens concluded:

> [W]ith a very high level of agreement—that ***assuring the functioning of society*** should be the first immunization goal followed in importance by ***reducing the individual deaths and hospitalizations due to influenza*** (i.e. protecting those who are most at risk). Because of the still high importance of the second goal, the groups added that the first goal should be achieved using the minimum number of vaccine doses required to assure that function. This would allow the remaining doses to be used as soon as possible for those at highest risk of death or hospitalization. There was little support for other suggested goals to vaccinate young people first, to use a lottery system, or a first come first served approach as top priorities. (Public Engagement Pilot Program on Pandemic Influenza 2005, 7)

Although the NC IOM/DPH Task Force learned much from the PEPPI report, it felt it had not learned enough. The Task Force wanted to establish ethical guidelines for a wide range of scarce medical resources. Vaccines would not be the only scarce medical resource in an influenza pandemic. So too would be antiviral medicines, ventilators, hospital and nursing home beds, masks, and health care professionals' time. Complicating the Task Force's allocation deliberations was the empirical fact that during an influenza pandemic priorities inevitably shift depending on whether prevention of disease (early stages) or treatment of disease (later stages) is central. Thus, the Task Force would need at least two sets of allocation guidelines: one for healthy people who needed vaccines and other preventive measures in order not to get sick; and another for sick people who needed treatment.

The NC IOM/DPH Task Force's list of possible allocation criteria included:

1. Priority should be given to assure the functioning of society.
2. Priority should be given to reduce the incidence or spread of disease.
3. Priority should be given to reduce illness, hospitalizations, and death due to the influenza.
4. Priority should be given to protect people with the most years of life ahead of them.
5. There should be no priority given for the distribution of limited health care resources to ensure that everyone has an equal chance of being protected. (NC IOM/DPH Task Force 2007, 49–50)

Although most of the Task Force wanted to limit its deliberations to the five possible allocation criteria listed above, at least one member of the Task Force wanted to add Ezekiel J. Emanuel's allocation criterion of "quality of life years left or the life cycle principle" (Emanuel and Wertheimer 2006, 854). The idea behind this criterion is that "each person should have an opportunity to live through all the stages of life," with priority given to young adults over young children (around one year old, say). Emanuel's reasoning for favoring young adults over young children is that young adults *supposedly* have more developed interests, hopes, and plans than young children, but like young children have not had an opportunity to realize them (Ibid). In other words, young adults have consciously articulated to themselves their school, career, marriage, and family plans, whereas young children have not. Thus, dying during an influenza pandemic would entail more suffering for a young adult than a young child.

For all the merits of Emanuel's criterion, the objection can be raised that if a young child survives an influenza pandemic, he/she will probably live to be a young adult with the kind of plans noted above. Moreover, given the fact that people are living ever longer and healthier lives, who is to say that a 40, 50, 60, 70, or even 80-year-old has had a chance to realize their hopes and interests? What if someone wasted the first 40 years of his or her life and wanted to use the next 40 years or so to make up for their wasted years? Why should his or her plans count less than a young adult's plans? If it adopted Emanuel's criterion, would the Task Force be perceived as ageist? To be sure, Task Force members thought that during an influenza pandemic many grandparents would willingly sacrifice their lives for the lives of their grandchildren, but this sentiment was captured in the less controversial principle that priority should be given to protect people with the most years of life ahead of them. Without the Emanuel principle ever coming to a vote, it gradually disappeared from the Task Force's radar screen, resurfacing as a "mention-only" in the Task Force's final report (NC IOM/DPH 2007, 50, footnote c).

In addition to largely ignoring the Emanuel criterion, the Task Force loudly rejected the first-come, first-serve criterion. It made no sense to Task Force members to give vaccines to people who could not benefit from them just because they got first in line for them. Therefore, said the Task Force, many sorts of unfairnesses built into the "first-come, first-served" criterion, beginning with the fact that not everyone has the means to get to a vaccine-delivery location. During the aftermath of Hurricane Katrina, for example, it became clear that many of the people left behind did not have the transportation or help to flee. Should people be penalized an influenza pandemic simply because they have no access to transportation?

In the end, the NC IOM/DPH Task Force recommended a relatively nuanced list of ethical guidelines for a fair allocation of scarce medical resources during an influenza pandemic. The intent behind the Task Force's allocation guidelines was threefold: (1) to preserve lives of workers critical for the functioning of society; (2) to prevent the spread of the disease; and (3) to treat people who could benefit from the treatment. Having previously been advised that its ethical allocation priorities would need to shift, depending on the state and severity of an influenza pandemic, and on whether preventive resources (both nonpharmaceutical and pharmaceutical) or treatment resources (both nonpharmaceutical and pharmaceutical) were under consideration, the Task Force issued the following ethical guidelines for distributing scarce medical resources:

(a) Allocation of vaccines (pharmaceutical prevention resources) should be made with the primary goal of assuring the functioning of society and the secondary goal of minimizing the spread of the disease.
(b) Allocation of nonpharmaceutical prevention resources (such as personal protective equipment) should be made with the goal of assuring the functioning of society and preventing the spread of the disease.

(c) Allocation of antivirals (pharmaceutical treatment resources) should be made with the primary goal of minimizing illness, hospitalization, and death and the secondary goal of assuring the functioning of society.
(d) Allocation of nonpharmaceutical treatment resources (e.g., ventilators and hospital beds) should be made with the goal of reducing illness, hospitalization, and deaths (NC IOM/DPH Task Force 2007, 53).

In addition to providing these four basic ethical guidelines, the Task Force stressed that within priority groups, decisions should be based on clinical and epidemiological factors only. They should not be based on socioeconomic status, gender, race, ethnicity, or, more controversially, immigration/legal-documentation status. (North Carolina has a large number of Hispanic immigrants, many with proper documentation, but an increasingly large number without proper documents.)

Conclusion

After a unanimous vote, the Task Force's final ethical guidelines were published with the title "Stockpiling Solutions: North Carolina's Ethical Guidelines for an Influenza Pandemic." I came away from the experience convinced that Stephen Toulmin had it right in his now quarter-century old article, "The Tyranny of Principles" (Toulmin 1981). Neither absolute adherence to principles, nor relativistic acceptance of all "moral" views, is likely to result in a set of ethical guidelines that most people in a highly diverse society can accept as substantially their own. Rather, any such set of ethical guidelines is likely to be built "taxonomically, taking one difficult class of cases at a time and comparing it in detail with other clearer and easier classes of cases" (Toulmin 1981, 31). The NC IOM/DPH Task Force stalled when it tried to agree on abstract definitions of terms like "duty," "obligation," and "responsibility," but it made substantial progress as soon as Task Force members began to share cases in which it was clear to them, for example, that a physician had a duty/obligation/responsibility to work and cases in which it was not clear. By comparing and contrasting clear and unclear cases, the Task Force was able to write ethical guidelines that, in its collective estimation, would help decision-makers handle, fairly and compassionately, all but the hardest cases—the kind of cases which tragically result in someone or some group being harmed despite everyone's best intensions and efforts to avoid this state of affairs.

I left my role as co-Chair of the NC IOM/DPH Task Force convinced that when an influenza pandemic arrives, the kind of ethics most likely to persuade people to do their duty and more is not a rights-based, duties-based, or utility-based ethics, but a care-based ethics. We human beings are a very vulnerable lot. We are radically dependent on each other for survival and we need to view ourselves as folks in a lifeboat in the middle or the ocean with no visible sign of rescue. If there aren't enough supplies to go around until help arrives, we can do several things: we can ask for volunteers to jump off the boat; we can start drawing straws for who gets pushed off the boat; we can have a majority vote about which lives are most dispensable; or we can look in each others' eyes and see ourselves—fearful, hopeful, and in need of compassion. Then start paddling together to get to shore, knowing that although we might not all make it, we did not turn on each other in our panic. What we need most to weather a pandemic is an ethics of trust, reciprocity, and solidarity. If we have that, we will have the most precious health care resource of all.

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TB Matters More

Michael J. Selgelid, Paul M. Kelly, and Adrian Sleigh

Abstract Tuberculosis (TB) is the second leading infectious cause of mortality worldwide and arguably the most important neglected topic in bioethics. This chapter: (1) explains the ethical importance of TB, (2) documents its neglect in bioethics discourse, (3) maps the terrain of ethical issues associated with TB, and (4) advocates a moderate pluralistic approach to ethical issues associated with TB.

Keywords Ethics, infectious disease, tuberculosis (TB), drug resistance, quarantine, health care access, essential medications, justice

Bioethics and Infectious Disease

Medical research resources are poorly distributed. This is illustrated by the 10/90 divide, a phenomenon whereby less than 10% of medical research resources focus on diseases responsible for 90% of the global burden of disease (Resnik 2004). While medical research focuses on development of profitable products, research and development (R&D) on infectious diseases remains largely neglected. This is because infectious diseases primarily affect poor people who cannot afford even inexpensive medications. The world's most urgent health care needs remain largely neglected as a result.

An analogous misdistribution of research resources applies to bioethics. Though infectious disease should be recognized as a topic of primary importance for bioethics, it has historically been neglected by this discipline (Selgelid 2005; Francis et al. 2005). There are numerous reasons why infectious disease warrants the central attention of bioethics. First, the historical and likely future consequences of infectious diseases are almost unrivalled. Throughout history, infectious diseases have caused more morbidity and mortality than any other cause, including war (Price-Smith 2001); and they are currently the biggest killers of children and young adults. The continuing threat of infectious disease is revealed by the extent of AIDS, TB, and malaria; the increasing number of newly emerging infectious diseases (such as Ebola, SARS, West Nile Virus, and avian influenza); the growing problem of drug

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resistance (which may imply return to a situation analogous to the pre-antibiotic era); and the specter of bioterrorism. Second, because they can be contagious and cause acute illness and death, infectious diseases raise difficult ethical questions of their own (Smith et al. 2004; Selgelid 2005). Public health measures for controlling epidemics may include surveillance, mandatory treatment or vaccination, and coercive social distancing measures such as isolation and quarantine. Because measures such as these may conflict with human rights to privacy, consent to medical treatment, and freedom of movement, an ethical dilemma arises. How should the social aim to promote public health be balanced against the aim to protect human rights and liberties in the context of diseases that are to varying degrees contagious, dangerous or deadly? Third, because infectious diseases primarily affect the poor and disempowered, the topic of infectious disease is closely connected to the topic of justice, a central concern of ethics.

Bioethics has not entirely ignored the topic of infectious disease. AIDS, in particular, has received a great deal of discussion in the bioethics literature. In a related development, public health ethics has become a rapidly growing subdiscipline of bioethics as is evidenced by a number of recent books (Coughlin et al. 1998; Beauchamp and Steinbock 1999; Gostin 2002; Boylan 2004; Anand et al. 2004; Selgelid et al. 2006; Balint et al. 2006; Dawson and Verweij 2007) and (as of 2008) a new journal—*Public Health Ethics* (Oxford University Press). At least some of this literature has emphasized infectious disease in particular. With the exception of AIDS, however, bioethics discussion of infectious disease remains in its infancy, and coverage of topics has been patchy at best (Tausig et al. 2006). Much of the emerging literature has focused on SARS, pandemic influenza, and bioterrorism in particular. There has also been an increase in relevant debate about intellectual property rights in pharmaceuticals—and the barriers patents pose to medication access in poor countries (Schüklenk and Ashcroft 2002; Cohen and Illingworth 2003; Sterckx 2004; Pogge 2005; Cohen et al. 2006).

Neglected Disease

Tuberculosis (TB) is a bacterial infectious disease that is usually spread by coughing. TB illness is debilitating in the short term; and it is associated with high mortality if untreated, and with significant disability even if successfully cured. Whilst pulmonary TB (disease affecting the lungs) is the most common and most infectious form of the disease, TB can affect any part of the body. TB is strongly associated with poverty and is common in less-developed countries, particularly in Asia, Africa, and South America. There has been a resurgence of TB in relation to the HIV/AIDS pandemic, particularly in sub-Saharan Africa (Dye et al. 2007). The public health implications of TB are enormous. Until recently TB was the world's leading infectious cause of mortality, and it is now second only to AIDS.

It is surprising and unfortunate that there has not been much focused discussion of ethical issues associated with TB,[1] which is arguably the most important neglected topic in bioethics. Because TB kills nearly as many people as AIDS each year, one would expect TB to receive a proportionate amount of discussion in health ethics literature. There are, furthermore, good reasons for thinking that the problem of TB is even more ethically important than AIDS. In the vast majority of cases TB drugs can provide cure, and they are much less expensive than AIDS medications. While 1.6 million people die from TB each year (WHO 2007a) and 2.1 million die from AIDS (UNAIDS 2007), the former deaths are, economically speaking, much easier to prevent. A standard course of TB medication can cost as little as US$10 or US$20, and TB therapy is considered to be one of the most cost-effective health care interventions. In best case scenarios, AIDS medication costs as little as $100 for a year of treatment in developing countries, but it often costs much more. In the case of AIDS, furthermore, lifelong treatment is required because no cure exists. Given cost considerations, the case for increasing access to TB medication appears stronger than the case for increasing access to AIDS medication (which is not to say that the case for increasing access to AIDS medication is not itself enormously powerful). In 1998, only 56% of those in need had access to TB therapy recommended by World Health Organization (WHO), and the rate was only 23% just a few years earlier in 1995 (Lienhardt et al. 2003). There have been impressive gains in access to TB services in many countries in recent years, and approximately 62% of those in need were receiving treatment in 2007 (Floyd 2007). Significant gaps remain, however, in many of the countries where TB is most prevalent (Dye et al. 2007).

A final reason for thinking that TB is ethically more important than AIDS is that the former, being airborne, is both contractible via casual contact and much more contagious. While behavior modification (with respect to IV drug use and sexual practice) can essentially eliminate the risk of infection with AIDS, TB can be passed from one individual to another via coughing, sneezing, and even talking. In many ways, then, the threat to "innocent individuals"—and public health in general—is greater in the case of TB.

Though the ethical importance of TB at least rivals, if it does not surpass, the ethical importance of AIDS; the former has received comparatively little attention from bioethicists. The lack of attention to ethical issues associated with TB is revealed via searches on the Internet. A *PubMed* search of titles and abstracts (conducted in October 2007) for the terms "ethics" and "AIDS" yielded 2,998 entries; while a similar search for the terms "ethics" and "tuberculosis" yielded only 179. Rather than reflecting difference in ethical importance, the disproportionate amount of bioethics attention to AIDS in comparison with TB reflects the fact that

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[1] A recent exception was the workshop organized by Anne Fogot-Largeault—with participation of Mary Edginton, Lourdes Garcia-Garcia, and Brigitte Gicquel—on "TB Ethics" at the 8th World Congress of the International Association Bioethics (2006) in Beijing. We also admit that the New York epidemic of the 1980s and 1990s received some important coverage.

the former disease has affected an economically powerful and articulate community and has been much more highly politicized.

The global TB status quo, meanwhile, is alarming. The World Health Organization (WHO) declared TB a global health emergency in 1993. One third of the world population is currently infected with latent TB. Approximately nine million people develop active illness each year, and "there are between 16 million and 20 million persons with active tuberculosis at any one time" (Gandy and Zumla 2002, 385). Though a cure for TB has existed for over 50 years, and though in the 1950s TB was believed to be eradicable, TB "is now more prevalent than in any previous period of human history" (Gandy and Zumla 2002, 385). The TB burden is highest in Asia, which accounts for two thirds of the global burden of TB (WHO 2006b). The Southeast Asia Region has the *largest number* of new incident cases, accounting for 34% of incident cases globally. The *incidence rate* in sub-Saharan Africa, however, is nearly twice as high—"at nearly 350 cases per 100,000 population" (WHO 2007b). Like most other infectious diseases, the burden of TB is most heavily shouldered by the poor: 95% of TB cases and 98% of TB deaths occur in developing countries (Gandy and Zumla 2002). This is because the poor lack good nutrition, and this weakens their immune systems. It is also because crowded living and working conditions, and lack of sanitation and hygiene, increase chances of exposure and infection. Because the poor so often lack access to (even inexpensive) medical care, they are more likely to suffer adverse outcomes when infection occurs. Direct and indirect costs of illness can have a catastrophic effect on TB sufferers and their families (Bates et al. 2004; Jackson et al. 2006). Matters have been made worse by the growing HIV/AIDS epidemic. Those living with HIV/AIDS are much more likely to contract TB, and more likely to develop severe illness when they do (Harries and Dye 2006).

Though the impact of TB is most heavily felt in developing countries, the emergence and spread of multidrug-resistant TB (MDRTB) poses serious threats to developed nations as well. A primary cause of drug resistance is the failure of patients to always complete a full course of TB medication. This often occurs in developing countries when patients cannot afford to continue therapy, cannot afford time off work to visit health providers, or cannot afford travel to clinics. Another cause of drug resistance is the weakness of health care infrastructures in poor countries. Patients often fail to complete therapy because hospitals and clinics in poor countries fail to maintain a steady supply of standard TB medications (Farmer 1999; Farmer 2003). Drug resistance is also driven by the market presence of drugs that are low quality, old, or often counterfeit.

Like ordinary TB, drug-resistant TB is contagious. With increased global trade and travel, drug-resistant TB spreads frequently from country to country. Though it is usually curable, MDRTB requires longer and more expensive treatment. Ordinary TB can be treated with a six month course of medication costing US$10–20. MDRTB takes two years to treat, and treatment can be up to 100 times more expensive. The "second-line" medications used to treat MDRTB are, furthermore, both more toxic and less effective than the "first-line" drugs used to treat ordinary TB.

The problem of untreatable TB is suddenly on the rise. In 2006, the US Centers for Disease Control and Prevention (CDC) and WHO announced the emergence and spread of "extreme" or "extensively" drug-resistant TB (XDR-TB). MDRTB is defined as TB resistant to at least two (namely isoniazid and rifampicin) of the four first-line TB medications. XDR-TB is defined as TB resistant to at least two of the four first-line TB medications and at least two of the six second-line medications (a fluoroquinolone and an injectable agent; CDC 2006; WHO 2006a). A recent study showed that 20% of TB isolates from around the world were MDRTB and that 10% of these were XDR-TB. XDR-TB was found in every region, and the study showed that isolates of MDRTB obtained from the USA, Latvia, and South Korea were, respectively, 4%, 19%, and 15% XDR-TB (CDC 2006). The most dramatic epidemic of XDR-TB is currently underway in South Africa. A study in March 2006 showed that 41% of suspected patients in Tugela Ferry were infected with MDRTB and that 24% of these had XDR-TB. Of the 53 patients with the latter, 52 died within 25 days (MSF 2006). Many are worried that XDR-TB may "swiftly put an end to all hope of containing the [AIDS] pandemic [in Africa] through treatment". According to one expert: "There is no point investing hugely in ARV [anti-retro viral] programmes if patients are going to die a few weeks later from extreme drug-resistant tuberculosis" (Boseley 2006). Implications of XDR-TB for the international community are starkly revealed by the CDC's conclusion that XDR-TB "has emerged worldwide as a threat to public health and TB control, raising concerns of a future epidemic of virtually untreatable TB" (CDC 2006).

Mapping the Terrain of Ethical Issues Associated with TB: A Research Agenda

Bioethics research in the context of TB should address the following issues.

Duty to Treat

A common topic in bioethics discussion of infectious disease has been the question of health workers' duty to treat patients infected with diseases that pose risks to health workers themselves. A related question concerns the duty of society, or the health care system, to provide safe conditions for health workers through provision of masks, room ventilation, and other infection control measures in hospitals and clinics. Most of the debate has thus far focused on AIDS, SARS, and avian influenza. The existing literature reveals that there are no simple answers to these kinds of questions and that different issues arise in the context of different diseases (Reid 2005). Though these questions are pertinent to TB, given that it is highly contagious—and increasingly dangerous in the context of MDRTB and XDR-TB, and/or when health workers are living with HIV (Cobelens 2007)—they have in the specific context of TB received little if any dedicated discussion in mainstream bioethics literature. Bioethics should examine the extent of risk involved with treating TB patients; the nature and extent of health care workers' "duties" to face such risks; possible means (and ethical justification) for reducing such risks through improvement of infection control in health care settings; and the propriety of rewarding health workers willing to face greater risks (Savulescu, in discussion) and/or the propriety of compensating those who actually become infected on the job (University of Toronto Joint Centre for Bioethics 2005).

Clinical Research

A major topic of debate in the context of HIV/AIDS research has been the question of what should count as an ethically acceptable control arm in studies involving human subjects. Most of the attention has focused on placebo controlled studies of mother-to-child transmission of HIV in Africa. Critics argued that these studies conflicted with the Declaration of Helsinki requirement that patients in the control arm of a study should receive the "best proven" or "best current" therapy for the condition in question (Lurie and Wolfe 1997). Others argued that it would have been too expensive to provide such treatment in developing world contexts—and that no harm was done because patients were denied no treatment they would have received if they had not participated in the studies (because the standard of care in poor countries was *no treatment* to prevent vertical transmission of HIV). Given that the WHO has recently declared that the standard of care for MDRTB requires provision of second-line drugs, it will not be surprising, given what commonly occurred in the context of HIV, if there are proposals for studies where control arm subjects would not receive this expensive, high level of care (apparently) still required by the Declaration of Helsinki. Would it be wrong to deprive control arm subjects of second-line drugs if they would not receive them if they did not participate in the study in question—given the poverty situation in the local context? How are the ethical issues in the context of TB similar to, or different from, those that arose in the context of HIV/AIDS?

Another issue arising in clinical research involves the management of third-party risks. A study of a new drug for resistant strains of TB, for example, may pose risks to third parties. If the investigational drug is not effective, then a patient-subject who receives it may remain infectious and thus endanger family members and other close contacts. Isolation of the patient-subject or informed consent of third parties might thus be called for. This general issue has been neglected by research ethics guidelines (Francis et al. 2006).

Treatment Exclusion

There have been reports of prescription practices in poor countries where health workers decide to exclude TB patients from treatment in cases where it is believed that the patient is unlikely to complete therapy (Singh et al. 2002). While withholding treatment from unreliable patients may serve the aim to avoid promotion of drug resistance, a practice like this may be inappropriately discriminatory. Such a practice may also have counterproductive results if infectious patients remain at large in the community. Because the ability of health workers to make sound judgments about such matters is suspect, the extent and quality of institutional policy calling for patient exclusion warrants further analysis. In addition to concerns about unjust discrimination, a major question is whether or not, or why, it is reasonable to think that the harm to excluded individuals would be outweighed by greater goods to society in the way of public health. These are partly, though not entirely, empirical questions—i.e., about what the actual harms and benefits are (to individuals and society, respectively). The more ethico-philosophical question is how benefits to society should be weighed against harms to individuals.

Obligation to Avoid Infecting Others

If there is a duty to do no harm, then infected—or potentially infected—persons have duties to avoid infecting others (Harris and Holm 1995; Verweij 2005). This interesting and important topic has received surprisingly little attention in general, and discussion to date has primarily focused on AIDS and influenza. Bioethics should examine the extent to which a duty like this applies in the context of TB in particular. Because it would be unreasonable to expect potentially infected persons to take all possible measures to avoid infecting others, appropriate limitations to the duty must be considered. Because TB is transmissible via casual contact, anyone who has been breathed or coughed on by someone who *might* (for all one knows) be infected with TB should, epistemologically speaking, consider herself to be “potentially-infected”. But that means almost all of us! (This is just one of the ways in which the case of TB is different from AIDS.) Even those who actually have been in (limited) contact with someone sick with active TB, however, will usually not themselves become infected as a result. Though potentially deadly and considered highly contagious, TB is not nearly so contagious as the flu. (This is just one of the ways in which the case of TB is different from flu.) To what extent should someone who knows she has been exposed to TB limit her interactions with others afterwards? The answer will partly depend on whether we are talking about ordinary TB, MDRTB or XDR-TB—*if these details are known.*

Third-Party Notification

In cases where a contagious patient fails to take adequate precautions to avoid infecting others—and fails to warn close contacts about his infectious status—then the question of whether or not the health worker should inform identifiable third parties at risk arises. On the one hand, notification of third parties about a patient's health status would breach the widely acknowledged patient right to confidentiality. On the other hand, failure to warn could (especially in the context of XDR-TB) conflict with the innocent third party's right to life—which many would say is more important than the incautious patient's right to confidentiality. This matter is complicated because a routine practice of breaching confidentiality may decrease trust in the health care system, reduce health-seeking behavior, and thus drive the epidemic underground. What the actual public health implications of third-party notification would be is an empirical question that warrants further study.

Domestic Surveillance

Mandatory TB testing in schools, the workplace, or elsewhere in the community may potentially conflict with the right to privacy. If information concerning the health status of individuals is not well protected, then stigma and discrimination will result. Surveillance measures, on the other hand, are sometimes important to the protection of public health. Bioethics should consider the extent to which current surveillance measures are—or the extent to which more wide-reaching surveillance measures would be—justified in the context of TB, especially now that MDRTB and XDR-TB are growing threats to global public health.

Migrant Screening

It is common for countries to screen migrants for TB before granting entry visas. Some have questioned the public health efficacy and/or cost-effectiveness of a practice like this in comparison with other means of TB control (Coker 2003). Whilst identification of active disease offshore is a commonly used method for TB control in countries with a low prevalence of TB (and sometimes countries with high prevalence), it is not always possible to perform due to the lack of resources or a lack of time prior to arrival (Coker 2003). Additionally, one-off screening for TB with x-ray does not completely eliminate the risk of TB transmission to the public in the receiving nation due to the lifetime latency of the disease (MacIntyre et al. 1997). The offshore TB screening policy relies on a "user pays" philosophy, where visa applicants are responsible for the costs incurred. Aside from questions of equity, where the poor who are most likely to have TB are also least likely to be able to pay for the screening tests, this model works well when a private sector health system is in operation. The International Organization for Migration (IOM) has called for a "paradigm shift from exclusion to inclusion" to address this, amongst other unintended effects of premigration screening for the benefit of the migrant and the host nation (Maloney 2004). In many countries from which refugees are resettled, there are no private for-profit radiological or microbiological facilities and government clinics are stretched to capacity. Is it appropriate for developed countries to shift costs for their public health onto the overburdened health systems of other, less well-resourced, countries? Additional ethical issues arise in the context of asylum seekers. This form of migration has posed enormous problems in the northern hemisphere. In situations like this, host countries' duties of beneficence potentially conflict with duties to protect public health. Ethical issues associated with migrant screening in the context of infectious disease are a generally neglected area of discussion that is becoming increasingly important in the contemporary era of "globalisation" and "emerging infectious diseases". These issues are especially pertinent in the context of TB.

Social Distancing

In the past, patients with infectious TB were isolated in sanatoria for prolonged periods—and sometimes even for life. This was done to protect others from infection. Even today, in many countries, it is common to isolate patients with pulmonary symptoms (i.e., "active TB") until they are deemed uninfectious—usually about two weeks after therapy is started. Such detention is usually brief and voluntary. It is common, however, to coercively confine patients with active TB, and sometimes patients with inactive TB, when they refuse to take their medicine or when it is believed they are unlikely to adhere to treatment regimens (Coker 2000).

Bioethics should consider the extent to which (coercive) restriction of movement is ethically justified in the name of public health protection against TB. Of particular importance is the question of what should be done with XDR-TB patients, who pose threats of infection with an especially dangerous form of TB whether they take their medicines or not. Defenders of confinement in the context of treatable TB sometimes suggest that confinement is justified when patients are at least given a choice between confinement and treatment—the idea being that this respects their autonomy (Bayer and Dupuis 1995). If XDR-TB patients are confined because they are untreatable, then no autonomous choice would remain. Though this does not go to show that mandatory confinement is therefore inappropriate, the point is that the question of what to do with XDR-TB patients is not automatically settled by conclusions about what to do with noncompliant patients with treatable TB. Additional new questions are whether or not, the extent to which, or the conditions under which, it would be ethical to quarantine the large number of people exposed to, though not known to be infected with, XDR-TB—or those suspected, though not known, to be infected with XDR-TB (Singh et al. 2007)—while diagnostic confirmation is awaited.

Coercive long-term confinement may again become common in the case of patients actually diagnosed with (untreatable) XDR-TB. In a widely reported case in Arizona, for example, an XDR-TB patient has been detained in a prison hospital for over a year (Democracy Now 2007). And there are already calls in Africa for a return to compulsory sanatoria for such patients (Sakoane 2007). If the spread of untreatable

XDR-TB becomes sufficiently alarming, we may be faced with quarantine and confinement at a scale not seen for decades. In 2007 a patient suspected of infection with XDR-TB was subjected to the first US federal isolation order since 1963.

Among other questions, the following should be further considered: (1) the extent to which coercive social distancing measures are justified in light of the available evidence (or lack thereof) regarding their efficacy and (2) arguments calling for compensation provision to those whose liberties are coercively restricted.

It is true that untreatable TB was the norm prior to development of cures in the middle of the 20th century, and we should examine historical debates regarding the social acceptability of confinement and so on that took place in public health circles in the pre-antibiotic era. No developed discipline of bioethics existed at that time, however, and so it remains to be seen how policy decisions made then will be viewed under the lens of rigorous ethical analysis. More importantly, given population growth and globalization, the contemporary world is different from that when untreatable TB previously existed. Because population dynamics have changed, there is no reason to assume that public health solutions to untreatable TB in the past (even if it is determined that such policies were ethically and epidemiologically sound at the time) will be appropriate to the contemporary world.

Mandatory Treatment and Ethical Issues Associated with DOTS

As indicated above, it is commonly the case that (treatable) patients are required to either undergo therapy or be held in confinement. Insofar as the threat or actual use of force is involved, TB treatment involves coercion and thus conflicts with individual autonomy (despite the fact that patients are usually given at least some choice in the matter). The worldwide standard of care for TB treatment is known as Directly Observed Therapy, Short Course (DOTS). Among other things, DOTS involves health or social workers' observation of patients' medication-taking; and patient cooperation is (often) part of what is required to avoid detention. Though DOTS has (arguably rightly) been hailed as a great success in global TB control (partly because it promotes patient "compliance" and thus helps prevent drug resistance) ethical issues are raised by the coercion involved. It is generally thought that informed consent to medical treatment is important—and that it must be voluntary. Autonomy, however, may be outweighed by societal benefits if the stakes are sufficiently high. Additional issues involve threats to privacy and dangers of stigmatization in contexts where DOTS practices are visible to the community; and the costs/inconvenience of DOTS in comparison with unmonitored treatment (especially when we are talking about reliable patients). Though issues associated with mandatory treatment and DOTS have perhaps received more bioethics attention than others considered in this chapter, much of the debate to date has focused on the limited context of New York City in the 1980s and 1990s (see Bayer and Dupuis 1995 and reference therein).

Coercive in the Prevention of Zoonosis

Coercion is also involved in attempts to remove *Mycobacterium bovis* ("bovine TB") from the food supply in rich countries by culling infected herds and pasteurizing milk. In part this is done to increase the safety and value of bovine (or ovine and other herbivore) products, especially milk and cheese. In poor areas of the world with ongoing high rates of TB among cattle or buffalo and use of raw milk products, bovine TB still causes much disease among humans, usually as an extra-pulmonary infection of the throat (scrofula), stomach, abdomen or bones. Although control of animal TB may seem to be of obvious benefit to a community, the affected farmers may object to testing and culling of their infected animals, even when paid compensation, if herds cannot easily be replaced with disease-free equivalents. Also, farmers may be emotionally attached to the animals, especially dairy cattle, the main target for control of bovine TB. Another issue arises with compulsory pasteurization of milk. Some people even break the law to exercise their "right to consume natural products". How important are these liberties—and are they outweighed by public health benefits requiring coercion? Again these are, but only partly, empirical issues.

Justice and the Distribution of Health Resources

As a disease of poverty, TB raises issues of international distributive justice. Though sufficient resources for health improvement are lacking in poor countries, there are numerous powerful moral (egalitarian, utilitarian, and libertarian) and self-interested reasons for wealthy nations to do more to help improve health care in poor countries (Selgelid OnlineEarly 2007). These issues are complex and intertwined with the above questions regarding liberty violating public health measures. If health care provision and thus global health were better to begin with, for example, then the occasions upon which liberty infringing public health measures are called for would arise less often.

In addition to improving access to existing medications, increased R&D for drugs and diagnostics is sorely needed in the fight against TB. At present, "[w]orldwide only $20 million is spent annually for clinical trials for TB drug[s] compared to around $300 million for HIV drugs in the US alone" (MSF 2007). Bioethicists should debate recent proposals (Pogge 2005; Kremer and Glennerster 2004) and current activities (Moran et al. 2005) aimed at stimulating R&D on neglected diseases—and the extent to which they are apt for TB in particular. They should also examine the extent to which *targeted* funding for TB control is warranted in comparison with other infectious diseases. Because it has been argued that donor aid should aim to improve developing countries' general health care infrastructures—and improvement of general health indicators—rather than targeting particular diseases such as AIDS and TB (Garrett 2007), the propriety of targeted TB funding should be evaluated. Because infectious diseases, including drug-resistant infectious diseases such as XDR-TB, fail to respect international borders, bad health in poor countries threatens global public health in general. The strength of associated self-interested reasons for wealthy nations to help reduce TB in poor countries (through targeted or untargeted funding) should therefore, finally, be a major focus of analysis.

A "Moderate Pluralist" Ethical Approach to TB Control

Our recommended approach to ethics and infectious disease may be characterized as "moderate pluralism". This approach aims to identify the plurality of (intrinsic) values at stake in the context under study and strike a balance between potentially conflicting values without giving absolute priority to any one value in particular. In the context of XDR-TB, for example, the utilitarian aim to promote public health *might* best be promoted through coercive confinement of infected patients. Such a policy, however, would conflict with apparent rights and liberties of infected individuals; and it is not generally believed that individual rights and liberties should be sacrificed whenever this would promote the greater good of society. Resolving a conflict like this requires assessment of the overall threat to society, assessment of the centrality/importance of the rights under threat, and consideration of features that might make one value (i.e., utility) or the other (i.e., liberty) especially important in the context in question. Most ethicists, policymakers, and ordinary citizens would, upon reflection anyway, deny that either of these two social values should always be given absolute priority over the other. The ideal solution to conflict between values is to bypass the conflict to begin with. We should thus, whenever possible, aim for a policy that promotes both utility and liberty—and also equality, another legitimate social value—at the same time. TB reduction via increased health care provision would reduce the frequency of occasions where we are faced with the conflict between utility and liberty under consideration; and it would likely also promote equality (given that TB reduction would generally involve improving the situation of those who are worst off).

This is not to say that the initially considered conflict would never eventuate if TB reduction occurs. Difficult decisions will need to be made in cases where conflict is unavoidable; and a principled rationale for favoring one value over another is needed in cases of conflict. One idea is that the aim to promote utility should be weighted more heavily as a function of the extent to which utility is threatened. Another idea is that the weight of a right/liberty should be weighted as a function of its centrality. More basic rights/liberties deserve more protection than others. When catastrophe would result from protection of the most basic rights, however, then even these must be compromised. We sometimes think it is appropriate to violate the most basic right of all—i.e., the right to life in time of war.

When rights violations are found to be necessary in the context of TB, amends can be made by compensating individuals whose rights are compromised (Ly et al. 2007). The living conditions of those confined should be made as comfortable as possible—and those who succumb to liberty restrictions should perhaps receive additional (e.g., financial) rewards. It would be unfair to expect coerced individuals to shoulder the entire cost of societal benefit. If a net social dividend results from liberty infringement, then part of this should be returned to the victims of coercive social policy. This is a matter for reciprocity (University of Toronto Joint Centre for Bioethics 2005).

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Ethics of Management of Gender Atypical Organisation in Children and Adolescents[1]

Simona Giordano

Abstract Atypical gender identity organisation (AGIO) is a serious medical condition in which the phenotypical appearance is experienced as alien by the person affected. AGIO is source of great distress, and obtaining medical treatment is for many a life-or-death matter. Many of those who cannot receive treatment are at high risk of suicide. AGIO is not only a problem of personal health, but also a public problem, because sufferers are often exposed to discrimination, abuse and violence, and each act of discrimination, abuse and violence is a public issue. Thinking about AGIO represents a great challenge for us all. It involves rethinking about gender identity in a more comprehensive way, inclusive of phenomena that go beyond the classic gender divide 'male-female', and thinking of ways of ensuring all citizens, whatever their gender identity, a secure and peaceful place in society. I explain what AGIO is, how it manifests itself, and provide a brief history of AGIO. I offer an overview of risks and benefits of available treatments. I analyse the ethico-legal issues that surround AGIO. In particular, ethics of interfering with natural development, competence in minors, validity of informed consent, role of the family, moral and legal responsibility of professionals for omission of treatment and ageism. I conclude that medical treatment should be offered, even to minors just after the onset of puberty, if the child has a profound and persisting AGIO, if she/he is competent to make a judgement on the matter, and if treatment is likely to enhance his/her quality of life. Deferring treatment till adulthood is not a morally neutral option, and it is indeed unethical, if the child is likely to be harmed by pubertal development.

Keywords Gender identity disorder, suspension of puberty, acts/omission, ageism, competence in minors, informed consent, international guidelines for treatment of gender identity disorder

Imagine how you would feel if, tomorrow morning, you were to wake up to find yourself in an male body, with a man's voice and a man's face looking back at you from the mirror, with early morning beard and moustache stubble, with no breasts,

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[1] Part of this chapter relies on Giordano (2008a, b).

M. Boylan (ed.) *International Public Health Policy and Ethics*,

an Adam's apple, large male feet and hands, a body covered in thick, black hair and a penis and testicles. […] Do you think that you'd feel as if you were going crazy? […] This terrible thing has happened to me and it is worse than you could ever imagine (A patient, personal communication)

Introduction

Atypical gender identity organisation (AGIO—term first used by Di Ceglie 1995, Chapter 2) is a 'rare condition in which individuals experience their "gender identity" as being incongruent with their *phenotype* [physical appearance]. The personal experience of this discomfort is termed *gender dysphoria*. In its profound and persistent form, it is known as *transsexualism*' (GIRES et al. 2006).

In many cases, the discomfort begins in childhood. Between 40 and 70 new children a year are referred to specialised clinics in the UK, whereas the University Hospital in Gent (Belgium) reports seeing one new child a week, and the numbers of applications seem to be growing exponentially (De Sutter 2006, personal communication).

AGIO is not just a problem of private health. It has important public repercussions. Growing in a body that is experienced as inappropriate is for many sufferers terrifying and intolerable, and taking whatever step is necessary to undergo transition to the other gender is for many a life-or-death choice. Many of those born in areas of the world where early treatment and sex-change surgery are unavailable emigrate clandestinely in countries where they will be able to transition to the other gender; they may become prostitutes in order to pay for reassignment surgery, thus exposing themselves to HIV, STDs, imprisonment, violence and abuse. Sometimes, in order to survive in the cold winter nights on the pavement, they resort to heroin, thus again adopting criminalised behaviours and exposing themselves to life-threatening conditions (Farias 1994). Even those who do not need to emigrate often do not receive timely medical treatment, and end up buying hormones off the illegal market and injecting them at unregulated dosages and without medical supervision and monitoring. Transgender people are also particularly at risk of abuse and violence. At school, bullying towards children with unusual gender/sex orientations is common practice (GLSEN 2005; see also 'Information for Schools', at www.gires.org.uk/Web_Page_Assets/frontframeset.htm), and homophobic bullying has severe long-term effects (Adams et al. 2004; Grossman and D'Augelli 2006). There have even been cases of children killed by their peers by reason of their atypical gender identity (Di Ceglie 2000, p. 466). Transgender adults are also at high risk of violence; it is reported that 39 transgender people were killed in 2003 in brutal ways (December 4, 2003, issue of *Workers World* newspaper http://www.workers.org/ww/2003/trans1204.php). It cannot be claimed that these people choose risky lifestyles and willingly expose themselves to violence: Those who do not receive treatment are left without recourse, and 'people without recourse are not free' (Korsgaard 1993, p. 59).

Medicine now offers means to help children and adolescents with AGIO, and thus help to limit discrimination, ill health and criminalised behaviours. These are puberty suppression, cross-sex hormones, surgery and, of course, psychological support. Cross-sex surgery is nearly invariably offered only to adults (one known exception is Natalia, from Argentina, who convinced the Courts to grant her permission to obtain cross-sex surgery at the age of 17; El Mundo, www.elmundo.es). However, if AGIO is tackled early enough, when the child has not yet completed pubertal development, he or she can be assisted in his/her gender development in a monitored and supervised way, with great advantages in terms of physical and psychological health as well as social functioning. With puberty suppression and administration of cross-sex hormones, children and adolescents would be spared the anguish of developing an unwanted body and could explore their real gender identity under medical supervision. This would protect them from taking hazardous steps to obtain medical help from non-medical sources and from spiralling down into depression, suicidality and even in the criminal system. Later they could undertake much less invasive surgery, as puberty suppression would prevent development of unwanted body characters of the biological gender, which only invasive surgery can remove.

Treatment of children and adolescents with AGIO is surrounded by important ethical and legal issues (see *Re Alex [2004] FamCA 297*. Reserved files—by Court Order the File Number and names of Counsel and Solicitors have been suppressed—narrate the long and heart-breaking story of Alex, who underwent a long and complex court case, at the age of 13, to receive early treatment). In order to understand whether it is ethical to offer treatment to minors with AGIO, it is necessary to clarify what AGIO is, what the condition of those affected is and the benefits and risks of available treatments.

I will argue that there are strong ethical reasons to suspend the development of children with profound and persistent AGIO at early stages of puberty, if deferring treatment exposes the child to great suffering and harm. It is important to bare in mind that many untreated children would rather take their life, and indeed try to take their life, rather than growing in the alien body. Considering the devastating effects of spontaneous development for these children, I suggest that, in order to assess the ethical legitimacy of puberty suspension, the overall welfare of the child needs to be considered, and not just the potential risks and benefits *of the medications*. If the child is competent to make a decision on the matter, if treatment is likely to prevent psychological suffering, to reduce painful, costly and more risky treatments in adulthood, to improve the patient's physical, psychological and social adaptation and to promote a overall better quality of life for the patient, treatment should be offered. Far from being an 'ethically neutral option', deferring treatment in these cases would be unethical.

Brief History of AGIO

Gender identity disorder was first included in the DSM-III in 1980. The notion of transsexualism is also relatively recent. Harry Benjamin, an endocrinologist who worked in New York, introduced it in the 1950s. Although the nosology is recent, AGIO as always been part of human history (Mills 2006):

> *God, said the Jewish chronicler, created man in his own androgynous image – 'male and female created he them', for in him both were united. Mohammed on his second coming, says the Islamic legend, will be born of a male. Among Christians, Paul assured the erring Galatians, there was no such thing as male or female – 'all one person in Christ Jesus'. The Hindu pantheon is frequented by male-female divinities, and Greek mythology too is full of sexual equivocations, expressed in those divine figures who, embracing in themselves strength and tenderness, pride and softness, violence and grace, magnificently combine all that we think of as masculine or feminine.*
>
> *[…] The Phrygians of Anatolia […] castrated men who felt themselves to be female, allowing them henceforth to live in the female role, and Juvenal, surveying some of his own fellow-citizens, thought the same plan might be adopted in Rome. […] Hippocrates reported the existence of 'un-men' among the Scythians: they bore themselves as women, did women's work, and were generally believed to have been feminized by divine intervention. In ancient Alexandria we read of men 'not ashamed to employ every device to change artificially their male nature into female' – even to amputation of their male parts.* (Morris 1974, pp. 35–38)

The Night, sculpted by Michelangelo (Di Ceglie 1998b, p. 185), represents someone with both male and female attributes. In the representation of *The Night*, gender ambiguity is pictured as nearly a dreamy state.

Although gender ambiguity has always been part of human history, arts and mythology, western medicine has been caught unprepared to provide help to those who need to deal with the discordance between their gender identity and their sex characteristics. Jan Morris, who sought assistance for transition to the other gender in the 1950s, tells us of expensive and fruitless trips to Harley Street in London, visiting psychiatrists and sexologists:

> None of them – she wrote – knew anything about the matter at all, though none of them admitted it. […] Could it not be, they sometimes asked, that I was merely a transvestite, a person who gained a sexual pleasure from wearing the clothes of the opposite sex, and would not a little harmless indulgence in that practice satisfy my, er, somewhat indeterminate compulsion? Alternatively, was I sure that I was not just a suppressed homosexual, like so many others? (Morris 1974, p. 40)

Gender ambiguity struggles to find space among our mental categories (on this see Connolly 2003). The default assumption seems to be that a person is either a man or a woman, and that if a person transitions to the other gender he or she will then unequivocally belong to the other gender. This, however, is not the case for many people. Many of us live in a *chiaroscuro*; there are female and male parts to our selves, and gender identity for many of us includes both of these parts. The polarisation male/female fails to mirror the reality that many people experience—where they have male and female facets and they cannot force their identity to one or the other gender. Alice Dreger writes:

> Some people really are born male by all conventional standards and really do end up with the gender identities of women. And vice versa. And some people's gender identities really do seem to change over time. Moreover, some people never settle into a simple male or female gender identity. But all these people are forced by the revisionist history required by the state and most of the medical profession and everyone else to tell only the 'man trapped in a woman's body' or 'woman trapped in a man's body' story. 'They got my sex

> wrong at the start' is the only story that seems to be acceptable. Okay, you can be trans, but only if you cooperate in changing your whole history so that you fit into the two-sex model. (Dreger 2006)

This quote refers to the New York City's proposal to allow people who have not undertaken cross-sex surgery to change their birth certificates to match their innate gender identities. Although this theme is different from the topics of this chapter, Dreger's quote tells something of relevance here. AGIO is not necessarily an illness ('having the wrong body'), and is not necessarily a condition in which the person wants to belong to other gender. Gender organisation is individual and subjective, and can be monothematic or comprehensive. AGIO, thus, might not necessarily mean 'being born in the wrong body': it might also signify a more complex process of identification with different aspects of both genders. It is mistaken to assume that gender identity must be, for every person, either feminine or masculine.

Intra-psychic, Physical and Social Dimensions of AGIO

AGIO has three interrelated dimensions: intra-psychic, physical and social.

Intra-psychic dimension

Di Ceglie has described the intra-psychic experience of children as follows: 'Their interests, their play, their fantasies, their way of moving or talking, their way of relating to friends, or their way of seeing themselves do not fit the body that they have and the way that other people perceive them as a consequence of their bodily appearance. One might say that their psyche lives in a foreign body. […] The child feels driven to live in this confusing and bewildering condition' (Di Ceglie 1998, p. 186).

Physical Dimension

AGIO does not generally cause physical alterations. AGIO children generally develop 'normally', in accordance with their biological sex. It is this physical dimension that horrifies the sufferer, in that biological sex is experienced as alien. In some relatively rare cases, AGIO appears in concomitance with other conditions, which might alter normal development. These could be chromosomal, like the Turner Syndrome and the Klinefelter Syndrome. Other conditions are hermaphroditism, anomalous genitalia, congenital adrenal hyperplasya, androgen insensitivity syndrome and alpha-reductase deficiency. In these cases, the sexuality of the individual might be ambiguous, for example, if the genitalia are ambiguous, or if enzymes prevent complete virilisation in biological male, or if chromosomal anomalies are present. Ghosh and Walker have provided a synthetic and clear account of these medical conditions and their relationship to AGIO (Ghosh and Walker 2006). As they explain, AGIO should not be confused with these other conditions, although sometimes it might be triggered by them, as some of these conditions might contribute to create profound uncertainty over the sense of the self and over gender identification. Typically, however, AGIO sufferers have a clear phenotypical appearance that reflects their biological sex and an incongruent gender identity. AGIO is thus classified as a psychiatric illness. Recent research suggests, however, that the causes of AGIO might be hormonal and neurological, and not just psychological (GIRES et al. 2006).

Social Dimension

AGIO also has a social dimension, in two ways: first, AGIO is, to an important extent, shaped by social categories and stereotypes about gender identity. AGIO becomes particularly stressful within a certain sociocultural context. We struggle to contemplate gender ambiguity or differences as one of the many, normal paths open to individuals, and the psychological distress experienced by the sufferer and the family is partly due to the difficulty of accepting the reality of ‘a third way’ (Connolly 2003). Second, children and adolescents are exposed to bullying, abuse and denigration, as well as to open physical violence (Di Ceglie 2000, p. 458). When a person is discriminated against, or subject to abuse and violence, his/her story is no longer private, but assumes public connotations that deserve public attention.

The threefold distress to which children and adolescents with AGIO are exposed makes life unbearable to many of them: Young people with AGIO are at high risk of suicide (Di Ceglie 1998, p. 194; Di Ceglie et al. 2002).

Therapies: Three Stages

Therapy for AGIO includes three stages (Royal College of Psychiatrists 1998, p. 5):

1. Wholly reversible interventions
2. Partially reversible interventions
3. Partially irreversible interventions[2]

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[2] I owe this original classification to Bernard Reed.

Wholly Reversible Interventions

The first stage of treatment is temporary suspension of pubertal development. This treatment is offered in cases where the gender dysphoria is diagnosed as being profound and highly likely to persist. The endogenous production of oestrogen in girls and testosterone in boys is temporarily suppressed. G*onadotropin-releasing hormone analogues* (GnRHa) are the best available drugs. These act on the pituitary gland and block the pituitary hormone secretion.[3] These drugs are sometimes called 'hypothalamic blockers', or simply 'blockers'. These could be given to children after the onset of puberty, but before the substantial development of secondary sex characteristics. This is around what is known as Tanner Stage two (http://en.wikipedia.org/wiki/Tanner_stage).[4] Puberty suppression releases the stress of the child and allows the child and the clinician to assess whether the dysphoria is likely to persist. If puberty is suppressed successfully, the child can have a 'real life experience'. This involves adopting the role of the other gender, in order to experience the congruence with presumed innate gender identity. In the centres that offer such endocrinological treatment, the child also receives psychological support. After a period on blockers, the child/adolescent might decide to go on with therapy, and, eventually, to begin cross-sex hormones (see next section). Alternatively, she/he might wish to revert to the phenotypical sex, and interrupt therapy. By resuming endogenous sex hormone production, the pubertal development would restart normally. For this reason, blockers are regarded as a reversible intervention (see Sections —'Suspension of Puberty: Benefits' and 'Suspension of Puberty: Risks').

Both the British Society of Paediatric Endocrinology and Diabetes (BSPED), and the Royal College of Psychiatrists (Royal College of Psychiatrists 1998) regard 'blockers' as a therapeutic tool. Blockers, however, can also be regarded as a diagnostic tool, as one of their primary functions is to enhance understanding of the real nature of the patient's discomfort (Cohen-Kettenis T Peggy 1998).

The time at which suppression or inhibition of endogenous sex hormones should begin is controversial. The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders states that the adolescent (note: not the child) can receive the hormone-blocking medication, provided that he or she has commenced puberty and he/she has had a persistent desire to change sex throughout the childhood. Box 1 cites these guidelines.

The Royal College of Psychiatrists recommends that adolescents have experience of themselves in the post-pubertal state of their biological sex. However, it contemplates the possibility of earlier interventions (Royal College of Psychiatrists 1998, p. 5).

BSPED, instead, assumed that puberty should be complete before any treatment could start.

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[3] I am grateful to Professor Mike Besser for this specification.

[4] The precise development can be measured by assessing testicular and breast development and levels of sex hormones (Delemarre-van de Waal and Cohen-Kettenis, 2006).

Box 1: The Harry Benjamin Standards of Care (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 10)

Adolescents may be eligible for puberty-delaying hormones as soon as pubertal changes have begun. In order for the adolescent and his or her parents to make an informed decision about pubertal delay, it is recommended that the adolescent experience the onset of puberty in his or her biologic sex. […] In order to provide puberty-delaying hormones to an adolescent, the following criteria must be met:

(1) Through childhood the adolescent has demonstrated an intense pattern of cross-sex and cross-gender identity and aversion to expected gender role behaviors.
(2) Sex and gender discomfort has significantly increased with the onset of puberty.
(3) The family consents and participates in the therapy.

Box 2: BSPED (BSPED, p. 2)

An adolescent should be left to experience his/her natural hormone environment uninterrupted until:

(A) Development of secondary sexual characteristics is complete.
(B) Final height has been achieved.
(C) Peak bone mass has been accrued (ideally).

BSPED withdrew its approval from its own guidelines in October 2006 after questions were raised about their clinical appropriateness (puberty cannot be 'suspended' if it has already completed its course) and credibility (no date of publi-cation and authorship was claimed). However, it is important to understand the experience of children who have been treated according to the BSPED guidelines, in order to understand the ethics of treating minors with AGIO. The passage in Box 3 is written by an adolescent whose care has been organised under the BSPED guidelines.

This is not an isolated experience. Bran Fenner and Rickke Mananzala (FIERCE) in collaboration with Z. Arkles and Dean Spade (Sylvia Rivera Law Project) describe the state in which children are left, when they are refused blockers at the beginning of puberty:

> *For these youth, being turned away for hormone treatment at clinics has a number of effects. First, it further alienates them from medical providers, about whom they may already feel distrust or fear. Because of this increased distrust, many may not return for*

Box 3: Sixteen and a half-year-old (M→F) not been treated until pubertal development was complete.

I […] began my puberty at the age of ten, so I have lived with this profound physical wrongness for over six and a half years. The last two and a half years have been horrendous for me, with my body becoming so disgustingly adult male that I cannot bear it. […] My body will never, ever be as I would like it to be and now, unfortunately, it is really a case of damage limitation. […] at the moment, I am living in a limbo land – my name is […] and I dress in female clothes, but I have facial and body hair, which makes me feel horrible, I am the wrong shape for the clothes that I wear and I have genitalia which is completely alien and upsetting and which protrudes through my clothes. […] If I could have started on blockers at Tanner Stage Two (this, for me, was at the age of about twelve) […] I would have been able to avoid the worst physical effects of male puberty; as it is, I am going to have to spend years, and a lot of money, trying to get rid of the many physical male attributes that I could have avoided. […] I still have many years of being covered, from head to toe, with thick, black hair to look forward to.

> *primary care, HIV testing, STD treatment and other essential care. […] Besides creating a disincentive for other medical care and alienating youth from medical services, these age-based denials also create a necessity for youth who feel that hormone therapy is essential to their survival to seek this care out elsewhere. For many, this care is the only way to express their gender fully so that they can seek employment, attend school, and deal with every day interactions in their new gender. Without hormones, many have a difficult time being perceived by others correctly, opening them up to consistent harassment and violence. For many young people […] taking hormones feels like a life or death need, and they will do whatever is necessary to get this treatment. Many, when rejected at a clinic based on age, buy their hormones from friends or on the street, injecting without medical supervision at dosages that may not be appropriate and without monitoring by medical professionals. This opens them up to high risk for HIV, hepatitis, and other serious health concerns. Additionally, many youth have difficulty raising money to buy these hormones illegally because they do not have parental support for their transition and face severe job discrimination as young transgender applicants. For many, criminalized behaviour such as prostitution is the only way to raise the money. Doing this work makes them vulnerable to violence, trauma, HIV, and STD infection, and entanglement in the juvenile justice system […]. Once a young person enters the juvenile justice system, the stigma of delinquency usually follows them throughout life and they often cycle into the adult criminal justice system upon maturity.* (Fenner and Mananzala, 2005)

Delemarre-van de Waal and Cohen-Kettenis concur that: ‘the experience of a full biological puberty may seriously interfere with healthy psychological functioning and well being’ (Delemarre-van de Waal and Cohen-Kettenis 2006, online publication at p. 3). In February 2007, the UK newspaper *The Telegraph* reported the news of a 12-year-old boy, treated for AGIO in Germany. This appears to be one of the youngest children officially treated for AGIO. Experts claimed on that occasion that treatment was administered in light of the *trauma* that can affect children with AGIO when their body begins to take the shape of the unwanted gender (*Telegraph*, 1–2–2007).

In order to understand whether there is any reason to defer treatment, thus leaving children and adolescents to grow in their biological phenotype, it is important to understand the clinical benefits and risks of various therapies.

Suspension of Puberty: Benefits

1. Suspension of puberty immediately reduces the patient's suffering (Cohen-Kettenis and Pfafflin, 2003, p. 171).
2. 'Blockers' improve the precision of the diagnosis. Adolescents are given more time to explore their self and their gender, without the distress of the changing body.
3. 'Blockers' can also help identifying children who are false positives. Delemarre-van de Waal and Cohen-Kettenis argue that early administration of blockers might *increase* the incidence of false positives. However, later discussion in their paper suggests that appropriate diagnosis *decreases* the chance of treating false positives. 'Making a balanced decision on SR [sex reassignment] is far more difficult for adolescents, who are denied medical treatment (gnRHa included), because much of their energy will be absorbed by obtaining treatment rather than exploring in an open way whether SR actually is the treatment of choice for their gender problem. By starting with GnRHa their motivation for such exploration enhances and no irreversible changes have taken place if, as a result of the psychotherapeutic interventions, they would decide that SR is not what they need' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 12).
4. Suspension of puberty reduces the invasiveness of future surgery. In Female-to-Male (F→M), it would avoid breast removal; in Male-to-Female (M→F) it would avoid painful and expensive treatment for facial and body hair; moreover, the voice will not deepen, and nose jaw and crico-cartilage (Adam's apple) will be less developed. This will avoid later thyroid chondroplasty to improve appearance and cricothyroid approximation to raise the pitch of the voice[5] (Cohen-Kettenis and Pfafflin, 2003, p. 171).
5. Better psycho-social adaptation is associated with early physical treatment (Cohen-Kettenis and Pfafflin, 2003, p. 171).

However, there are risks to be considered in suspending puberty.

Suspension of Puberty: Risks

A major concern is the impact of GnRHa on development. Administration of GnRHa slows the pubertal growth spurt. This can represent an advantage for M-to-F,

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[5] I owe this clarification to Terry Reed.

as it makes it more likely for them to achieve an ultimate height within the normal female range. However, the obvious question is whether reduction of the rate of growth has any side effects on bone formation and metabolism. GnRHa inhibits the production of endogenous sex hormones and thereby impacts on the formation of bone mass. Later administration of cross-sex hormones can increase bone mass, but long-term effects on bone mass development and sitting height are unclear. Peak bone mass can only be measured when patients are about 25-years old, and such a long-term follow-up has not yet been performed.

Another concern is the effect of GnRHa on the brain. Males and females show different brain development, especially in amount of grey matter. The effects of suppression of puberty on the brain are not known (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 13).

Currently, the only centre that monitors the consequences of blockers over an extended period of time is the Department of Medical Psychology and Pediatrics in Amsterdam. The Amsterdam team sees around 70 children every year. According to their estimates, two third of the *adolescents* (age 12–18) who apply for treatment are diagnosed as having profound and persistent gender identity disorder and will then be treated. Only 20–25% of *children* (under 12) who are seen at their centre suffer persisting dysphoria and, following the Department's procedures of assessment, will be treated (information kindly offered by Cohen-Kettenis, T. Peggy, personal communication 2007). According to the Royal College of Psychiatrists it is not clear how many children with gender dysphoria will become transsexual adults (Royal College of Psychiatrists 1998, p. 5; Di Ceglie 2000, p. 462). According to another study, nearly all those who experience dysphoria in adolescence will become transsexual adults (Wren 2000).

These estimates should only be taken as a rough indication. Given that patients who are refused therapy or who decide to suspend therapy are not followed up, it is impossible to establish whether they will eventually transition to the other gender as adults or elsewhere. This might be inevitable but to some extent impinges upon the reliability of statistics of incidence and prevalence of AGIO in the general population, and on the way AGIO develops when it is manifested early in life.

The selection process in Amsterdam includes rigid psychological and endocrinological assessments. Until they undergo surgery (after the age of 18) patients are seen by the endocrinologist and by the psychologist at least every 3 months, although the psychologist is available for more frequent sessions. The endocrinological and psychological follow-up is meant to observe and prevent any abnormal development and adverse consequences of treatment. All parties should be convinced that treatment is in the best interests of the child (Cohen-Kettenis, personal communication 2007; for more information see Delemarre-van de Waal and Cohen-Kettenis 2006)

Follow-up includes assessment of bone density and body composition—yearly; skeletal age—yearly, endocrine and metabolic parameters—every 6 months—and anthropometry (overall height, weight, sitting height, skin folds, waist and hips)—every 3 months. 'Laboratory measurements include levels of gonadotrophins and sex hormones, metabolic parameters such as fasting glucose, insulin, cholesterol, high-density lipoprotein and low-density lipoprotein levels. In addition, safety parameters, such as renal and liver functions, are estimated' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at pp. 8–9).

These studies show that later administration of cross-sex hormones makes it possible to manipulate overall height and achieve *quasi*-normal height. (Cohen-Kettenis and Delemarre-van de Waal 2005).

Additional concerns regarding blockers are their effects on the reproductive capability. Specialists in Belgium have explored these effects (De Sutter 2005). De Sutter explains that the use of blockers in early puberty might prevent the storage of sperm (for M→F children) and of ova (for F→M children) for future reproductive purposes. However, the suppression of spermatogenesis in males is temporary and can be restored by interrupting treatment. A boy, whose puberty has been suppressed before spermatogenesis has occurred, could decide to stop treatment long enough for spermatogenesis to start, once he is a bit older, if he wishes to collect and store sperm for reproductive purposes (this of course would mean that he would have to accept the masculinising effects of endogenous testosterone on his body). He can then continue with treatment for transition to female gender.

Collection of ova in females is less problematic. The treatment has little impact on the already formed ova. They may be collected and stored at the time of oophorectomy (De Sutter 2005).

An additional problem for trans-girls is that the genital tissue available for the later creation of a vagina will be less than would otherwise have been available, but this problem could be resolved with appropriate surgical intervention.

The results of current studies are encouraging. Suspension of puberty at an early stage seems to have no significant and non-controllable adverse side effects. Peter Lee and Christopher Houk (USA) write: 'We believe suppression of pubertal sexual characteristics is warranted when there is evidence of pubertal onset. Suppression of pubertal sex steroid production and thus secondary sexual characteristics can be effectively and safely accomplished using gonadotropin-releasing hormone analogues (GnRHa)—an intervention that is both temporary and reversible' (Lee and Houk 2006).

Preliminary evidence leads to the conclusion that there are sound clinical grounds for commencing treatment soon after the onset of puberty. Questions can be raised, however, as to the *ethical* legitimacy of suspension of puberty, and these will be discussed in the last seven sections. I shall now outline the partially reversible interventions, and their risks and benefits.

Partially Reversible Interventions

Partially reversible interventions refer to masculinising and feminising hormones.

Cross-sex hormones have the following benefits:

1. They initiate the development of the secondary sex characteristics that accord with the innate gender identity.

2. They make it easier for the person to have a real-life experience by beginning to alter the physical appearance to accord with the new gender role.
3. They allow the person to explore what it feels like to be the other gender, thus making it possible to make a better-informed choice about irreversible interventions.

There is no agreed protocol as to the dosage, or as to the type of hormones that should be offered, as the case history below shows (Box 4):

The difference in national protocols has the inevitable and unfortunate consequence of promoting 'medical tourism'. US experts report[6] that patients, who are not treated adequately in some European countries, travel to the USA to receive privately paid treatment. Those who cannot afford this, as we have seen above, are forced to suffer or attempt other, often illegal, and, above all, unsafe routes.

Risks of Cross-Sex Hormones

Risks are mainly cardiovascular. Cross-sex hormones seem to increase the likelihood of occurrence of serious/fatal cardiovascular diseases in patients already at risk (smokers, obese patients, patients with heart diseases, hypertension, clotting abnormalities or some endocrine abnormalities). Most of these risks concern mainly adults and generally do not apply to children and adolescents.

In trans-women, oestrogens and progestins may also cause infertility, weight gain, emotional lability, liver disease, gallstone formation somnolence and diabetes mellitus. In trans-men, testosterone may cause infertility, acne, emotional lability, increased sexual desire and hepatic dysfunction and even malignant liver tumours (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 15).

BOX 4: ***Case history***

A sixteen and a half (M→F) at Tanner stage 5 (and therefore already fully grown in the biological male phenotype) is treated in the UK with analogue GnRHa, followed later by 5 mcg of ethinylestradiol per day. This would be increased every 6 months. In Gent, in Amsterdam and in the USA ethinylestradiol is not utilised in cases like hers. Beta oestradiol (in the USA this is called Estrace) is used, because it is a natural oestrogen and because it has shown lower association with thrombosis. The dosage of beta oestradiol that she would be recommended is comparable to 30–50 mcg of ethinylestradiol—much higher than the dosage that the patient would receive in the UK.

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[6] Private communication.

One final important risk associated with cross-sex hormones is that the treatment is only partially reversible. If a patient decides to interrupt treatment, effects such as voice change and beard growth cannot be changed, although possibly ameliorated, and breast development in males through administration of oestrogens and progestins can be only removed with surgery.

International guidelines on treatment for AGIO recommend that masculinising and feminising hormones should not be administered before the age of 16 (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 10). These guidelines, moreover, insist on the support of the family. Later sections will examine the ethico-legal issues around setting age limits for access to treatment and around the involvement of the family.

Irreversible Interventions

These refer particularly to surgery.

Surgery represents the final stage of treatment, although hormone intervention is an additional lifelong treatment. The benefits of surgery are self-evident. The patient has finally obtained a body in line with the innate gender identity. According to a study, body satisfaction significantly increases in the vast majority of cases (Cohen-Kettenis and Delemarre 2005).

Risks of surgery include normal risks associated with all surgery. Additional risks concern body dissatisfaction (Cohen-Kettenis et al. 2003): in some rare cases the person wishes to revert to the original gender. Reversing surgery involves expensive and invasive procedures, which in some cases can only be partially successful (GIRES 2005). Even for those who 'successfully' transition to the other gender, satisfaction might be incomplete. The reasons for partial satisfaction can be diverse. First, to be *one or the other* is not everyone's reality. For some, ambiguity is the reality, and such will be the case after transition. Incomplete satisfaction might also be a function of the life history of those who transition. It is possible that many of those who have had to struggle a great deal to have cross-sex surgery feel great uncertainty over the self due to their life experiences, often populated by unemployment, emigration, prostitution, abuse, criminalisation and violence or, at least, struggle with the medical system to receive adequate care.

International and national guidelines agree that surgery should not be carried out before the age of 18 (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, p. 11; Royal College of Psychiatrists 1998, p. 6), although, as mentioned earlier, in September 2007 the Courts of Argentina granted permission for cross-sex surgery to a 17-year-old patient, Natalia. Section 'Ageism' will discuss the ethical issues around the determination of age limits for access to treatment.

Ethical Issues: Playing God

The treatment for transsexualism in minors is surrounded by many ethical and possibly legal issues. One of the main issues that can be raised is about the ethics of playing God or playing with nature. There might be an intuitive distrust or revulsion over medical interventions that interfere with spontaneous development. Medicine itself is, however, a discipline aimed at changing the course of events and nature for the better. Other authors have rejected the objection against medical interference in the course of nature as unsustainable and I shall not repeat debates already widely covered in ethics and bioethics (Ryan 1995; Harris and Giordano 2003). If there is reason to believe that minors will benefit from suspension of puberty and cross-sex hormones, it is ethical to provide these treatments. Our emotions and intuitions should leave room for reasoned judgement upon the minors' welfare.

Other ethical issues concern children's competence to make informed decisions about their condition.

Competence and AGIO

AGIO is currently classified as a mental illness. Mental illness can be believed to jeopardise the sufferer's decision-making capacity; in particular, his/her capacity to consent to treatment for the illness itself (MHA 1983, s. 63). There are grounds for challenging the classification of AGIO as a mental illness (Giordano 2008a). Arlene has also pointed out the potential damage of considering individual gender expressions as mental illnesses, and the ethical dilemmas of needing a psychiatric diagnosis in order to obtain medical treatment (Arlene 2006). However, even if AGIO was appropriately conceptualised as a mental illness, this would not *ipso facto* entail patient incompetence. Although there are difficulties inherent in the determination of competence (Mason and McCall Smith 2006, p. 334), the presence of a mental disorder does not necessarily affect capacity to consent to medical and psychiatric treatment, including treatment for the mental illness (Department of Health 2000, para 15.9–15.24; Mason and McCall Smith 2006, pp. 263–264; Giordano 1999, 2001). The fact that AGIO is currently classified as a psychiatric illness should not remove presumption of competence in patients and applicants.

Minors and Competence

Another worry might be whether minors can give genuine and legally valid consent to treatment for AGIO. Health care professionals, in particular, might be concerned about legal liability for treating minors with AGIO. The first stage of therapy, in order to be effective, should begin early in puberty, and it can be asked whether minors under the age of 16 can make competent decisions on treatment that has significant effects on their development.

In Anglo-Saxon jurisdictions a person is deemed competent if she/he understands in broad terms the nature of his/her condition, purposes of proposed treatment and alternatives, and can balance risks and benefits of proposed treatment and alternatives. It is not excluded that children can display competence. Competence 'does not depend on the age of the child, but on subjective features of the child in respect to the particular treatment proposed' (Jones 2006, p. 129).

Some jurisdictions protect the right of the child to consent to medical treatment. The UK Family Law Reform Act 1969, for example, at Section 8, states that a minor who has attained the age of 16 years *can give valid consent to any surgical, medical or dental treatment*. Where a minor has by virtue of Section 8 given effective consent to treatment, it shall not be necessary to obtain consent from his/her parent/s or guardian (Brazier 1992, pp. 361–371). 'Surgical, medical or dental treatment' includes any procedure undertaken for the purposes of diagnosis, and this section also applies to any procedure (including the administration of an anaesthetic) that is ancillary to that treatment. There is no apparent reason for excluding treatment for AGIO from under the umbrella of treatments covered by Section 8 of The Family Law Reform Act 1969.

In the Anglo-Saxon legal panorama, children *under 16* can also be competent to make medical decisions. *Gillick v West Norfolk and Wisbech Area Health Authority* ([1985] 3 A11 ER 402 HL) established that a child under 16 is competent and can give an effective consent to medical treatment providing that she/he had reached:

> … sufficient understanding and intelligence to be capable of making up his own mind in the matter requiring decision. ([1985] 3 All ER 402 at 409 e-h per Lord Fraser and at 422 g-j per Lord Scarman; See also *R v D* (1984) 2 A11 ER 449)

Although the implications of Gillick in terms of children's right to autonomy are discussed (Freeman 2006), 'Gillick competence' is regarded as the landmark of adolescent autonomy in health care (Eekelaar 1986, p. 1).

In order to satisfy a request for treatment, not only the request has to be competently made, but also treatment has to be in the minor's best interests. Whether treatment is in the minor's best interests is a matter on which health care providers are called to deliberate, on the basis the evaluation of each individual child. However, should the health care provider find that treatment is in the child's best interests, there would be no reason to deny it on the ground that the applicant is incompetent by reason of age or by reason of AGIO. There is in fact no reason for assuming that children with AGIO cannot be competent, in the way described by law, to make a judgement upon medical treatment for their conditions (for more detailed discussion of competence and the courts in gender reassignment cases see Jones 2006; See also Whittle and Downs 2000).

There is, however, a more general issue. It can be asked whether informed consent for treatment of AGIO can be given at all.

Can Informed Consent Be Given at All?

In order to be valid, consent needs to be informed. Information about the risks and benefits of treatment is material to the decision. However, Sections 'Suspension of Puberty: Risks', 'Risks of Cross-Sex Hormones' and 'Irreversible Interventions' have shown that the risks of treatment for AGIO (including risk of incomplete satisfaction) have not been fully established. It may be believed that this makes it impossible to give valid informed consent to gender transition. Children and adolescents might be believed to have greater difficulty in foreseeing how they will feel in the future, due to the scarcer capacity of their long-term judgement and scarcer knowledge of the self, and therefore more at risk of giving invalid consent.

The idea that partial unpredictability invalidates consent is mistaken. If it were not possible to consent to interventions whose outcome is uncertain, it would follow that medical research involving human beings is always unethical, and this is clearly not the case. In order to give valid consent, the applicant must receive as complete as possible information about treatment, and has to be informed about the unknown risks of each stage of therapy. The person will ponder the unknown risks of treatment with its potential benefits, and will set them against the all-known psychological and physical effects of non-treatment.

It could be objected that even if the person is competent to take unknown risks, and even if consent is genuine and legally valid, it is still unethical to expose people, especially minors, to unknown side effects that could affect their future life.

Although this concern is understandable, the belief that treatment is unethical if there is a degree of unpredictability is mistaken. Indeed the complete outcome of many medical treatments is unknown before they commence. If the potential risks were so high and of such a type that no reasonable person would take them, then indeed a question could be raised as to whether it is ethical to offer such a treatment, even if the applicants were fully competent. However, preliminary evidence suggests that no severe or uncontrollable side effects are involved in treatment for AGIO. Evidence shows that, instead, *not being treated* is devastating for most children and adolescents with profound and persistent AGIO, many of whom try to take their life if they do not obtain appropriate medical care, and therefore the certain and real side effects of *not receiving treatment* might, for many, outweigh any unknown potential risk of treatment. If it can reasonably be expected that therapy improves the applicant's quality of life or can save his or her life, it is not unethical to satisfy the request for treatment—it might indeed be unethical to deny it.

This has wider implications. This implies that, in judging whether or not to treat, health care professionals should evaluate what is likely to happen to the applicant if he or she does not receive treatment, and not only what is likely to happen if he or she does receive treatment. In other words, health care professionals should take into consideration the consequences of their omissions, as well as those of their actions. This might seem to go beyond professional responsibilities: clinicians might feel that they should assess the clinical benefits and risks of therapies and that they are not responsible for what happens to people outside their clinics. Although the extent to which all of us, including health care professionals, are responsible for omissions is open to debate, it is a mistake to believe that omitting to treat is a morally neutral option. There are both ethical and legal grounds for considering carefully what would happen to the applicant if he or she was not treated, or treated with hormones and in doses that he or she finds unhelpful.

Acts and Omissions

Doctors are not obliged to provide medical treatment upon request, if treatment goes against their clinical judgement or their moral values. However, the entitlement to omit treatment, like any other entitlement, is not absolute. For example, a doctor who refuses to perform an abortion on the basis of conscientious objection could be held negligent, if his omission exposes the woman to serious and imminent risks.

Gillick also implies that doctors should evaluate the consequences of their omissions ([1985] 3 All ER 402 at 409 e-h per Lord Fraser).

Doctors are required to look at what is likely to happen to applicants *if they fail to administer requested treatment*. I am not suggesting that a doctor should be held accountable for murder if he refuses to treat an applicant, and she commits suicide as a result: holding ourselves *equally* responsible for our omissions bears probably a too stringent moral responsibility (Husak 1980). However, certainly inaction is not necessarily a 'morally safe place' to be in. When we know that, if we fail to do something, the consequences for our omissions are serious and potentially fatal for others, we have some moral responsibility for those consequences. In fact, on Hall's account, the decision not to treat could be regarded as an action, not as an omission—and this would further explain in what sense doctors are responsible for not treating (Hall 1989). In AGIO, omitting to treat at the right age, or treating with doses of hormones that the patient finds unhelpful, may cause great harm to the child (see Section 'Wholly Reversible Interventions'). This harm can be prevented by blocking pubertal development and administering appropriate doses of cross-sex hormones at a later stage.

So far, we have seen that there is no reason to believe that treatment of children and adolescents with AGIO is undue interference with nature (or with God's will—an argument that should be left to the faith of each individual); there is no reason to assume that children with AGIO are incompetent to make decisions about their conditions, or that valid consent cannot be gathered; finally, I have argued that early treatment is not unethical—indeed, it might be unethical not to satisfy a request, when the child is competent and the risks of not treating appear to outweigh potential risks involved in therapy. There are further ethico-legal issues relating to the involvement of the family and determination of age of access to treatment, which will be examined in the next and final sections.

The Involvement of the Family: Ethico-Legal Grounds

Anglo-Saxon jurisdictions accept that a competent 16-year-old person—and in some case, a competent child below that age—can commence treatment *without parental consent*. In Section 'Ethical Issues: Minors and Competence', we have seen that in the UK, the Family Reform Act 1969 establishes that where a minor has given effective consent to treatment, it shall not be necessary to obtain consent from his/her parent/s or guardian.

International guidelines on treatment for AGIO, however, state or imply that the family/guardian's consent is conditional to the initiation of therapy (The Harry Benjamin International Gender Dysphoria Association's Standards of Care for Gender Identity Disorders 2001, pp. 10, 16), and experts agree that 'adolescents need the support of their parents in this complex phase of their lives' (Delemarre-van de Waal and Cohen-Kettenis 2006, online at p. 6).

The principle of consistency (Giordano 2008) requires that similar principles apply to similar circumstances. If different principles apply, there must be relevant differences that justify difference in treatment. For minors with AGIO, participation of the family is of crucial importance. Unlike other medical treatments (like, for example, the provision of contraceptive advice and treatment in Gillick), transition to the other gender involves the family in a profound way: gender reassignment determines a modification of the whole family dynamics, and it is essential that the family supports and participates into the various stages of the transition. This might explain why guidelines and experts insist upon obtaining consent of the family/guardian. Many applicants are indeed accompanied and supported by their parents. Due to the importance of family involvement in order to achieve good outcome, it might in reality be difficult for a child to persuade a health care provider that it is in his/her best interests to receive treatment for AGIO where the parents/guardian's consent is withheld.

However, a veto a priori against treatment without parental consent is difficult to justify. Unless it can be shown that parental consent is *always* essential to successful adaptation to gender reassignment, health care professionals should be open to the possibility—albeit remote—of treating children without parental consent. It cannot be assumed that parents always serve or even understand their children's best interests, and the decision to treat should ultimately be made in the best interests of the child. In the unfortunate and possibly rare cases in which parental support is not available, clinicians should assess whether *not receiving treatment* is ultimately better for the competent applicant than being treated without parental support.

Ageism

International guidelines set out strict age-related criteria for access to treatment (see Sections 'Irreversible Interventions'). The determination of a particular age of access to gender reassignment is ageist. Ageism is unjust discrimination by reason of age. Decisions regarding whether or not an applicant should receive treatment should not be based on age, but on the applicant's competence and capacity to benefit from treatment. Competence and capacity to benefit from treatment often are a function of age, but this is not always the case. Indeed, in AGIO capacity to benefit from treatment is inversely proportional to age, in that it decreases as puberty advances, and competence, which generally matures with age, sometimes is manifested very early in life.

The World Health Organisation (WHO) and the United Nations (UN) have formally established that 'ageism', including ageism in health care provision, is unethical (*Brasilia Declaration on Ageing*, WHO, 1-July 1996, Available at http://www.oneworld.org/helpage/info/brasilia.html; UN International Year of Older Persons 1999, Available at http://www.un.org/esa/socdev/iyop/).

Age-based discrimination is a violation of one of the most fundamental human rights, the right to equality meant as non-discrimination. According to the European Charter of Human Rights, age, together with sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability and sexual orientation (Article 21, Non-discrimination), is an arbitrary feature that does not justify difference in treatment (Besson 2005; Available at http://www.europarl.eu.int/charter/default_en.htm; See also the Convention for the Protection of Human Rights and Fundamental Freedoms as amended by Protocol n. 11, 4 November 1950, Article14, Prohibition of discrimination, Available at www.echr.coe.int/Convention/webConvenENG.pdf; the Convention for the rights of the child (2 September 1990), Preamble, Available at http://www.unhchr.ch/html/menu3/b/k2crc.htm; the European Social Charter (Revised; 3 May 1996), Part IV, Article E., Available at http://conventions.coe.int/Treaty/EN/Treaties/Html/163.htm).

Ageism generally refers to the treatment of the older patient, and the declarations by the WHO and the UN are normally meant to protect the equal right of the older person to access medical treatment. However, there is no reason why one should think that only older patients can be discriminated against by reason of their age. Younger people can be discriminated against on similar grounds. Refusing to treat someone because he is too young is an unjust discrimination based on age. Setting up age limits for access to treatment, in one direction or the other, is a form of ageism. Health care professionals need to provide valid reasons to refuse medical treatment: they need to show that the treatment is not in the best interests of the applicant, or that the applicant is incompetent to make such a decision at this stage of his/her life and the risks of the treatment outweigh its expected benefits. Appeal to age alone is ethically unsound and incongruent with ethical principles stated in virtually all conventions and declarations of human rights and fundamental freedoms.

Health care professionals could argue that it is irresponsible to treat children, when the outcome of treatment is uncertain. However, if it is irresponsible and/or unethical to provide treatment whose risks and benefits are uncertain, then this is so *regardless of the age of the applicant*. Treating an adult would be as unethical as treating a child.

This does not mean that treatment of AGIO must be offered, that doctors have a moral and legal obligation to treat children who request it. It means that the rationale for withholding treatment must be made out on other grounds, and not on the basis of the age of the applicant.

Conclusions

AGIO is a serious medical condition: minors with atypical gender development sometimes begin to suffer as early as at the age of 4 or 5 and the distress increases as they grow older. Many of those who cannot receive treatment are at high risk of suicide. AGIO also represents a great challenge for society. The distress associated with AGIO is partly determined by rigid social categories and stereotypes relating to gender identity. It is expected that gender identity will conform to the phenotype and also that a person be either a male or a female. However, for many people it is not possible to identify themselves with one gender, and they experience both genders in their person. AGIO thus induces us to rethink gender identity in a more comprehensive way, inclusive of phenomena that go beyond the classic gender divide 'male-female'. AGIO is also a public problem because sufferers are often exposed to discrimination, abuse and violence, and each act of discrimination, abuse and violence is a public issue. Thinking about AGIO means thinking about ways of ensuring all citizens, whatever their gender identity, a secure and peaceful place in society.

Endocrinology now offers the possibility to suspend puberty and administer cross-sex hormones in adolescence. This raises ethico-legal issues that have not been addressed in depth in bioethics literature. This chapter has analysed these issues. In particular, the question of whether it is unethical (or even illegal) to offer treatment for AGIO to young adolescents has been examined. Some might believe that it cannot be ethical to interfere with nature, or that it is unethical to provide children with treatment whose long-term risks are not fully established. I have argued that there are no ethical or legal grounds for deferring treatment until puberty is complete and the applicant is a young adult, because, at that stage, the damage caused by natural development might be difficult to undo. Indeed, it might be unethical not to treat as requested, if treatment is likely to prevent great harm and to save people's lives.

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Clean Water

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Abstract This chapter argues that there is a basic human right for clean water and sanitation. The present state of the world is not even close to providing this human right. Various considerations of the origins of the current problem are examined in the context of public health. Then some modest suggestions for beginning the process of positive change are recommended.

Keywords Water, sanitation, public health, human rights

There is nothing simpler and common *or* more complex and rare than water. H_2O is a rather simple molecule composed of two common elements. It is not very rare. Water covers more than 70% of the earth. It makes up to 60% of an adult and 70% or more of a child. We are largely composed of water. It is an essential ingredient of who we are and is necessary for our continued life. Though we can live up to a month without food, most will succumb in five to seven days if deprived of water.

And yet, finding the water that we need is very complex. The supply of potable clean (so-called blue) water is diminishing. At the same time, the population of the world is increasing. The WHO (2000) estimates that each person in northern climates needs 2 to 3 liters of water a day. This increases to 6 to 10 liters in hot equatorial climates. This creates a complex problem as one of the essential components of survival becomes scarcer. Lack of clean water puts up to 3.5 billion people annually at risk for disease (Ahmed 2002).[1] Every eight seconds a child dies from drinking unclean water (Children's Water Fund 2004). With increasing population, pollution, global business investment, and geopolitics, the issue of scarcity is critical (Boberg 2006; Global Water Futures 2005).

This chapter will introduce the reader to the problem of water first as a human right, and second within the context of public health. Turning to solutions, the third goal is to suggest a classification of the arena of action and finally to what might be done within that arena so that some progress might be made that will satisfy public health concerns within the context of human rights.

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[1] It should be noted that here and elsewhere the availability of clean water is also linked to the issue of sanitation.

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Water and Human Rights

It is the position of this chapter that public health policy (whether it be national or international) should be based upon moral principles rather than mere perceived expediency (Boylan 2004b). This accepted, what is the status of the moral right to water? Most of us would admit that water is very important—given that it is a biological necessity for life on a very regular basis. But how should we understand this? In order to obtain clarity on the issue, we must return to the foundation of all ethical rights and duties. Now, of course, these are justified in various ways according to the normative theory that is put forth by the proponent.[2] This author puts forth a rights-based theory that is justified by the natural human inclination toward purposive action (Boylan 2004a, chapters 1–2). Those goods most necessary for purposive action are those goods to which all potential agents have the strongest claim (i.e., they are most embedded regarding the foundations of the possibility of action). The claims are derived via biological, philosophical, psychological, and anthropological analyses of Homo sapiens, as such. It is not a claim of Jamal or Juanita as individuals, but is a species-level attribution.

I have tried to sort out these sorts of claims hierarchically as follows:

The Table of Embeddedness[3]

Basic Goods

Level One: *Most deeply embedded*[4] (that which is absolutely necessary for human action): Food & water/minimum sanitation, clothing, shelter, protection from unwarranted bodily harm (including health care)

Level Two: *Deeply embedded* (that which is necessary for effective basic action within any given society)

- Literacy in the language of the country
- Basic mathematical skills
- Other fundamental skills necessary to be an effective agent in that country, e.g., in the United States some computer literacy is necessary
- Some familiarity with the culture and history of the country in which one lives
- The assurance that those you interact with are not lying to promote their own interests
- The assurance that those you interact with will recognize your human dignity (as per above) and not exploit you as a means only
- Basic human rights such as those listed in the US Bill of Rights and the United Nations Universal Declaration of Human Rights

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[2] I discuss some of these fundamental justifications in Boylan (2000).

[3] Boylan (2004a, chapter 3).

[4] "Embedded" means proximity to the fundamental goods that allow the possibility of purposive action.

Secondary Goods

Level One: *Life enhancing*, medium to high-medium embeddedness

- Basic societal respect
- Equal opportunity to compete for the prudential goods of society
- Ability to pursue a life plan according to the Personal Worldview Imperative
- Ability to participate equally as an agent in the Shared Community Worldview Imperative

Level Two: *Useful*, medium to low-medium embeddedness

- Ability to utilize one's real and portable property in the manner he or she chooses
- Ability to gain from and exploit the consequences of one's labor regardless of starting point
- Ability to pursue goods that are generally owned by most citizens, e.g., in the United States today a telephone, television, and automobile would fit into this class

Level Three: *Luxurious*, low embeddedness

- Ability to pursue goods that are pleasant even though they are far removed from action and from the expectations of most citizens within a given country, e.g., in the United States today a European vacation would fit into this class
- Ability to exert one's will so that he or she might extract a disproportionate share of society's resources for his or her own use

If readers would accept the Table of Embeddedness (or something like it) as the grounds for species' rights claims, then all individuals within the species would also possess these claims on the basis of logical subsumption. If rights and duties are correlative, then all others have a duty to provide the claimant his or her rights claims (subject only to the caveat of "ought implies can"). In Boylan (2004a) I concentrate upon duties within a society, but there is no reason to stop there.[5] Since water is named as a first-level basic good, and since this is the strongest right claim (because it is most highly embedded to the possibility of human action), then the claim right to water is as strong as any other claim right, and the duty to provide all with potable water is also the highest.

Various other rights claims that get in the way of providing water to all are weaker on the table of embeddedness. For example, political liberties (often sought via war and embargos) are a level-two basic good. Visions of social castes such as aristocratic or oligarchic orderings are level-one secondary goods. Economic development falls either at level-two or level-three secondary goods (depending upon net profitability and proximity to essential action). All these pretenders (and others) are less embedded than the claim for clean water. Thus, in a conflict, the right to clean water wins every time.

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[5] I am presently working on a manuscript that intends to do just this from a regional and a global perspective.

The argument becomes even stronger when one realizes that water when adulterated can also turn into a source of unwarranted bodily harm. Thus, in two respects the right to potable water is very strong, indeed. In order to appreciate this in greater detail, let us turn to the basic areas where water becomes a crucial agent in maintaining public health.[6]

Water and Public Health

There are four generally accepted categories of water as a contributing agent to human disease (Whiteford and Whiteford 2005, 9–10; Gleick 2004, 7–9). These are:

1. *Water-borne diseases*. These diseases occur directly as an individual drinks contaminated water. The principal cause of this contamination is human waste. Untreated waste gives rise to protozoan, bacterial, and viral diseases. These most commonly attack the human intestines. Specific diseases that are water-borne include cholera, typhoid, hepatitis, ameobiasis, giardiasis, *Taenia solium* taeniasis, ascariasis, hookworm, trichuriasis, and strongyloidiasis. These often attack groups of people causing local epidemics that are often deadly.
2. *Water-washed diseases*. These diseases occur when there is not enough water for proper hygiene or cooking sanitation. People cannot rid themselves of contaminants that they might come in contact with and as a result become ill including trachoma, typhus, and diarrheal diseases.
3. *Water-based diseases*. These diseases come from hosts that live in water during part or all of their life cycles. When people bathe, swim, or wash their clothing, the contaminated water may come into contact with their skin. Diseases such as schistosomiasis, dracunculiasis, and lung flukes (caused by carrier snails) affect as many as 200 million people in 70 countries (WHO 2000). Elimination of such "black water" would solve this source of disease.
4. *Water-related insect vectors*. These diseases include those spread by insects—such as mosquitoes—that breed in water. These insects infect humans with malaria, onchocerciasis (river blindness), West Nile fevers, yellow fever, and dengue fever.

One should also add to this list the sanitation infrastructure. In most of the world, this infrastructure is lacking or incomplete (Reilly and Babbitt 2005; WHO 2000). With almost 60% of the world's population at risk for death because of one or more of these four categories (and their causal connections with poor sanitation), we are not very far along the road of reaching the United Nations' Millennium Development Goal 7, target 10 to "halve by 2015 the proportion of people without sustainable access to safe drinking water" (UNDP 2003).

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[6] Boylan (2004a, part two), makes the case that because the justification is at the species level, individual rights claims naturally can be attributed to all subsets within the species: countries, regions, ethnic groups, etc.

Ever since the classic case of Dr. John Snow in the mid-nineteenth century in London who discovered that a common source (the Broad Street pump) was the cause of a cholera outbreak, public health officials have been keen on using the powerful tool of water control for short-term disease control and sanitation/pollution efforts for long-term solutions (Hempel 2007; Johnson 2006).

In Dr. Snow's London, the solution was rather straightforward. There was one country involved and a limited number of polluting sources. In the case of modern water contamination, it can be more complicated (Stevens 2006; Börkey 2006; Barah 1996). There are many players and interests at stake. This makes crafting a solution more complicated. In order to make suggestions on what might be done, it is necessary to examine the various stakeholders and power brokers to set the stage for our drama.

A Description of the Action Arena

There are various actors in our action arena. The ones that this section will examine are: nature, humankind's basic activities, international organizations and treaties, global corporations, and intra-national dynamics.

Nature

Genuine water availability is a function of the hydrological cycle. The cycle works this way: the sun's heat evaporates water into the atmosphere. The heat of the sun, the dryness of the prevailing air, and the wind *control the speed* of this process. The heated liquid becomes gas. This gas rises in the atmosphere, becomes colder, and as a result condenses into precipitation. The water returns to terrestrial land striking the soil, streams and lakes, and man-made coverings. The water also returns to marine (ocean) locales. Marine water is returned by evaporation while terrestrial water is also returned by flora in the form of transpiration.

The total amount of water on earth is fixed. It is continually changing from solid to liquid to gas. It is a self-renewing cycle. A sense of where water is located can be set out as follows.

Figure 1 illustrates how most water on the planet is marine salt water (not proximately useful for domestic activities of life). For human needs, the most important of these water reservoirs is surface terrestrial water (lakes), rivers, and underground terrestrial water. These are the primary, proximate sources of potable water. The large geographic regions that support these rivers, lakes, and underground terrestrial water are called water basins (Boberg 2005). For example, there is a single water basin that supports Lake Superior that extends across states of Minnesota and Wisconsin and into Ontario, Canada. This is important. The geography of the land creates the conditions that make rainwater and melted snow move in particular directions. This geography does not recognize artificial man-made boundaries such

Terrestrial atmosphere: 4.5
Marine atmosphere: 1.1
Ice and snow: 43,500
Biomass: 2.0
Surface terrestrial water: 350
Rivers: 35.0
Underground terrestrial water: 15,300
Marine: 1,400,000
Terrestrial precipitation: 107.0
Terrestrial evaporation and transpiration: 71.0
Marine precipitation: 398.0
Marine evaporation: 434.0
Volumes in 10^{15} kg (10^3 km^3)/fluxes in 10^{15} kg year^{-1} (10^3 km^3 year^{-1})

Fig. 1 Where water is on earth (NRC 2005)

as nations and intra-national divisions. Because of their size, water basin management can be rather difficult (Fischhendler and Feitelson 2005).

Smaller divisions within water basins are called watersheds. Watersheds are topographical units that are more recognizable to local control. Because of their more limited scope there has been more success in creating and executing water management programs within watersheds.

The strategy for water management of watersheds is to focus upon the particular ecosystem that supports it. Since an ecosystem is naturally self-sustaining and interactive, it provides a good model for adaptation and management. By beginning with the natural sustainable dynamic, we have a pattern or goal to try to re-create or approximate. Water basins are more difficult because they are affected by many different ecosystems and may cut across more than one biome. This means that many different strategies must be undertaken (according to the circumstances) and that the interaction between these may result in counterproductive outcomes.

It is important to emphasize that we should not be overly anthropocentric about water management. It is not only humans that need water. There are three other natural classes that depend upon water to maintain their identity. The first of these is the land itself. The structural integrity of hills, topsoil, and even mountains over time can be altered by too much or too little water. If one considers the problem from a land ethics point of view, then water management is important to maintain the land as it is (Leopold 1949). Many in the United States have not considered the needs of the land itself. Strip mining and poor agricultural practices have often had the effect of altering the character of the land—and the character of the land is a crucial element in the creation of ecosystems and biomes.

Sometimes the land can be a source of pollution. This often occurs due to extreme weather conditions in which large areas of land mix with water and block out sunlight, and possibly affect the oxygen content of water. However, this is a sporadic rather than a regular occurrence.

Second is the flora. Plants need water, minerals, and sunlight to survive. Minerals are a function of the land's character. Water availability is determined by the water basin and watershed dynamics. Sunlight is sensitive to the atmospheric medium that separates plants from sunlight entering the earth's exosphere. Without adequate water, plants will die. When plants die they affect the land because they cease to fix minerals into the soil as well as to maintain topsoil. Again, the entire ecosystem or biome can significantly alter.

Third is the fauna. Animals need clean water to stay alive and complete their life cycle. Animals provide nourishment to plants through their excretions and the decomposition of their bodies. They also participate to help plants to pollinate and promote vigorous growth by their eating habits.

Both flora and fauna can contribute to water contamination. In the first case dead trees (for example) can become habitats for bacteria that are harmful to other ecosystem members. In the second case, animal defecation and animal carcasses both provide more virulent host opportunities for parasites and bacteria to thrive. These events can work to the detriment of other animals that drink from the stream or pond.

It is most often the case that the question of water is viewed from the anthropocentric viewpoint, but it is important to see the biocentric position, as well.

Humankind

Of course humans (like other animals) require clean water to stay alive and complete their life cycles. Humans drink water and use it to wash themselves and to clean food preparation items and apparel (domestic usages). In addition, because humans are toolmaking creatures and bent on habitat alteration, humans require water for many of their life activities. In fact, unlike other animals, humans use water most to support these activities. Worldwide humans use water for the following classes of action: agriculture—70%; industry—20%; and domestic (daily life of drinking, cooking, bathing, washing dishes, etc.)—10%. This works out differently according to the world region involved.

What Fig. 2 tells us is that most of the water that humans use is not directly concerned with the activities of day-to-day living (domestic uses). Other animals only consume water for domestic purposes and those purposes are rather limited to drinking and sometimes to bathing. Because 90% of fresh water worldwide is involved in agriculture (most often for the purpose of irrigation) and industrial uses,

	Agricultural (%)	Domestic (%)	Industry (%)
Europe	40	15	45
N. America	50	10	40
Australia/Oceania	60	28	12
S. America	62	25	13
Africa	80	15	5
Asia	70	10	20

Fig. 2 How water is used around the world (Boberg 2005)

this may provide an area of hope for the future *if* better and more efficient practices are developed. At present, both agriculture and industry are great sources of pollution. In agriculture, fertilizers mix with the water. In most cases this means mixing human and animal fecal matter into water that will runoff into either ground water (affecting the watershed) or into local streams and lakes. This mixture of water and fecal matter creates a breeding ground for parasites, bacteria, and viruses that will constitute a threat to the health of humans and animals.

When farmers use chemical fertilizers the situation is not much better. Chemical fertilizers can also affect the ecosystems of rivers, lakes, and marine bodies of water. These chemicals act as poison and can have the effect of killing large numbers of animals and affect human health as well by raising the risk of cancer and other diseases.

Industrial wastes are much like the chemical runoff from farms except the by-products are often more toxic. Some extreme cases, such as Love Canal, can cause epidemic illness that is often fatal (Reed 2002). Thus the activities of humans constitute a real threat to clean water. This exponentially exceeds the impact of the land or fauna or flora upon the supply of clean water.

Social/Political Entities

Since humans deleteriously affect water so much, it is useful to identify certain combinations of humans and their behaviors as key actors in the tragedy of water contamination. These entities are the social and political constructs of human culture. Beginning with the largest they include international organizations (such as the United Nations, and its various operational bodies such as the World Health Organization (WHO), and the policies and treaties that flow from these). Other international bodies such as the World Bank can also play pivotal roles in the financing of public health initiatives that otherwise might not occur.

Secondly, there are international companies whose business ventures within a country often play a pivotal role in the consequent water pollution. As was noted in Fig. 2, this ensuing industrial impact can be significant in total water usage. And baring governmental restraints (corporations are often loath to lower their bottom line by making investments that have no direct shareholder value (such as voluntary pollution controls)), there is no realistic change in sight.

Third are the international relations between countries. Since water basins are often situated over extended geographic regions that overlap to two or more countries, what happens in one place can have an immediate effect in another. This requires cooperation. But what if relations between the countries are strained? The result, sad to say, is often close to the worst possible outcome.

Lastly, is the role of intra-country, local government. Local populations see water as an asset to their own communities. Their interests may be different from other localities. This is similar to the problem between countries with the exception that within one nation it is often easier to find some sort of peaceful, political resolution of the problem.

Thus, the stage is set with the players and their props. Now we must view the agents of crisis that bring our drama to a climax.

Key Obstacles to Progress

The plot thickens in our drama as we set out some of the underlying conflicts between our leading characters. This chapter will highlight two classes of conflict: humankind versus nature and social/political conflicts.

Humankind Versus Nature

The preeminent conflict concerning water between humans and nature, as such, revolves around agriculture. As we saw in Fig. 2, agriculture uses up to 80% of a region's water resources. This is more the case in poorer countries than in rich ones. The poorer countries are the ones with the fewest indigenous resources to address the problem. Because of the fertilizer problem (mentioned earlier), there is a continual problem with finding clean water due to water-borne and water-based factors. But there are also nature issues in the artificial re-creation of water basins. This is often accomplished by the construction of large dams. Dams are often created for water management. The principal aims are controlled irrigation and electricity. But the construction of dams comes at a price. By interrupting the natural flow of water, ecosystems along with the animals and plants they support are greatly disrupted.

Those living on the streams that have been diverted will likely suffer from water-washed factors. The new body of reservoir water may (unless proper sanitation measures are observed) be subject to water-borne disease and new habitats for water-related insect vectors. Thus, dams can be the instruments of disease (Manderson and Huang 2005; Johnson 2005). Dams also exemplify water allocation changes with winners and losers.

In short, the law of unintended consequences is so prevalent with large water management projects that it is essential that as much caution as possible be used. This is often called the principle of precautionary reason.

Humans can live with nature (even sloppily) without much incident so long as the human population does not get too large. Just like any other animal species, when one exceeds its sustainability ratio, given a particular ecosystem in a particular time, then problems occur. In nature, starvation and disease step in to cull the numbers. In the case of humans, this is an unethical solution when we have the power to stop it (contra Malthus 1798). This is because each human has a claim right to level-one basic goods.

However, often we move in this direction indirectly when we create opaque contexts. In an opaque context two synonymous entities are not linked due to the mode of expression.[7] Thus, if I am correct about this, people do not interrupt the water cycle because they want to cause disease and death. Rather they do so because they have some other, immediate prudential aim in mind. The fact that the aim will *also* cause disease and death is not seen (because of the context).

This may *explain* why people act to disrupt the cycle when their own personal needs are at stake, but it does not *justify* the act itself. Dams and other alterations of the natural flow of waters to other regions (such as from the Colorado River to California for irrigation—in the United States; Rowell et al. 2005; Glenn et al. 1996) are examples of altering the hydrological cycle. As per above, when we interfere with natural systems, we do so at our peril. We may be involved in artificially raising expectations in the region receiving the water and at the same time harming the source of that water by removing the mass of liquid from its geographically situated hydrological-cycle location. Thus, the most important point about the human–nature conflict is the potential long-term damage that interruption and degradation of this cycle can cause.

Social/Political Conflicts

The next area to consider concerns inter-human constructions. First, there is economic development. There are at least two dynamics at play here: industry as such and the effects of globalization. As we saw in the last section, industry uses up to 45% of a region's water. Aside from the problems mentioned earlier about untreated runoff from industry there is the further problem of the commercialization of water (Mulreany et al. 2006; Payen 2005). Privatization of water management in various poorer countries around the world has had the affect of limiting domestic access to poorer people within the society (Whiteford and Cortez-Lara 2005; Guillet 2005). This is because the goal of private companies (without public oversight; Boylan 2008) is profit. The social goal of equal access to clean water among all segments of society is not in step with the private goal of returning shareholder value. The most common way access is restricted is by price. This creates a shortage of water among the poor and an increase in water-washed disease. The poor often turn to untreated water and are then subject to water-borne disease, as well.

Even in the G8 wealthy countries, the commercialization of drinking water occurs. An example of this is bottled water whose sales have been increasing by 10% per year (Gleick 2004). Bottled water represents a possible move toward making this the option of choice for human consumption. But bottled water costs as much as $1,000 per m^3 in California in 2003, while municipal water in the same

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[7] For example, " 'Tully was a Roman' is trochaic while 'Cicero was a Roman' is not trochaic" even though Tully is a synonym of Cicero. Synonyms should render an equal context, unless there is another variable at hand: here the scansion of the lead word. When the context of expression makes synonymous relationships unclear, then there is an opaque context (Quine 1960, 142–146).

locale is \$1 per m^3. This is an example of a paradigm of transferring attractive potable water to a high-cost delivery system when the quality of the water is not significantly better than the municipal water (Gleick 2004). One could imagine a possible scenario in which bottled water acquires 80%+ market share and local governments decide to be less diligent in maintaining the quality of municipal water for drinking (thinking that most people *buy* their drinking water via bottled water). With an 80%+ market share this is probably a true assumption. But what about the other 20%? These would be the people who could not afford to pay the prices for bottled water. They would then be subject to water-washed and water-borne diseases. It is not too great of a stretch to imagine a future scenario not too much different from this. The commercialization of water—even in affluent countries can pose potential risks.

Further, the overlay of globalization intensifies some of these problems and adds new ones. For example, the scarcity problem in Equador created a water-borne cholera outbreak that was focused in poor areas (Whiteford 2005). Also, globalization has led to deregulation through treaties designed to nurture economic growth, e.g., NAFTA and FTAA. But some of the regulations that have been scrapped protect water and the environment. Sometimes, a water payment system is set in place in which water pollution levels can be bought and sold in an effort to lower macro contamination. But often the effect is to transfer water protection away from the poor and dispossessed to the affluent centers of industrial wealth (Hong 2000).

This chapter has taken the position that water is a level-one basic good of agency. Thus, there is no justification that it be treated as a level-two or level-three secondary-good subject to barter and commercialization. The nature of the basic goods is that they are commonly claimed and cooperatively delivered. Systems of capitalistic distribution that aim at efficiency at the expense of equity should not be the default distribution mechanisms of basic goods of agency (Boylan 2004a).

Second, it deals with the dynamics of social discrimination. For purposes of brevity let us confine ourselves to gender and economic differences. In much of the developing world (as mentioned above) poor areas are often severely short changed in being provided potable water and proper sanitation. Since it is often the case that the preponderance of those most affected in these situations are women and children (Ferguson 2005), unequal access to clean water and adequate sanitation ends up as de facto gender discrimination. This is especially compounded in sub-Saharan Africa in which there is an epidemic of HIV/AIDS. Poor women are statistically more at risk in this region and thus their immune systems are compromised. This puts the female and juvenile population at even greater peril in the face of contaminated water. People with compromised immune systems are more likely to contract serious diseases that they otherwise might have been able to thwart off. Thus, the availability of clean water further underscores the sorry plight of poor women and children in developing countries.

The social and political causes continue to haunt subsistence societies with a markedly higher differential impact upon marginalized peoples. This is hardly an appropriate response to delivering a good to which all humans have a basic claim right. The plot has reached its crisis.

A Few Modest Proposals

The clean water debate in developing countries has largely been driven by the World Bank that has sought to instigate competitive, market-based solutions to problems that I argue above are really cooperative domains requiring competent government oversight. The current system is disintegrating quickly. Some restorative action is desperately needed. Here are a few modest proposals that this author feels will begin the process of recovery.

Conceptual

1. Public Health Principles should be guided by morality (e.g., valid claim rights).
2. There should be a general acceptance that clean water and sanitation are a level-one basic goods. Since all basic goods constitute claim rights that entail correlative duties, the entire world must accept its duty to provide all people on the planet with clean water and sanitation. This is a strong moral ought.
3. There should be a general acceptance that the interests of the poor, women, and children, etc. are included in #2.
4. There should be a general acceptance that natural environmental systems be respected. The principle of precautionary reason should always be applied when tampering with any ecosystem, biome, watershed, or water basin.
5. All interruptions in the natural order should be required to meet the burden of proof that the intervention will create a sustainable outcome. This thesis should be subjected to public and scientific scrutiny before proceeding.
6. Economic development should not be mixed up with executing moral duty. If option A will give more economic development at the expense of the poor and if option B will give less economic development but recognize the societal duty to provide clean water and sanitation to all, then B should trump A.[8]

Concrete

1. International organizations, such as the World Bank, should not try to mix evangelical capitalism in their development grants to subsistent societies.
2. Competition and commercialization of water as a resource should be avoided until all citizens within a society have access to clean water and sanitation.
3. An international body with stature, such as the United Nations, the WHO, the IMF, and the World Bank should monitor all new water projects with respect to the principle of precautionary reason and environmental sustainability (above).

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[8] In Boylan (2004a, chapter 8) there are some further nuances to this.

4. The wealthy nations of the world should devote substantial resources (progressively: according to their ability to pay) toward the capitalization of substantial sanitation and water purification projects at both the national and local levels in subsistent societies (monitored as per #3).
5. Wealthy societies should look within their own countries in order to avoid compromising the availability of water for domestic use (including the monitoring of agricultural and industrial pollution).
6. A binding system of arbitration should be established to adjudicate international disputes concerning pollution and watershed/water-basin management as well as verifiable alterations in the hydrological cycle within a region.

Conclusion

This chapter has argued that every person on earth has a very strong claim right to clean water. The sad reality is that a large portion of the world lacks potable water and proper sanitation. This fact creates a nest of public health problems—mostly due to the ensuing infectious diseases and parasites via the modes of water-borne and water-based situations. Lack of water (water-washed) and water-related insect vectors are also sources of morbidity and mortality. Too often those who are *not* subject to these public health challenges have met these states of affairs with a shrug of the shoulders. This reaction is unacceptable. The solutions that have been tried over the past 20 years have not really been effective. This is because they have been aimed at the affluent segments of society. The billions who constitute the poor are not improved by capitalist-inspired market solutions. Level-one basic goods require concerned, competent governmental oversight for the sake of society. We are about to begin the final act of our drama. Let us do everything we can to avoid our drama becoming a human tragedy.

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