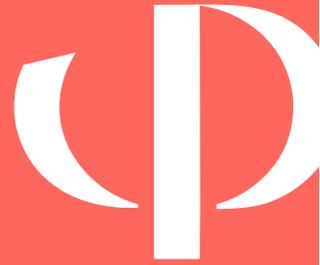


# Philosophy and Medicine



FALL 2013

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# Philosophy and Medicine

MARY RORTY AND MARK SHELDON, EDITORS

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## FROM THE EDITORS

Mary Rorty

STANFORD UNIVERSITY

Mark Sheldon

NORTHWESTERN UNIVERSITY

Welcome to the latest edition of the newsletter: *plus ça change, plus c'est la même chose*. No—wait! It's not the same thing after all! A new format (thanks, Erin), and a new chair of our committee on philosophy and medicine—welcome, Nir.

The Eastern Division session on just health care occupies the majority of this issue, with contributions from Marcus Arvan, Len Fleck, Lily Frank, Amanda Favia, and a superbly footnoted piece by Govin Persad, plus a contribution from Paul Menzel on cost-effective analysis. In a continuation of the spring issue's tribute to our fallen heroes, Heather Gert has allowed us to reprint her musings on an underexplored aspect of her father's philosophy, his thoughts on human nature (plus a picture of him receiving an honorary degree from his alma mater, the University of Cincinnati). And—not only a poem, but a book review! (Why don't you write one, too? You're reading the book anyway—you might as well put it to use!)

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## FROM THE CHAIR

### *Philosophy and Medicine: An Agenda*

Nir Eyal

HARVARD UNIVERSITY

It is an honor to take over as the new chair of the APA committee on philosophy and medicine, a position that over the years was held by some of the central contributors to bioethics.

The committee's activities consist largely of putting together the newsletter and committee-sponsored sessions at the divisional meetings. I would like for us to continue both activities and make some additions. Let me describe briefly the plans for the upcoming committee-sponsored sessions—a collaboration between the new committee and last year's committee, which was led by immediate past chair, Rosamond Rhodes. Then I shall say a word on where the committee might head in the coming three years.

I have learned a great deal from working with Professor Rhodes and the committee on planning this year's sessions. The committee-sponsored session for the upcoming APA Eastern Division meeting, titled "Epistemology of Medicine," was put together by Miriam Solomon (Temple University), who will also chair it. This panel will address questions at the intersection of epistemology and medicine. Epistemological inquiry can help evaluate central trends in contemporary medicine. Cases in point include the shift from reliance on clinical judgment to evidence-based medicine, the extensive use of meta-analyses, new attention to the potential biasing effects of conflicts of interest, and the shift from basic science to more translational medicine. Doctors rarely heed insights in epistemology (and in cognitive psychology) that bear on methodology in medicine—but these insights remain pertinent. This panel will seek to learn from such insights on the merits of recent trends in medicine. In "How to Think about Mechanisms in Medicine," Robyn Bluhm (Old Dominion College) will explore the role of mechanistic reasoning in the evidence-based paradigm that typically eschews discussion of mechanisms. In "Studying Studies, Induction of Inductions, and Hearing Hearsay: The Continuing Challenge of Computational Meta-Analysis," Kenneth Goodman (University of Miami) will explore epistemological controversies about meta-analysis. Finally, Jason Scott Robert (Arizona State) will look at the translation "from bench to bedside" that is needed in clinical research.

For the APA Central Division meeting, former committee member Leonard Kahn (United States Air Force Academy) is organizing and chairing a panel on "Ethics in Reproductive Technology." A year ago, the American Society for Reproductive Medicine declared the freezing and the thawing of women's eggs to be a safe, normal procedure, and the field is currently expanding and undergoing rapid structural changes. This past spring, Robert Edwards, who had co-developed in vitro fertilization, passed away. In the panel, Leslie Francis (University of Utah) will discuss the relevance of ongoing injustice (e.g., disability discrimination, and injustices with respect to access to health care) to the use of advanced reproductive technologies. Matthew Liao (New York University) will argue against the position that infertile couples should adopt instead of using publicly financed assisted reproduction to create new children. Rebecca Kukla (Georgetown) will discuss ethical and conceptual problems with using "fertility" and "infertility" as scientific or medical categories, featuring the example of prophylactic "fertility-preserving" technologies for patients about to undergo cancer treatment. Glenn Cohen (Harvard University) will assess the conditions under which the law may legitimately regulate reproductive behavior and which theories might grant it such legitimacy.

The APA Pacific Division will include a committee-sponsored panel on the definition of death and the so-called “dead donor rule.” That “death panel” will debate when you are dead and whether we need to wait for you to die in order to whisk away your organs. The panel was orchestrated by Michael Nair-Collins (Florida State University), who will also chair. Walter Sinnott-Armstrong (Duke University) will discuss what makes death bad and how this evaluation affects how we should define death in transplantation practices and laws. Joan McGregor (Arizona State) will discuss philosophical problems in the 2009 President’s Council on Bioethics report, which argued that the concept of brain death lacks adequate scientific and pathophysiologic evidence and concluded that a new philosophical rationale was needed for brain death. George Khushf (University of South Carolina) will defend the dead donor rule and a so-called “whole brain criterion” for determining death. Don Marquis (University of Kansas) will attack the dead donor rule and the whole brain criterion, as well as the (present) cardiac death criterion for determining death in transplant settings.

The philosophy and medicine committee has done a heroic job under Rosamond Rhodes, coordinating numerous panels and newsletters. We should continue to coordinate both. In addition, Professor Rhodes proposed that we try to organize an essay contest, and we have started discussing details with her, as well as ways around logistical bottlenecks. Former committee member Leonard Kahn has volunteered to maintain and edit our new website, [www.apaonline.org/group/medicine](http://www.apaonline.org/group/medicine).

I also hope to add a new emphasis to the committee’s work. Bioethics was created with a focus on clinical medicine, as performed in highly developed countries. It was considered most prestigious to ask whether upon the patient’s request we should pull the plug of an enormously expensive life-sustaining machine, and what to make of recent technologies that border on science fiction. But the majority of living people do not have access to anything like the medical services or health personnel that we in the developed world are accustomed to. They have quite different needs, and these needs raise a different set of ethical and philosophical questions. Is it permissible to provide cheap and poorer quality care to the global poor when low price per patient would enable treatment and prevention for many? Should we insist that there is a human right to vital yet very expensive medical resources like dialysis, given that some countries simply cannot afford them? When doctors leave poor populations for richer pastures, is it ethical to force them to stay and take care of those who need them the most? Is it ethical to conduct medical experiments that would be impossible but for patients’ unjust lack of alternative sources of care? What medical services, if any, do rich countries owe patients in poor countries? What do they owe the undocumented work migrants they host?

It is also increasingly recognized that the so-called social determinants of health—factors like air pollution, the salt content in food, the quality of housing, and the availability of sports facilities and parks—have a far greater impact on health than does health care. Accordingly, the most relevant ethical questions may affect these less-explored determinants. Is there a human right to social conditions that tend to improve health? How legitimate is it to intervene with

private workplace organization in the interests of employee and customer health? Do patients who were given sports facilities but failed to use them and consequently developed disease have a lesser claim for medical assistance? Do we owe citizens freedom from pollution, equal freedom from pollution, or *maximin* freedom from pollution?

Rather than focusing exclusively on clinical bioethics in affluent societies, it would be exciting if panels also paid close attention to ethical questions surrounding the health of the global poor and population health. All of us on the committee look forward to hearing your further ideas on new directions for the study of philosophy and medicine.

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## ARTICLES

### *Nonideal Justice and a Decent Health Care Minimum*

Marcus Arvan  
UNIVERSITY OF TAMPA

I am going to suggest that any robustly substantive account of what constitutes a decent health care minimum is unjustly paternalistic, and that the people whose lives and health are at issue in determining a decent health care minimum should be understood as having a collective right—founded in the rights of individuals to justice—to determine what constitutes such a minimum in their social-political context, through their expressed preferences as a group, *provided their preferences are broadly constrained by the following background conditions*: (1) adequate understanding of relevant facts about human health and modern medicine, (2) instrumental rationality, and (3) the general ideal of the equal treatment of individuals.

#### PROBLEMS WITH EXISTING THEORIES

Existing theories of human rights and of justice—and existing accounts of a decent health care minimum—tend to deal poorly with two things.

First, they tend to deal poorly with issues of *transitional justice*. So, for example, consider Rawls’s theory of domestic justice.<sup>1</sup> Rawls argues that a well-ordered society would be one in which, among other things, everyone enjoyed a fair value of equal basic rights and liberties. People like Norman Daniels have attempted to extend Rawls’ theory to the justice of health care distribution.<sup>2</sup> Rawls only provides a detailed theory, however, of a fully just or well-ordered society. He provides no account of the costs that people should have to endure in nonideal—or less-than-fully-just conditions—to transition toward a just society. And Rawls is far from alone in this regard. Almost all existing theories of justice focus on *ends* to be achieved, as opposed to appropriate and just *means* for getting there—and I think that those that do focus on means (for example, Amartya Sen’s *The Idea of Justice*<sup>3</sup>), don’t do so appropriately, for reasons that will become clear shortly.

The same is generally true of theories of human rights. Existing theories of human rights specify certain *ends* that people supposedly have rights to: things like basic liberties, means of subsistence, freedom from torture and other

forms of abuse, and—according to some theorists—a right to democracy. But these theories also tend to ignore the question of what people might have a human right to *vis-à-vis* achieving those ends. While some theories of human rights affirm, for example, rights to national self-determination, other transitional questions tend to be ignored. For example, should someone have to endure the effects of crippling economic sanctions so that they can, *in time*, enjoy the things that are commonly thought to be human rights? It is surprising how little attention this question has received in the human rights literature. I've tried to begin rectifying this situation in my own work, and will say more about how I've tried to do so shortly. But before we get to that, there's a second issue to consider.

Existing theories of justice and human rights deal poorly, I believe, not only with transitional issues but also with the *ordering* of ends themselves under nonideal conditions. It is one thing to say, as Rawls does, that people in a well-ordered society would prioritize equality of basic rights and liberties above economic justice; it is quite another to say what rights and values should be prioritized by people and policy-makers under *unjust* conditions. Consider, for example, a people living in a situation that is unjust in multiple respects: where people don't enjoy equal basic rights or economic justice. Further, suppose the economic injustices are intuitively the worse of the two: the inequalities of basic rights and liberties are fairly minor, but poverty is widespread (though, let's say, not crippling). What do justice and human rights require in this case? Must political liberties be prioritized over economic justice? Here, again, I think existing theories are unsatisfactory. Let me begin to explain why.

In order to figure out what is required by justice in the real, nonideal conditions in which we live, we need some *theory* of these things: a *nonideal theory of justice* that tells us (A) which sorts of costs people should have to endure for the sake of transitioning toward just ends (whatever we take those to be), and (B) how opposing ends, or values, ought to be prioritized and why, under nonideal conditions. Allow me to begin explaining what form I think such a nonideal theory of justice should take, and why I think that, on any plausible such theory, any substantive account of what constitutes a decent health care minimum is unjustly paternalistic.

### COMMON GROUND ON JUSTICE

Although there is of course great disagreement about the nature and content of justice, the history of liberal moral and political philosophy has been broadly dominated by one powerful idea: the idea that justice is, in some sense, a matter of treating people as *free and equal* to one another. Different theorists, of course, understand the relevant notions of freedom and equality differently. Libertarians hold that each person is equally entitled to live freely—however they wish—so long as they respect the rights of others. In contrast, liberal egalitarians like Rawls hold that each person is equally entitled to freely direct their lives as they see fit within social-political systems that afford people a *fair* distribution of equal basic rights, liberties, opportunities, income, and wealth. Thus, in a broad sense, liberal moral and political theorists of very different backgrounds agree on the value of freedom and equality; they just differ greatly on how to understand these things.

I am going to suggest today that greater agreement on the nature and value of freedom and equality can be reasonably expected when dealing with *unjust* social-political conditions, however these are understood. Let us begin by reflecting a bit more, first, on the idea that justice involves respecting human freedom. Notice that different liberal theories of justice—as disparate as they may be—are all committed, at least in the first instance, to enabling people to live as *they* see fit, not as others may see fit *for* them. Libertarians, for example, tend to hold that people should be free to order their own affairs, as long as they don't violate the rights of others, whereas liberal egalitarians tend to hold that people should be free to order their own affairs, provided they do so in a manner that respects and upholds a fair social-political system. Liberalism, in short, involves a strong—though defeasible—presumption in favor of freedom and *against* *paternalism*.

### DIFFERENCES ON PRIORITIES

The next point for our purposes is that people in nonideal conditions may have very different, rationally defensible views and preferences about what constitutes a *decent* health care minimum in their own case. Indeed, one of the most striking things about world poverty and lack of health care—particularly in light of cultural and historical differences—is how different their human costs are in different contexts. Consider first a people living fruitfully in a rural, agrarian setting, living far below the international poverty line but with plenty of natural flora and fauna to eat, and clean natural sources of water to drink, with little to no access to modern medicine. Although I realize I may be accused of romanticizing this kind of situation, it is, as a matter of fact, not hard to find many people living in these conditions today *endorsing* their agrarian lifestyle as healthy and sustainable. Although people living in these conditions typically do want some manner of modern health care (if informed of their options)—iron deficiency, for example, is rife in certain agrarian populations—it can be rational, I believe, for people in these situations to desire far less health care than people living in very different situations. After all, consider what often happens in today's world. Agrarian populations are forced off of their lands and into urban slums for the sake of economic development. In terms of poverty reduction, this looks good. People are making wages whereas before, in a rural setting, they were making nothing. Yet now their overall quality of life is far worse. They lack access to free, clean water; they have to buy food at the market (which they can't afford), as opposed to growing it themselves; and children have to spend their days in gigantic toxic waste dumps hunting for rotten food and goods to sell.

Given that this is the way that “progress” in the real world often (I would say, typically) actually operates, I believe it can be *rational*, all things considered, for people in certain contexts to prefer less development and far less health care than people in other settings. After all, health care does not come for free. When hospitals and clinics open, industry, economic development, urbanization, and all of their ills typically follow. One cannot, as it were, separate out health care distribution from these things in the real world. The development that follows greater health care distribution can, all things considered, make people far worse off than they were previously. And so, I think, it can often be rational for people to prefer *less* health care, not more.

Let us now return to the liberal idea that justice is a matter of freedom and equality. Given that free people can rationally have very different views about what constitutes a decent health care minimum in their own case, I want to say that justice is a matter of people having an *equal right to freely decide for themselves what a decent health care minimum is for them, given the relevant tradeoffs associated with different types and amounts of health care distribution, in the context in which they live.*

### NON-IDEAL JUSTICE

The question then is this: What *is* it to respect each person's equal right to that? It is at this point that I would like to introduce you to my wider project: the theory of *nonideal justice as nonideal fairness*.<sup>4</sup> The basic idea of nonideal justice as nonideal fairness is simple: When it comes to the two general issues I introduced earlier—the distribution of transition costs and the ordering of ends under nonideal, real-world conditions—justice is a matter of *not arbitrarily favoring anyone over anyone else.*

This basic idea is, I think, quite intuitive and should appeal to people from a diverse array of philosophical perspectives. However else one thinks about justice, the issues of how to deal with *injustice* are similar: rectifying injustice will impose costs on people, and may involve *competing ends* (for example, political versus economic justice). However else one thinks about justice, justice intuitively requires settling these issues in a manner that *does not arbitrarily favor*—for instance, on the basis of race, gender, religion, and so on. This is the basic idea of what I call nonideal justice as nonideal fairness.

The next question is this: If this is what nonideal justice is, what is the best way to theorize about it? I have argued elsewhere that the right answer is a variation of Rawls's original position: a *nonideal* original position.<sup>5</sup> Let me briefly explain why. Rawls uses the original position to argue for principles of justice to govern a fully just, *fair society*. He asks us to imagine everyone in society situated behind a veil of ignorance—one that permits no one to deliberate on the basis of self-individuating characteristics like one's own race, gender, talents, and so on—and then deliberating to principles of justice for a well-ordered society. A couple of assumptions, however, are crucial to how Rawls uses the original position. Rawls has the parties—every person behind the veil of ignorance—assume that they are deliberating about (A) reasonably favorable conditions (conditions under which full justice can be obtained), and (B) conditions of strict compliance (conditions under which everyone, and all institutions, strictly comply with whatever principles of justice are ultimately selected).

My general claim about nonideal justice is this. One need not accept Rawls's theory of a just society—the theory of *justice as fairness*—to think that *unjust* conditions should be dealt with fairly. One can be a libertarian, or a Marxist, or whatever, and think that *injustices* should be resolved in a way that doesn't *arbitrarily* privilege anyone. And, indeed, I think this is a natural way to think, regardless of one's broader social-political leanings. A libertarian, for instance, has just as much reason as a Rawlsian for thinking that a just response to injustice shouldn't *arbitrarily* impose costs on anyone. My final general claim then is this: if one does think this, one

should be prepared to utilize a *variant* of Rawls's original position—a nonideal original position in which the above assumptions about reasonably favorable conditions and strict compliance are dropped—to theorize about nonideal justice. Let me now explain how I think this should work.

Rawls has the parties to his original position deliberate *rationally* behind the veil of ignorance. They are to do so because the veil of ignorance ensures their deliberations are fair. Things should be different, however, if we are talking about a nonideal original position. Nonideal justice, whatever else it is, is surely not a matter of being fair *vis-à-vis* all points-of-view. If we were to imagine people deliberating rationally behind a nonideal veil of ignorance—one where each person knew they could turn out to be *anyone* under unjust conditions—the nonideal original position would, in effect, model an equal right to lobby for *just and unjust* points-of-view. This intuitively isn't right. People have an *obligation* not to pursue injustice. Accordingly, I believe we should imagine the parties to a nonideal original position as deliberating from a background desire for justice, however one understands that (for example, libertarian justice, Marxist justice, etc.). They will deliberate behind a nonideal veil of ignorance—one where they know many people won't actually comply with their ideals—but still, deliberate in *light* of the correct ideals, for the simple reason that, again, nonideal justice is a matter of transitioning toward a more just situation.

The next question is precisely what status or force this desire for justice should be. I believe that because existing theories of human rights and justice abstract away from the issues of transition costs and priorities under nonideal conditions, there is no good reason to hold that the obligation to desire just end results must dominate individuals' preferences regarding the costs of transition or prioritization of competing ends (i.e., political versus economic justice) under nonideal conditions. Each person in the nonideal original position should be understood as having an *equal right*, subject to the constraints of fairness imposed by the veil of ignorance, to lobby for their preferred weightings of just ends versus transition costs and other priorities they might rationally have as individuals in nonideal conditions.

### PRINCIPLES OF NON-IDEAL JUSTICE

Here, then, is what we have so far. I propose that we understand nonideal justice in terms of the following:

- (1) Rational individuals,
- (2) guided by a background concern for just ends (however one cashes those out)
- (3) deliberating behind a veil of ignorance about
- (4) how to best advance their weighted preferences of just ends versus transition costs and other priorities,
- (5) under nonideal conditions.

This is, obviously, a real mouthful in need of a lot of cashing out—cashing out that, unfortunately, we lack adequate time for today. What I would like to do, then, is cash out the model's implications at a very schematic level, and apply

them to the issue of the day: defining a decent health care minimum.

I want to say that the parties to a nonideal original position, as just described, should agree—very broadly—to principles of nonideal justice that confer upon each person the following:

- (A) An *equal right and opportunity* to
- (B) Lobby for and advance their *rational* preferences regarding the transition costs and social-political priorities (i.e., economic vs. political justice),
- (C) So far as those preferences are guided by a *background desire for just ends* (however just ends are understood: I assume they include equal political rights, etc.).

If this is correct, then, nonideal justice with respect to health care specifically is

- (A) Ensuring that each person has an *equal right and opportunity* to
- (B) Lobby for and advance their *rational* preferences regarding what constitutes a decent health care minimum, given the specific context in which they live, so long as
- (C) Those preferences are guided by an appropriate background desire for just ends (e.g., equal political rights, etc.).

These three conditions are, obviously, highly schematic. They each need to be made more precise in ways we can only gesture toward today. Allow me, then, to briefly discuss some issues with each condition.

First, condition (A): What is it for everyone to have an *equal right and opportunity* to lobby for and advance their rational preferences vis-à-vis decent health care standards? Offhand, this condition suggests a democratic—or, failing that, a quasi-democratic—process for specifying a decent health care minimum in a given social-political context. Since not everyone can have their way—one person might find one set of health care provisions decent and another might not—an equal right and opportunity to lobby for and advance one’s rational preferences vis-à-vis decent health care standards would plausibly involve a *collective* process of deliberation: one where all relevant stakeholders are afforded as equal an opportunity as possible to have their voices heard. Of course, in the real world, collective deliberations are almost always messy and unfairly dominated by a few powerful voices. Although this raises difficult issues, let us say for now that processes for arriving at an appropriate health care minimum for any social context should aim to *approximate, as far as possible, a democratic procedure*.

Now let us turn to (B): What makes a preference regarding decent health care standards *rational*? At a minimum, it seems reasonable to suppose that a preference is rational here only if it is *adequately informed*. If a person lacks adequate knowledge of health care basics, there is little reason to regard their preferences—whatever they might

be—as rational. If a person lacks basic knowledge of modern medicine and health care—in other words—what their options are, their preferences are founded in a kind of ignorance. So, nonideal justice has to minimally involve informing people who putatively fall below what we might otherwise think is a “decent” health care standard of the forms of health care they could realistically come to enjoy. I assume, secondly, that a rational individual not only wants to be informed of his/her options but also *understand* them. A person who doesn’t want modern medicine because s/he just doesn’t believe what s/he is hearing intuitively isn’t in an adequate position to evaluate his/her options rationally.

Now let us turn to (C). What makes a preference regarding health care standards consistent with a background desire for just ends? Here’s a very rough—but, I think, compelling enough—first answer: Because there is a consensus in liberal moral and political philosophy that *discrimination in general* is unjust—and here I mean discrimination on the basis of race, gender, physical and mental handicaps, religion, and age discrimination—preferences regarding what constitutes a decent health care minimum cannot be permissibly influenced by any such form of discrimination. Justice requires us not to tolerate any standard for a decent health care minimum that systematically disadvantages—or plays into an overall social-political structure that disadvantages—girls and women, children, minorities, and so on.

Again, all of this is admittedly schematic. Still, I think the overall picture is plausible. If the picture is on the right track, justice requires a decent health care minimum not to be imposed on people by standards drawn up by others, but rather to be decided *collectively, by the persons whose lives and health are at issue, through a process which as far as possible approximates:*

- (A) Ensuring that each person has an *equal right and opportunity* to
- (B) Lobby for and advance for their preferences regarding what constitutes such a minimum, provided
- (C) The preferences collectively expressed are plausibly based on adequate information and understanding regarding modern medicine and the kinds of health care they could realistically come to have access to, and
- (D) The preferences collectively expressed are not based on any overt or latent discriminatory values or beliefs.

#### NOTES

1. John Rawls, *A Theory of Justice* (Cambridge, MA: The Belknap Press of Harvard University Press, 1971).
2. Norman Daniels, *Just Health Care* (Cambridge University Press, 1985).
3. Amartya Sen, *The Idea of Justice* (Cambridge, MA: The Belknap Press of Harvard University Press, 2011).
4. See Marcus Arvan, *A Nonideal Theory of Justice*, Ph.D. dissertation (University of Arizona, 2008).
5. *Ibid.*

## *Parsimonious Care: Does Ockham's Laser Belong in Medicine's Black Bag?*

Len Fleck

MICHIGAN STATE UNIVERSITY

### THE BACKGROUND PROBLEM

In 2012 total health care costs in the United States reached \$2.8 trillion or about 17.9 percent of our GDP. If nothing is done to alter that trajectory, then by 2019 total health care costs in the United States will be about \$4.5 trillion or 20 percent of expected GDP.<sup>1</sup> One sort of response to these economic facts is that they are morally uninteresting. This is a free society; we can spend as much as we wish on health care. It is not as if we are spending this money on bombs and other weapons of mass destruction. Our investment in health care is noble and compassionate (at least for the well insured). Moreover, health care is a job-creating engine in our economy. However, this response is superficial at best and morally troubling at worst.<sup>2</sup> It is morally troubling for at least two reasons.

First, health care spending, especially at the federal and state levels, tends to "crowd out" dollars needed to support other worthy public interests, such as education and environmental protection. This is because Medicare and Medicaid are entitlement programs, which means that these programs do not actually have fixed budgets in any given year. Rather, federal and state governments are obligated to spend whatever it might take to meet the health care needs of the elderly and the poor who qualify for Medicare and Medicaid. In 2012 the federal government spent almost \$600 billion on Medicare. If we remain on the same spending trajectory for Medicare until 2019, then in that year we will spend just under \$1 trillion on Medicare. To further clarify what "crowding out" means in operational terms, if Medicare stays on the same spending trajectory for 2013–2022, then aggregate Medicare expenditures for that ten-year period will be about \$8.5 trillion.

Second, uncontrolled health care spending, whether in the private or public sectors, has the morally troubling consequence of increasing the number of uninsured and underinsured in the United States. As health care costs increase for employers (now about \$15,000 for a decent family health plan), marginal employers drop health insurance as a benefit or else require economically onerous co-pays from employees earning less than \$15 per hour. And, as taxes increase at the state or federal level to cover Medicare or Medicaid costs, taxpayers reject the idea of providing federally subsidized coverage for at least 30 million of the current 50 million uninsured in the United States. The Affordable Care Act will add about \$100 billion per year (with 6 percent annual increases) to the federal budget and a fraction of that to state budgets. Deficit spending decreases the *immediate* impact on taxpayers, but those costs will have to be paid at some point in the future.

An obvious question to ask is why health care costs have increased from about 5 percent of GDP in 1960 to almost 18 percent in 2012. There are multiple reasons for this,

but roughly half the annual increase is attributable to technological innovation and dissemination in health care. Ethically speaking, one might wonder whether many of these technologies are really meeting health care *needs*. However, as Daniel Callahan has astutely observed, these technologies typically *create* needs, as a practical and moral matter, as opposed to meeting pre-existing needs.<sup>3</sup> No one *needed* bypass surgery or coronary angioplasty or an artificial heart before these interventions were introduced into medicine. But these particular interventions now represent almost \$100 billion annually in health care costs.

If all these novel interventions yielded enormous medical good for each and every patient we would be faced with an enormously difficult ethical problem in trying to reduce health care costs. No matter what we chose to do by way of reducing access to these technologies in order to reduce costs we would be denying some patients either extra years of life or diminished quality of life when these patients would have as much a right to these health benefits as anyone else. However, this is not the actual state of affairs in health care. The fact of the matter is that patients benefit very differentially from accessing these various technologies. Some patients gain only marginally from these technologies while others gain many extra years of life, all for roughly the same cost per person with the same medical problem.

Given this background information and what is at stake, who should have responsibility for controlling health care costs? For political conservatives the politically and ethically preferred answer is that individual patients should make these decisions for themselves in the light of their understanding of their medical circumstances and options. That is, individuals should decide whether, for example, some life-prolonging intervention that might offer only a 30 percent chance of an extra year of life for \$70,000 is worth it to them. What political conservatives absolutely reject is the idea of government (through Medicare) making such rationing decisions and imposing them upon individuals. The ethical problem with the conservative's recommendation, however, is that access to needed health care will largely be related to individual ability-to-pay. From a liberal egalitarian perspective this is clearly unjust.

A fair-minded economist might argue that a \$70,000 intervention that offers only a 30 percent chance of an extra year of life just *is* (objectively) a bad buy. If so, then it ought to be a "bad buy" for everyone in those medical circumstances. However, in actuality an individual with a modest income and a marginal health insurance plan requiring that he pay 50 percent of that \$70,000 will be economically forced to forgo that intervention. But an individual with a very expensive and comprehensive health plan (heavily subsidized by taxpayers as a tax-free employee benefit) will be able to access that intervention at social expense, including expense to our individual with a modest income. This seems clearly unjust; someone less well-off is subsidizing access to marginally beneficial health care for the very well-off. Worse than that, even if this intervention offered a 90 percent chance of ten extra years of life, our individual with only a modest income and marginal health insurance would still end up having to deny himself this intervention. For those familiar with health care cost containment research the RAND experiment offered a sobering conclusion. Specifically, if

cost containment mechanisms directed at individuals (co-pays and deductibles) were used, then those individuals would be equally incentivized to deny themselves both very beneficial and very marginally beneficial health care.<sup>4</sup> This is not an outcome that a just and caring society ought to endorse.

### THE CORE PROBLEM

This brings us to the heart of the problem this essay is intended to address. Should physicians play a major role in controlling health care costs? Health policy analysts generally agree that physicians are responsible for at least 80 percent of health care spending that occurs in the United States.<sup>5</sup> This is because physicians write a script for a drug, or advise some specific surgery, or recommend some type of home care, or order assorted diagnostic tests, or recommend assessment by one or more sub-specialists, and so on. These are all things that patients cannot do. Patients may accept or reject a physician's advice, but only physicians can judge that some intervention is "medically necessary," which is what triggers payment by insurance companies. The rest of the argument is that physicians caring for individual patients are in a better position than anyone else to have a comprehensive picture of that patient's medical circumstances and medical options. In particular, those same physicians are in the best position (if not a perfect position) to judge the degree of benefit a patient is likely to gain from one or another intervention or diagnostic test relative to the cost of attaining that benefit.

With the above background in mind, the American College of Physicians recently made the following recommendation as part of its revised *Ethics Manual*: "Physicians have a responsibility to practice effective and efficient health care and to use health care resources responsibly. Parsimonious care that utilizes the most efficient means to effectively diagnose a condition and treat a patient respects the need to use resources wisely and to help ensure that resources are equitably available."<sup>6</sup> This passage caused something of a media firestorm at the time. It was interpreted by some as saying, "Your trusted personal physician is going to deny you care that he or she believes costs too much in order to save money for the government or for some managed care plan." In fairness to the American College of Physicians it must be noted that the earlier quotation is preceded by this statement: "The physician's first and primary duty is to the patient. Physicians must base their counsel on the interests of the individual patient, regardless of the insurance or medical care delivery setting." The authors then add that no matter how physicians are reimbursed, "physicians must not allow such considerations to affect their clinical judgment or patient counseling."<sup>7</sup>

Physicians seem to be given conflicting directives here. How can physicians be both loyal patient advocates (committed to protecting the best interests of the patient before him or her now) and just/prudent/parsimonious stewards of social resources (committed to not wasting limited social resources for very marginal and uncertain benefit for a patient)? In trying to get a handle on this question several critical questions need to be raised. First, how expansive is the requirement of loyalty to each and every patient? Is it limited at all by other moral obligations that a physician might have, such as obligations of care to the very next patient in the waiting room?

Second, who has the right to determine what the "best interests" of a patient might be? Are we talking about the "absolutely best possible health interests" as determined by the state of contemporary medicine? A physician would typically have a sense of what such interests might be, but the morally relevant question is whether that patient would have a just claim to the resources needed to satisfy those interests. The resources, after all, are common and limited. The patient may well have an autonomous desire to access to an unlimited degree all the resources needed to satisfy his absolutely best possible health interests, but it is far from obvious that any such autonomous desire is morally sufficient to generate a just claim to those resources.

Third, is the physician's obligation to provide only parsimonious care morally different from that physician making a rationing decision regarding the extent to which she would meet the health care needs of that patient? The American College of Physicians (ACP) did deliberately choose to frame their directive as being about parsimony rather than rationing. The term rationing carries with it the implication that a patient is being denied some medical test or intervention because it will likely yield too little benefit at too high a cost. The assumption is that the physician is making that judgment in relation to that individual patient, and in that respect is being disloyal to the best interests of that patient. The language of parsimony (and stewardship) is intended to get away from that implication. We may think of parsimony as being located roughly in the middle of the semantic space between "profligate" (wasting resources on a patient for no benefit) and "penurious" (being stingy with resources and risking harm to that patient). In characterizing what parsimony is about the ACP says that it is about "choosing wisely" or prudently so that resources are equitably available.<sup>8</sup> Further, physicians are supposed to use the most efficient means to reach a diagnosis and to treat a patient because otherwise resources are being wasted (and there is nothing morally commendable about wasting limited resources). This will strike many as a moral and medical truism. However, some critical comments are in order.

### WHAT IS PARSIMONIOUS CARE?

Many readers will be familiar with Dr. House of TV fame. He is a brilliant diagnostician. But in every episode of that program he goes off on a diagnostic odyssey (costly and inefficient) before he finally saves a patient's life. It is easy to make the judgment that his diagnostic odyssey was terribly inefficient, after the fact, and to identify what the most efficient way of getting the correct diagnosis would have been with the benefit of that hindsight. Such judgments, however, are entirely irrelevant to the world in which medicine is actually practiced, in which there is often considerable uncertainty and an abundance of misleading or ambiguous diagnostic clues. What is a loyal and parsimonious physician supposed to do in those circumstances? Should a parsimonious physician cease additional diagnostic tests when she is 80 percent confident her diagnosis is correct? Or should that confidence be at 90 percent, or 95 percent, or 99 percent? At what point should we (societal representatives) judge that diagnostic testing is wasteful and inefficient?

A representative from the ACP might respond that their real concern is with excessive diagnostic testing that is driven by liability concerns, what is usually referred to as

“defensive medicine.” Such tests are being done for the self-interests of the physician, not the benefit of the patient (so it is argued). However, Hermer and Brody, an attorney and a physician, doubt that things are quite that clear. They imagine a world in which the liability concerns of physicians have been completely addressed by all the legal reforms the AMA (American Medical Association) desires. They then contend that physicians would still be ordering most of the “excessive” tests they do now because they wanted to be very confident that they had gotten it right, that they would not be starting a patient on a course of therapy that could be potentially harmful to that patient.<sup>9</sup>

Another statistic that has been bandied about of late is that at least 25 percent of current health spending in the United States, \$700 billion, represents the wasteful use of health care resources. If this is mostly true, that would suggest that there is enormous morally permissible space in which physicians may behave parsimoniously without risk to the best interests of their patients, and without risk that they would be charged with making rationing decisions regarding their patients access to needed health care.<sup>10</sup> However, the language of wasteful care will often be used to semantically disguise marginally beneficial, non-costworthy care, the sort of care that is typically the focus of rationing judgments (and that politicians and policymakers are loathe to admit endorsing).

H. Gilbert Welch, a physician, contends in his book, *Overdiagnosed: Making People Sick in the Pursuit of Health*, that all sorts of standards for being “ill” have been altered over the past thirty years, such as lowering total cholesterol levels as the standard at which patients would be prescribed statins, or lowering the standard for judging that a patient has elevated blood pressure requiring medical intervention, or requiring annual screening mammograms for women starting at age forty, and so on. To use the cholesterol example, there was a time when a total cholesterol of 300 would be required to elicit medical attention, then 240, then 200, then 180. At 180 about 65 million Americans are candidates for statin therapy. That is, they have a medical need for statins. What precisely does that mean? It means that lowering total cholesterol by being on this drug will lower an individual’s likelihood of having a heart attack or stroke. However, as Welch points out, at the 300-level a substantial number of these heart attacks and strokes are prevented, but that number declines rapidly as we move to the 200-level or the 180-level.<sup>11</sup> At this lowest level the cost of averting each heart attack or stroke is several million dollars because the vast majority of patients taking this drug at this level will experience no practical benefit at all. Or to put it another way, if 65 million Americans were on statins before the major statins went off-patent in 2012, the annual aggregate cost of that one drug would have been \$70 billion.

Does that \$70 billion number represent a wasteful use of limited health care resources? After all, *some* number of heart attacks and strokes are averted, so it would seem to be a semantic stretch to judge that outcome as flat out wasteful. But if we were to add a qualifier, such as *somewhat* wasteful, then it would look as if we were approaching the semantic space of *marginally beneficial*. To put this point in practical form, if we (Medicare or managed care administrators) were to revert to an earlier standard for prescribing statins, such

as total cholesterol of 240, so that the resources thereby saved could be redeployed to meet other health care needs where greater benefit at lower cost would be obtained, should physicians who acted in accord with that directive be morally commended for offering only parsimonious care or morally condemned for rationing needed care by putting their patients at risk for an avoidable stroke or heart attack? My own answer to this question is that it would be just as correct to characterize this change in standards as an embrace of parsimonious care as a matter of health care rationing. The question that we really need to answer is this: Would physicians who went along with this directive be open to justified moral criticism for being disloyal to the best interests of their patients? We can turn to some paradigm cases to begin teasing out an answer to this question.

### IS HEALTH CARE RATIONING PARSIMONIOUS CARE?

The *Wickline* case occurred in the late 1970s in California but its final adjudication was not until the mid-1980s. Mrs. Wickline suffered a clot in her leg due to arteriosclerosis. She was eligible for the Medicaid program in California. Medicaid approved a ten-day hospitalization for the surgery but there were complications from the surgery. Her surgeon believed she needed to be in the hospital for an additional eight days. Medicaid would only approve payment for four days, so her surgeon discharged her after that fourth extra day, contrary to his best judgment. Nine days later she suffered a major complication at home that required amputation of her leg to save her life. The California Supreme Court rendered a verdict against her physician for failing to provide the care she was due. The primary argument of the court was that Mrs. Wickline’s physician had an obligation to protect *what he judged to be her best interests*. The only person who had the authority to discharge her from the hospital was her physician. No doubt he was under some pressure from hospital administration because the hospital was not going to be paid for those extra days. Nevertheless, the court ruled that he had to stand up to those pressures because his judgment was that those extra days were medically necessary. To put the matter in the language of this essay, her physician could not justifiably claim that he was providing ethically permissible parsimonious care by denying her those four extra days.

A contrasting case to Wickline would be the Nataline Sarkisyan case in California (2007). Nataline was a seventeen-year-old girl with a very advanced leukemia. She had failed two earlier efforts to defeat her cancer. She had also failed a bone marrow transplant and was in multi-organ failure with severe neurological complications. Her surgeon proposed doing a liver transplant at a cost in excess of \$250,000, but her managed care plan refused to authorize payment for that transplant. Her surgeon believed there was a reasonable chance that he could give her six extra months of life. Other surgeons familiar with the case argued that was an excessively optimistic prediction and that survival to six months was a very remote likelihood.

Given this case description, would a surgeon who was a loyal patient advocate be open to justified moral criticism if he failed to do everything possible to secure that liver transplant? My response to this question would be that if this

surgeon had been successful in securing that liver transplant he would have been open to justified moral criticism. One of the limits to legitimate patient advocacy is the justness of the patient's claim to some specific health care resource. Livers are a scarce medical resource. Securing a liver for Nataline for extra weeks of diminished life would mean denying that liver to someone else who could gain ten extra years of life or more. This is presumptively unjust. Apart from that issue, if the hospital was not paid for the transplant (because not authorized by the managed care plan), then those costs would be absorbed by charity care dollars from the hospital. Again, those dollars would have purchased much more in the way of high-quality care for many more poor and uninsured individuals in that hospital's service area than for Nataline. That too is an injustice not excused by that surgeon's alleged obligations of loyalty to his patient. We could describe the behavior required of the surgeon in these circumstances as a commitment to penurious care or as a legitimate rationing decision. In either case, that is the morally right thing to do, all things considered.

Next, I want to call attention to what I would regard as a very clean example of obligatory parsimonious care. Over the past several years a lot of hype has surrounded proton beam therapy, which requires a \$160 million building with walls twelve feet thick to house this piece of equipment. About twenty hospitals in the United States have built or are committed to building these facilities. One virtue of this therapeutic modality is that it can destroy cancerous brain tissue otherwise inaccessible to surgery while sparing healthy brain tissue. Unfortunately, the number of patients who really *require* this technology because they have no other option is relatively small. Consequently, hospitals need to use this technology for a broader range of medical circumstances, specifically, prostate cancer, because 240,000 men in the United States are diagnosed each year with this disease. The cost of a course of proton beam therapy for non-metastatic prostate cancer is about \$40,000. The problem is that another therapy, Intensity Modulated Radiation Therapy (IMRT), accomplishes precisely the same result for half that cost (because that equipment costs about \$3 million). This was scientifically demonstrated in research reported last year.<sup>12</sup> If anything, the authors reported there were slightly more gastrointestinal problems associated with proton beam therapy compared to IMRT. This would seem to be a clear circumstance in which physicians had a presumptive moral obligation to use IMRT for their prostate cancer patients rather than proton beam therapy. That is, this is clearly morally justified parsimonious care. However, it is easy to imagine that physicians attached to hospitals that invested in proton beam therapy would be expected to provide that therapy to patients instead of IMRT as long as insurance companies paid for it. And it is likely that some patients have been dazzled by the hype surrounding this therapy and might demand that their physician secure access to it rather than IMRT. But it should be clear that physicians acceding to such patient requests would not be morally warranted as a matter of loyalty to such patients.

We might refer to the above example as a matter of "pure" parsimony because patients receiving IMRT are giving up no medical benefit and they are costing the health care system half as much as patients getting proton beam therapy. In other words, we can clearly distinguish this situation from

one that would be correctly characterized as a matter of health care rationing. Choices such as this are not a threat to the loyalty that physicians owe their patients. There are a number of choices like that in medicine today. When physicians prescribe a generic version of a drug instead of a much more costly brand-name version of the drug, and that generic drug yields virtually the same mix of benefits and risks as the brand-name drug, then this too would be a matter of "pure" parsimonious care. While such substitutions often work exactly this way, this is not always true. If such a substitution yields equal medical benefit but the generic version causes a somewhat intense headache in 20 percent of patients that causes them to stop the drug, and if a physician refuses to seek an exemption for such patients from a managed care rule that requires this substitution, then that physician cannot claim his decision is morally permitted as a matter of parsimony (and that he has been a loyal patient advocate).

### THE LIMITS OF PARSIMONIOUS CARE

The problem is that "purely" parsimonious medical decisions might save the health care system \$10 billion or \$20 billion per year, but this is only a tiny fraction of the \$700 billion that some researchers describe as "wasteful" health care each year in the United States. As suggested already, what many researchers wish to include under the rubric of wasteful care is really marginally beneficial, non-costworthy care. Denying patients that care should be described as health care rationing. To illustrate, in the United States we do about 600,000 total knee replacements per year. The vast majority of these patients are elderly. Some managed care plans will require their surgeons to use a less expensive ten-year knee replacement in patients over the age of eighty instead of a twenty-year knee. The argument is that most of these patients will not reach age ninety, which is statistically true. But some number will. And they will be faced either with permanent disability/immobility or a much riskier surgery and medical complications beyond age ninety. If someone chooses to describe this as a matter of parsimonious care with the implication that a surgeon implementing such a choice is still a perfectly loyal advocate for that patient, this is disingenuous, especially if that surgeon says nothing to the patient about this substitution.

We need to consider what I will refer to as the flip side of the case above. One author writes: "Many patients with cancer want aggressive treatment until the very end, no matter how small the benefit or how great the toxicity."<sup>13</sup> This is extraordinarily expensive care with very little benefit. Nevertheless, many physicians will acquiesce to such patient or family demands. They might even be able to claim that they delivered that care in the most efficient way that was medically possible, and so in that respect they delivered that care parsimoniously. They might believe that this was what was required of them as loyal patient advocates. But I would argue that they would be mistaken in this last belief. In a health care system with limited resources to meet virtually unlimited health care needs (fifty million uninsured; twenty-five million underinsured), those end-stage cancer patients do not obviously have a just claim to that aggressive costly cancer care. If that is true, then loyal advocacy does not require that a physician provide access to care for patients to which that patient has no just claim. On the contrary, it would be morally objectionable for a physician to facilitate

such access for the same reason that it is wrong for a lawyer to facilitate his client in committing fraud.

Honesty requires me to say that I have no right to declare apodictically that cancer patients have no just claim on those expensive life-prolonging resources. The fact of the matter is that we have no agreement in our society regarding what are or are not the just claims of patients in terminal circumstances to expensive, marginally beneficial life-prolonging resources. What then is a good doctor, a loyal patient advocate, supposed to do in the face of this lack of societal agreement? It is not fair or reasonable to say that in the face of such lack of agreement a good doctor ought to give the patient or family the benefit of the doubt and follow their wishes. This would only exacerbate the problem of health care cost control.

### PHYSICIANS AND HEALTH CARE RATIONING

As noted earlier, physicians are necessarily at the heart of efforts to control health care costs.<sup>14</sup> There are two responses that are clearly morally inadequate. First, physicians might want to say that if the need for health care rationing is inescapable, then those decisions should be made at the uppermost levels of government or health plans. The implication is they would then carry out those orders. But if physicians did simply carry out such orders, they would have failed to assume the moral responsibility that is part of medicine. They would have to ask what it was that made those rationing protocols “just” or “just enough” that they could in good conscience carry them out. Also, even if those rationing protocols were “just enough” physicians would still have the moral obligation, as patient advocates, to judge whether the patient they were caring for now deserved to be considered a justified exception to a somewhat general rationing protocol that that patient otherwise fit under.

Second, the alternative to the first option would be to let physicians make their own rationing decisions in accord with their own sense of what was required of them as a loyal patient advocate. But such an approach would carry the risk of widespread unfairness. Two patients might be in precisely the same medical circumstances, say, the same end-stage cancer in a hospital ICU. Both might want aggressive life-prolonging care. In the one case the physician acquiesces to their demands; in the other the physician refuses their demands. In an open society patients would readily come to know and resent such arbitrary practices, especially if patients had little ability to change who their physician was in these circumstances. It is also reasonable to ask what physicians would consult in the privacy of their own consciences as resources for determining what was or was not a just rationing decision with regard to any individual patient.

There is another alternative, which I can only briefly outline. In my own work I have argued that a fair and reasonable and responsible approach to health care rationing is through inclusive public processes of rational democratic deliberation.<sup>15</sup> What we seek to achieve through such processes are shared social understandings of what rationing protocols we (all of us) are willing to impose upon our future possible selves in specific clinical circumstances because we judge those protocols to be “just enough.” What we want in any society as the core of justice is reciprocity

and fair terms of cooperation. If I would be willing to deny an eighty-year-old individual with late-stage dementia a \$40,000 implantable cardiac defibrillator to prevent a fatal arrhythmic event because the benefits to him would be too small and the cost to society too high, and if I judged such a protocol to be “just enough,” then I would have to be willing to endorse the application of that protocol to a future possible version of me in similar clinical circumstances. This illustrates what a very basic sense of fairness requires of us. This is what public, self-imposed rationing would look like, as opposed to rationing decisions imposed upon us by remote authorities.

If patients (as prior deliberators) have endorsed some set of rationing protocols as being “just enough” for their future possible selves (from behind a very real health-related Rawlsian veil of ignorance), then physicians can in good conscience act on those protocols in caring for their individual patients. To be clear, physicians would have been part of that earlier (and on-going) deliberative effort in order to make sure that those public rationing protocols were suitably informed with regard to the relevant medical knowledge. And physicians ought to have comparable conversations among themselves for both moral and practical reasons. If the conditions described here are met, then physicians can be just agents of societal efforts to control health care costs as well as loyal advocates of the limited just health interests of their patients. In other words, physicians will be able to wield Ockham’s laser responsibly in the service of just parsimonious health care.

### NOTES

1. Keehan et al., “National Health Spending Projections Through 2020.”
2. Emanuel, “We Can Be Healthy and Rich.”
3. Callahan, *What Kind of Life*, chapter two.
4. Brook et al., *Effect of Coinsurance on the Health of Adults*.
5. Reuben and Cassel, “Physician Stewardship of Health Care.”
6. American College of Physicians, “Ethics Manual,” 86.
7. *Ibid.*
8. Cassel and Guest, “Choosing Wisely.”
9. Hermer and Brody, “Defensive Medicine, Cost Containment, and Reform.”
10. Berwick and Hackbarth, “Eliminating Waste in U.S. Health Care.”
11. Welch, *Overdiagnosed*.
12. Sheets et al., “Intensity-Modulated Radiation Therapy.”
13. Wilson, “Cancer Care,” 573.
14. Reuben and Cassel, “Physician Stewardship of Health Care.”
15. Fleck, *Just Caring*.

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## Health, Health Care, and the Contraception Requirement

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### 1. Introduction

The Patient Protection and Affordable Care Act (PPACA) includes the provision that employer-based health insurance plans be required to cover contraceptives for their enrollees without cost-sharing. A common reaction to this provision in public discourse is that contraception is not health care, so private insurance plans should not be mandated to cover it, nor should publicly subsidized insurance plans pay for it. One frequently given reason for this position is that unwanted pregnancy is not a disease or disability.<sup>1</sup> On the other side of the debate, defenders of the contraception requirement in the PPACA argued that in many cases pregnancy carries significant health risks so contraception can be understood as a kind of preventive care. In addition, some kinds of hormonal birth control offer health benefits for patients taking it, such as the reduction of dysmenorrhea, lessening of acne, or the prevention of ovarian cysts.<sup>2</sup>

The primary goal of my paper is to offer two arguments in defense of the contraception requirement. The first has to do with the definition of health, and the second has to do with the goals of health care.

The first way to defend the contraception requirement is to show that health can be more broadly understood than merely as the prevention or cure of disease and disability. Critics of the contraception requirement typically claim that pregnancy is not a disease or disability, so its prevention is thus not a part of maintaining health. This argument assumes the biomedical model of health and disease, which is seriously flawed. If we adopt an alternative account of health, such as Lennart Nordenfeldt's holistic model, the

typical arguments against the contraception requirement do not work.<sup>3</sup>

## 2. THE BIOMEDICAL MODEL VS. THE HOLISTIC MODEL OF HEALTH

Consider Christopher Boorse's definition of health, which is one of, if not the most influential statement of the biomedical model of health. According to Boorse, very briefly, health is both "statistical normality of function" relative to age and sex, and the absence of disease.<sup>4</sup> On this view, "diseases are internal states that depress a functional ability below species-typical levels."<sup>5</sup> The key functional abilities that Boorse uses to measure disease are survival and reproduction.<sup>6</sup> Boorse argues that biology can tell us what constitutes normal functioning by understanding how our bodies' various functions contribute to our survival as a species.<sup>7</sup>

There are at least three kinds of criticism of Boorse's biomedical model. First is the worry that it does not capture the phenomenology of illness. In Havi Carel's words, it does not include the "lived experience" of health and illness.<sup>8</sup> On her view, going from being healthy to being sick involves substantial changes in personal agency and the way one interacts with one's social and physical world.<sup>9</sup>

Second is the normativist or constructivist critique, that the biomedical model falsely assumes that a definition of health can be free of normative elements.<sup>10</sup> Specifically, notions of health and disease cannot escape being infused with value judgments that are far from being objective or even universally accepted. Instead, they are "sociological, culturally determined value judgments."<sup>11</sup> For example, disability theorists have criticized Boorse's notion of normal function on the grounds that disability is "a social construction" rather than a "biological deficiency."<sup>12</sup> Normativists often point to the history of medicine, which is rife with examples of the medicalization of social, moral, or political acts, such as the characterization of masturbation, sexual desire (or lack thereof) in women, or the tendency in slaves to try to run away, as diseases.<sup>13</sup>

The third criticism is that Boorse's reliance on evolutionary theory and adaptation is misapplied or problematic.<sup>14</sup> For example, on Boorse's account, homosexuality may count as a disease, or a state of unhealth, since it is not statistically normal and it seems to hinder reproduction.<sup>15</sup>

Since Boorse's biomedical model of health and disease has serious flaws, including narrowness, alternatives should at least be considered. The danger of constructing a broader notion of health is that it might end up including too much. For example, the World Health Organization's definition of health is "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity."<sup>16</sup> This definition has been widely criticized for being vague and practically unusable.<sup>17</sup> One of its most problematic elements is that it seems to conflate health and happiness, which are two distinct (albeit related) states.<sup>18</sup>

But even if health can be more broadly understood than the absence of illness and disease, the best conception of health might still not have room for the contraception requirement in the relevant way. Assuming that the woman's reason

for using contraception is to prevent pregnancy, it might make sense to say that some minimal level of control of if and when one becomes pregnant is part of being healthy. Certainly health does not include complete autonomy over one's reproductive capabilities. We would not want to say that an eighty-year-old woman, who is unable to conceive, though she wants to, is unhealthy on those grounds. Nor would we endorse the broader claim that part of health is control over *all* of one's bodily functions. The fact that I cannot exert complete control over my resting heart rate does not make me unhealthy. On the other hand, if one has little to no control over when one urinates (incontinence), on many accounts this would constitute ill health.<sup>19</sup>

Nordenfelt's holistic theory comes close to meeting both of these standards for a definition of health. It isn't too broad and yet it can accommodate the idea that health includes a certain level of control over one's body. According to Nordenfelt:

A is completely healthy if, and only if, the organic structure of A is such that it enables A to achieve all his or her vital goals, given standard circumstances.<sup>20</sup>

A person's vital or essential goals are the goals which "are of especial importance for the person" to achieve or maintain.<sup>21</sup> Without realization of one's vital goals, "(a person's) satisfaction with life will be affected."<sup>22</sup> The goals include, but are not limited to survival, reproduction, the preservation of family ties, maintaining current residence, remaining employed, or finding better employment.<sup>23</sup> Importantly, according to Nordenfelt, not being able to meet one of a person's vital goals does not necessarily make that person sick or diseased; instead, it may mean that the person is not in a state of complete health.

Nordenfelt does not explicitly address contraception, but it seems plausible that some level reproductive autonomy could easily be added to his list of vital goals. The goal of being able to stay in one's own house is surely no more important than the goal of avoiding an unwanted pregnancy. In this way, on Nordenfelt's view, the inability to control when and if one conceives can be understood as an element of ill health. At least this inability would mean that the person is not in a state of complete health.

Health conceived of as the ability to achieve one's most important goals faces several objections. One significant objection is that the concept of a "vital goal" is not precise enough, that it captures too many desires.<sup>24</sup> A second objection is that Nordenfelt's account, like the WHO definition, ties health too closely to happiness or that it mischaracterizes happiness.<sup>25</sup> There is not time enough in this short paper to discuss Nordenfelt's and others' replies to these critiques, or the counter-responses. One promising but preliminary line of response to these difficulties with goal or interest oriented accounts of health involves applying Martha Nussbaum and Amartya Sen's work on capabilities to the definition of health.<sup>26</sup> On a capabilities approach, health is construed as a capability: "the ability to cope with the demands of life, or the ability to exercise key functionings," whereas what counts as a disease "depend[s] on whether it constitutes a lack of capability for that individual in those circumstances."<sup>27</sup>

### 3. HEALTH CARE BEYOND THE GOAL OF HEALTH

The second way to defend the contraception requirement is to show that health need not be the sole legitimate aim of health care. Critics of the contraception requirement assume that if pregnancy is not ill health, then it is not within the realm of what health insurance should pay for, namely, health care. In response, I argue that medical professionals have a set of skills and a body of knowledge relating to the human body. They need not only aim at health promotion and restoration. Even Norman Daniels, who endorses the strict biomedical model of health, concedes that health care professionals may aim at other goals. Their skills and knowledge can be used in a variety of ways to satisfy human interests, such as promoting individual autonomy by enabling women (and sometimes their partners) to decide if and when to procreate. It is for this reason that the services of medical professionals might be more aptly referred to as medical care, rather than health care.

One can hold the biomedical model of health and still agree with this claim, as illustrated in Daniels's work. An important piece of Daniels's Rawlsian theory of justice and health care is his account of species typical functioning, largely adapted from Boorse's biomedical model of health and disease. Daniels defines health as "the absence of pathology"; pathology being "any deviation from the natural functional organization of a typical member of the species (or) a departure from normal functioning."<sup>28</sup> Briefly, for Daniels, health is important from the perspective of justice because health problems, which are understood to be deviations from species-typical functioning, diminish equality of opportunity.<sup>29</sup>

Of course, being pregnant or being at risk of an unwanted pregnancy does not count as a deviation from species-typical functioning. Despite this, Daniels has argued that non-therapeutic abortions should be covered by a national system of health care because doing so is a way of "respect[ing] the equality of women."<sup>30</sup> He writes:

If we are right that nontherapeutic abortion services should be included because of our concerns about the equality of women, then treatment of disease and disability does not capture the class of services we are obliged to provide once we consider all of our obligations.<sup>31</sup>

Like abortion, contraception does not necessarily prevent, cure, or ameliorate disease. But if funding for non-therapeutic abortions can be justified on the grounds of the equality of women, then so can contraception. In other words, it seems consistent with Daniels's view to say that medical care can serve other important social goals besides the restoration and maintenance of health.<sup>32</sup>

A more expansive view of the goals and purpose of health care can be found in Julian Savulescu, who argues that the goals of health care encompass promoting well-being, not just promoting or maintaining health.<sup>33</sup> Having a disease or disability is only morally important because it "makes our lives go badly" and can interfere with our ability to do things that we value.<sup>34</sup> This means that sometimes health care should involve more than ameliorating disease and bringing people up to a level of species-typical functioning. It may

sometimes require, for example, cognitive enhancement above and beyond what is typical of the species, if this turns out to be an effective and affordable way of promoting well-being.<sup>35</sup> On this view, what we call health care is just a set of tools, institutions, and expertise that can be used to maintain and restore health, prolong life, and relieve pain, as well as achieve other goals.<sup>36</sup> According to this model, it is easy to see why the provision of contraception is part of health care—because it allows women to enhance their quality of life by controlling their reproductive capacities.

#### 4. CONCLUSIONS

Two common assumptions in the debate about the contraception requirement in the PPACA do not hold up to scrutiny. The first assumption is that since unwanted pregnancy is not a disease, contraception cannot contribute to maintaining health. Not only are there significant problems with this conception of health, there are also plausible alternatives to the narrow biomedical model of disease, especially Nordenfelt's holistic model. Second, even if one does not accept an expanded view of health, one need not see the maintenance and restoration of health as the sole goals of health care. Health care can aim at well-being, autonomy, equality, and even happiness. This clears the ground for a positive argument that the provision of contraceptives should be part of any publically funded health care plan.

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#### NOTES

1. The law includes an exception for insurance plans provided by religious employers. But I put claims of religious liberty, however spurious, to one side.
2. Maguire and Westhoff, "State of Hormonal Contraception Today"; Huber et al., "Non-contraceptive Benefits of Oral Contraceptives."
3. Nordenfelt, "Concepts of Health and Illness Revisited."
4. Boorse, "Health as a Theoretical Concept," 542.
5. Ibid.
6. Ibid., p. 7–8. However, Boorse is not merely saying that health is merely statistical normality, as Law and Widdows point out ("Conceptualising Health," 304). Boorse recognizes, for example, that "tooth decay," which is "nearly universal, but is still thought of as a disease because we are saying that it is not simply in the nature of the species—and we say this because we think of it as mainly due to environmental causes" (Boorse, "On the Distinction Between Health and Illness," 50, 59).
7. Tengland, *Mental Health*, 83.
8. Carel, "Can I Be Ill and Happy?"
9. Ibid.
10. Normativist or constructivist critiques of the biomedical model come in several different kinds and degrees. Whereas some normativist/constructivist critiques argue that the biomedical model is incomplete others argue that the entire notion of disease, illness, and health are constructed. Christopher Boorse first introduced the distinction between naturalists, weak normativists, and strong normativists in this context (Boorse, "On the Distinction Between Health and Illness," 50–51).
11. See Engelhardt, "Health and Disease," 1078; Engelhardt, *Foundations of Bioethics* (1996); Margolis, "Concept of Disease"; King, "What Is Disease?"
12. Caplan, Fiester, and Ravitsky, *Penn Center Guide to Bioethics*, 62.

13. Ibid., 61, and Engelhardt, "Disease of Masturbation: Values and the Concept of Disease."
14. See Gammelgaard, "Evolutionary Biology and the Concept of Disease"; Hofmann, "On the Triad Disease, Illness and Sickness"; Kovács, "Concept of Health and Disease"; Law and Widdows, "Conceptualising Health," 305.
15. Lewens and McMillan, "Defining Disease," 664; Engelhardt, *Foundations of Bioethics*, 200.
16. Official Records of the World Health Organization, no. 2, p. 100.
17. Callahan, "Concept of Health."
18. Saracci, "World Health Organisation Needs to Reconsider Its Definition of Health, 1409.
19. This is Gammelgaard's example, although she uses it in a slightly different way against the biomedical model of disease based in evolution. She argues that something like incontinence does not prevent an organism from surviving and reproducing but is clearly an instance of ill health or disease ("Evolutionary Biology and the Concept of Disease," 110).
20. Nordenfelt, "Concepts of Health and Illness Revisited," 9.
21. Nordenfelt, *Talking about Health*, 70.
22. Ibid.
23. Ibid.
24. Venkatapuram, "Health, Vital Goals, and Central Human Capabilities," 7; Schramme, "Qualified Defence of a Naturalist Theory of Health."
25. Schramme, "Qualified Defence of a Naturalist Theory of Health"; Law and Widdows, "Conceptualising Health."
26. Law and Widdows, "Conceptualising Health."
27. Ibid., 313.
28. Daniels, *Just Health*, 37.
29. Daniels, "Justice, Health, and Healthcare."
30. Daniels, "Normal Functioning and the Treatment-Enhancement Distinction," 314.
31. Ibid.
32. Leon Kass laments the fact that in recent years the scope of medical care has been expanded to include services that merely satisfy patient's desires (such as sex selective abortion, physician assisted suicide, or plastic surgery), or serve the interests of the state (through eugenics, or psychiatric behavior modification for criminals) (Kass, 1981, p. 5-7). The problem with this expanded understanding of the goals of health care is that the provision of these services by physicians runs the risk of turning them into merely "civil servants" with technical expertise. He calls for physicians to return to their role as promoters of health, understood as a state of "well-functioning" (Kass 1981, p. 23-24). There are at least two obvious ways to respond to Kass' criticism. First, it seems that the problem that Kass has with physicians participating in the kinds of activities he mentions is that he finds those activities morally problematic for independent reasons. Second, Kass does not however explain why there is anything particularly problematic about physicians taking on this new role as "civil servants."
33. Savulescu, "Justice and Healthcare," 3a.
34. Ibid., 2.
35. Ibid., 3.
36. Nordenfelt explicitly writes, consistent with this position, that: "[t]he physician could and should remain a technician. The formulation of vital goals should be in the hands of the individuals themselves. . . . Given a well-defined set of vital goals the clinician can use his expertise in theoretical judgment: what bodily and mental states are risk-factors for a subject's ability to realize his given set of goals?" (Nordenfelt, *On the Nature of Health*, 129-130).

## *The Right to Health: From Maximization to Adequacy*

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### I. INTRODUCTION

The International Convention on Social, Economic, and Cultural Rights (ICESCR) defines the right to health as "the right to the enjoyment of the highest attainable standard of physical and mental health."<sup>1</sup> In a world where so many are so far from this ideal, it is tempting not to investigate the contours of this right too closely.<sup>2</sup> I'll argue that understanding the right to health as a right to maximum health—to the "highest attainable standard"—is untenable, and we should instead recognize a right to *adequate* health.

I'll say some things about the project's aims up front. My goal is to uncover and highlight problems with our current understanding of the right to health, not to reject the right to health. Nor do I believe the language of rights inapplicable to health.<sup>3</sup> Rather, I agree with the ICESCR's drafters that the right to health is an important right, but argue that it needs to be reconceived so as to place it *on a par with*, rather than *above*, other important rights. My goal is to motivate the need to *redefine* the requirements for health care.

I will raise four concerns about conceiving of the right to health as a right to maximum health:

- (1) it encroaches on resources that could be used to realize other rights, such as the rights to education and to housing, or to achieve discretionary goals;
- (2) it is unable to differentiate crucial health needs from peripheral claims;
- (3) it undermines national and subnational regulations on health care;
- (4) it rewards adversarial advocacy by physicians and lawyers on behalf of particular individuals at the expense of population health.

I'll start with the first concern.

### II. MAXIMIZATION

#### **1. CROWDS OUT OTHER SOCIAL AND ECONOMIC RIGHTS**

The right to health is the only right the ICESCR defines as a right to the highest attainable—maximum—standard.<sup>4</sup> The rights to food and shelter are rights to adequate food and shelter, not to the maximum.<sup>5</sup> The right to work is the right to "just and favourable conditions of work" which ensure workers "a decent living," not to maximally remunerative or pleasant work.<sup>6</sup> This difference between the right to health and other rights potentially produces a situation in which the right to maximum health engulfs all resources not explicitly reserved for other ends.<sup>7</sup>

The idea that health's unique status should invariably give it pride of place over other social goods seems both overinclusive and underinclusive. Overinclusive, in that some aspects of health are comparatively unimportant and should not receive pride of place over other social aims.<sup>8</sup> Underinclusive, in that achieving a decent standard in other spheres of life via basic education, safe housing, functioning infrastructure, and tolerable working conditions seems every bit as important as protecting people's health.<sup>9</sup> These other essentials should not be held hostage even to important aspects of health. Indeed, as Amy Gutmann has argued, we should sometimes provide non-essential "quality of life" goods rather than maximally providing health care.<sup>10</sup>

One response defending the paramount value of health attempts to redefine health as coextensive with basic human welfare. So, for instance, anti-baldness medication would not improve health, while education would.<sup>11</sup> This stretches the conception of health beyond recognition.<sup>12</sup> It also mistakes instrumental aims for objects of final value: we do not value education or secure housing primarily because they improve health, but rather because they enable us to pursue life plans and participate in civic life.<sup>13</sup>

## 2. CANNOT PRIORITIZE CRUCIAL HEALTH INTERVENTIONS OVER OTHERS

Another problem with seeing the right to health as a right to the highest attainable standard is that it places all aspects of health on a par. Without a way of dividing adequacy from comfort and comfort from luxury, each person who finds herself short of the highest attainable standard of health now has a legal claim for redress.

This inability to rank and prioritize health goals can threaten society's ability to fulfill more important or cost-effective, but less high-profile, needs. For instance, malaria, childhood vaccination, and prenatal care in developing countries receive disproportionately less funding than conditions like HIV/AIDS or cancer.<sup>14</sup> Worse, the inability to set priorities and differentiate health interventions makes realizing the right to health seem like an undifferentiable "bottomless pit" into which infinite resources could be pumped.<sup>15</sup> Those able to contribute resources become reluctant to do so, and "rights fatigue" sets in.<sup>16</sup>

## 3. UNDERMINES STATE DISCRETION OVER HEALTH-RELATED RESOURCES

The right to health generates not only a positive duty to direct state resources to health promotion (which human rights theorists call the "obligation to fulfill"<sup>17</sup>), but also a negative duty "to refrain from interfering directly or indirectly with the right to health" (which human rights theorists call the "obligation to respect").<sup>18</sup> This negative duty is quite broad: it commands states to refrain "from denying or limiting access to health-care services."<sup>19</sup> It also specifically prohibits "limiting access to contraceptives and other means of maintaining sexual and reproductive health," "withholding, censoring or misrepresenting health information," and "infringing on the right to privacy (e.g., of persons living with HIV/AIDS)."<sup>20</sup>

At first blush, the above duty seems intuitive. The state certainly should not lie to citizens about health information, deny them contraceptives and essential medicines, or broadcast their private lives. But the duty goes too far toward libertarianism. If the state cannot deny or limit access to health-care services, it may be unable to restrict access to untested drugs.<sup>21</sup> Such an inability could undermine the clinical trial system, thereby putting patients at greater long-term risk.<sup>22</sup> The state also may not be able to set limits on expensive or inefficient health-care services, for instance by taxing expensive "Cadillac" health plans.<sup>23</sup>

The undermining of state discretion that a right to maximum health produces also raises health care costs. A market where each person is free to seek maximal individual health by any means she chooses may well generate pressures for physicians to specialize in expensive procedures rather than cost-effective ones.<sup>24</sup> As Joseph Stiglitz has argued, it may similarly incentivize the production of high-cost, low-benefit drugs and devices.<sup>25</sup>

The other more specific provisions also generate problems. If the right to health prohibits limiting access to contraception or abortion, does it prohibit local or national parental notification laws?<sup>26</sup> The prohibition on withholding or censoring health information, meanwhile, stands in tension with patient protection.<sup>27</sup> Finally, the prohibition on infringing on the right to privacy stands in tension with the aim of preventing communicable disease.<sup>28</sup>

On a more conceptual level, the loss of governmental discretion represents a loss of national and sub-national sovereignty. One advantage of governmental discretion is the ability of different localities and nations to experiment with different ways of providing health care.<sup>29</sup> The maximization conception exerts transnational control over every aspect of health promotion. Such an approach is likely to fail to take account of local diversity and local knowledge in favor of a top-down uniformity.<sup>30</sup>

## 4. ENCOURAGES ADVERSARIAL ADVOCACY

The right to maximum health is a highly individualized one, focusing as it does on each person's health. This can lead to adversarial advocacy in which each individual attempts to advance her right to maximal *individual* health, even when doing so does not contribute to—and, indeed, often undermines—broader access to health.

There are many such examples of adversarial advocacy depleting health care resources. One such case is that of Colombian *tutelas*—legal proceedings by which Colombian citizens could enjoin the national government to pay for lifesaving medical care. Despite each medical intervention seeming individually worthwhile, as an aggregate, the *tutela* system has been criticized for leading to runaway health spending and for diverting resources from preventive care.<sup>31</sup> Similar problems have occurred in Argentina, Costa Rica, and Brazil.<sup>32</sup> Indeed, a desire to avoid these bad consequences arguably led the South African Constitutional Court not to grant a *tutela*-like suit for provision of renal dialysis in *Soobramoney v Minister of Health (Kwa-Zulu Natal)*, despite the plaintiff's very sympathetic circumstances.<sup>33</sup>

Furthermore, legal norms of adversarial advocacy can also deeply influence medical norms, encouraging doctors to use the right to maximum health as a fulcrum to seek increased resources for their own patients at the potential expense of overall health.<sup>34</sup> Adversarial advocacy also makes a patient's medical well-being ultimately dependent not on medical need but on the advocate's skill, an undesirable outcome.<sup>35</sup>

### III. ADEQUACY

Ultimately, recognizing a right to maximum health saddles emerging international institutions and developing nations with the same problem facing established democracies like the United States, Germany, and Japan: the runaway cost of medical care and the threat that health care spending will crowd out other essentials. Some believe that the right to the highest attainable standard of health is inherently limited.<sup>36</sup> But the textual provisions they cite do not support such limits. "Progressive realization,"<sup>37</sup> for instance, only delays the inevitable runaway cost problem. The same is true for the observation that the highest attainable standard evolves over time:<sup>38</sup> the highest attainable standard at any given time may still be extremely demanding. Meanwhile, permission to realize the right only to a country's "maximum available resources" may absolve a country of blame for inter-country inequalities, but only after it has maximally cannibalized its non-health sector to provide those resources.

In light of the above worries, turn to the adequacy approach. Conceiving the right to health in adequacy terms has a substantial legal and theoretical pedigree. The Universal Declaration of Human Rights, which postdated the WHO's adoption of the "highest attainable standard of health" language, eschewed the WHO definition in favor of the language of adequacy: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family."<sup>39</sup>

#### 1. RHETORICAL OBJECTIONS TO ADEQUACY

Some worry that if we accept that the right to health is a right to adequacy, we will be left with no right to health at all after the process of political deliberation. Better, they believe, to publicly endorse a standard that is *more generous* than may actually be justified, and then adjust that standard downward as needed.<sup>40</sup>

This strategy is unappealing for several reasons. First, adopting a maximization standard may lead potential supporters to believe that the right to health is unrealizable and thus not worth pursuing.<sup>41</sup> Second, promoting a standard that one does not believe to be actually justified, in order to achieve one's desired ends, seems to disrespect fellow political participants.<sup>42</sup>

#### 2. ADEQUACY AND UNFAIR LIMITATIONS

Some complain that treating the right to health as an adequacy right will lead to unfair results, because wealthy people will be able to buy health care that goes beyond the adequacy standard, like costly cancer medication or organ transplants.<sup>43</sup> This sort of medical "tiering" strikes many as highly objectionable.<sup>44</sup>

The first thing to observe is that the alternative to adequacy—the right to the highest attainable standard—is *not* an equality right. Maximization does not guarantee equality:

rather, it permits maximal liberty to leverage both one's own resources and *societal* resources to achieve individual health for oneself. This is not obviously an egalitarian aim.

It is true that seeing health as an adequacy right will sometimes permit the wealthy to buy better health than the poor. But this stems from the fact that we countenance substantial intranational and international inequalities in *wealth*, which leave us the choice of either blocking exchanges that would convert wealth to health, or permitting inequalities in health. If the exchange were blocked, the rich person would still be free to purchase some other non-health good that the poor person could not afford. The rich person would be worse off than she would otherwise have been, and the poor person no better off.<sup>45</sup>

An adequacy right—unlike a maximization right—permits us to tax, as luxuries, medical procedures that are very expensive or that provide low benefits for high costs. These taxes could be reinvested in maintaining health infrastructure for the poor, or in other social aims like education. In contrast, a maximization right would potentially require the state or civil society to match, for each citizen, whatever health expenditures the wealthiest citizens decide on for themselves. Such a system is unsustainable and inefficient: it limits care by financial exhaustion, rather than by medical benefit or cost-effectiveness.

### IV. CONCLUSION: IMPLEMENTING ADEQUACY

The final challenge for the adequacy principle is to generate a principled standard. The maximization standard provides a natural upper limit—albeit, as I have argued, an impracticably high one. It tells us to direct resources to health care either until all have reached the highest attainable standard of health or until we run out of resources. In contrast, the adequacy standard has no built-in limit. We must set the limits ourselves. This is a challenging task, and I'm grateful to the other presenters for exploring this in more depth than I do.

One potential basis for an adequacy standard relies on democratic deliberation.<sup>46</sup> On this view, the appropriate standard for adequate health is whatever standard results from a fair process of deliberation about health care. However, pure democratic deliberation faces some difficulties. We generally accept certain counter-majoritarian checks on democratic deliberation, and universal human rights are often seen as one of those checks.<sup>47</sup> Thus, basing the content of a human right purely on democratic deliberation will either face problems of circularity or produce the risk of an unfair outcome that disadvantages certain minorities, or advantages groups that manage to capture the deliberative process. Despite these problems, I believe that some appropriately limited version of a democratic deliberation approach, perhaps beginning with something like the World Health Organization's Essential Medicines List, is the best way of developing an appealing account of adequacy.

Ultimately, reframing the right to health as a right to adequate health resources steers a middle way between two serious problems. Such an understanding neither refuses to recognize substantial positive rights to health, nor does it recognize rights so extensive as to be unworkable. More importantly, it harmonizes the right to health with

other important rights, rather than portraying health as a *sui generis* good. As such, an adequacy approach to the right to health deserves serious attention.

NOTES

1. International Covenant on Civil, Political, and Cultural Rights, G.A. Res. 22001 (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1966).
2. Cf. Mary Ann Glendon, "Knowing the Universal Declaration of Human Rights," *Notre Dame L. Rev.* 73 (1998): 1153–54 (describing drafters of the Universal Declaration as saying that "we agree about the rights but on condition no one asks us why") (quoting Jacques Maritain, "Introduction," in *Human Rights: Comments and Interpretations* 10 (UNESCO ed., 1949)).
3. Cf. Goodman, *supra* note 3, at 659 ("Secure access to health care can best be achieved not through a socially corrosive preoccupation with claiming and exercising rights"); Mark Siegler, *A Physician's Perspective on a Right to Health Care*, *JAMA* 244 (1980): 1591, 1595 (criticizing the use of "rights language" in the health care context as adversarial and as creating an undesirable relationship between physician and patient).
4. Amir Attaran, "Human Rights and Biomedical Research Funding for the Developing World: Discovering State Obligations under the Right to Health," *Health and Hum. Rts.* 4 (1999): 26, 31 ("The Article 12 right is tremendously ambitious in scope. It provides that the right to health inures to 'everyone' and that everyone should enjoy the 'highest attainable standard' of well-being. No other right in the ICESCR is framed in such superlative language.")
5. International Covenant, *supra* note 1, art. 11 ("The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions.") (emphasis added). See also O'Neill, *supra* note 3, at 429 (observing that the ICESCR conceives of the right to food as an adequacy right, but the right to health as a right to the maximum).
6. *Id.* art. 6.
7. See John D. Arras and Elizabeth M. Fenton, "Bioethics and Human Rights: Access to Health-Related Goods," *Hastings Ctr. Rep.* 39 (2009): 27, 31 ("Suppose that the government of a relatively resource-poor country has managed, after herculean efforts, to achieve what it considers a sufficient level of health care for all its citizens. . . . It now wants to turn its attention to other sectors of the welfare state—to enhanced education, say, or perhaps even to support of the arts. But according to a rigorous reading of this human right, the government must continue to spend more on health until it reaches not just a sufficient level, but the highest level attainable."). See also Nora K. Bell, "The Scarcity of Medical Resources: Are There Rights to Health Care?" *J. Med. and Philos.* 4 (1979): 158, 164 ("For a right to be absolute it must in all circumstances and for all times be undeniable. For the right to health care to be absolute in that sense would mean that in the allocation of scarce resources no cost could be spared in providing health care to everyone who needed it. It would mean that our rights to education, food, shelter, clothing, even property, etc., if they too are rights, would have to give way to this absolute right in cases of conflict."); Charles Fried, "Equality and Rights in Medical Care," *Hastings Ctr. Rep.* 6 (1976): 29, 31 ("And if we commit ourselves to the notion that there is a right to whatever health care might be available, we do indeed get ourselves into a difficult situation where overall national expenditure on health must reach absurd proportions—absurd in the sense that far more is devoted to health at the expense of other important social goals than the population in general wants.").
8. See Colleen C. Denny, Ezekiel J. Emanuel, and Steven D. Pearson, "Why Well-Insured Patients Should Demand Value-Based Insurance Benefits," *JAMA* 297 (2007): 2515–16 (highlighting and criticizing several high-cost, low-benefit medical procedures, including cancer therapies cetuximab and bevacizumab and spinal fusion for herniated disks); Ezekiel J. Emanuel and Victor R. Fuchs, "The Perfect Storm of Overutilization," *JAMA* 299 (2008): 2789, 2791 (proposing higher insurance co-payments for high-cost, low-benefit treatments).
9. See Rashi Fein, "Entitlement to Health Services Reappraised," *Bull. N.Y. Academy of Medicine* 66 (1990): 319, 322 ("A health sector grown bloated at the expense of housing, food, or education would

misallocate scarce resources. We do not need nor should we want an ever-growing health sector in no small part because we enjoy and desire other things as well."); Denny, *supra* note 15, at 2516 ("[S]piraling health care expenses lead to reduced spending for programs that affect other aspects of patients' lives. Because more must be spent on Medicare, Medicaid, and government employee coverage, states compensate by reducing public education budgets, scrapping construction projects, and generally cutting funding for nonhealth initiatives. Given increasing Medicaid costs, for instance, policy analysts see no end to hikes in state university tuition such as those seen in North Carolina, where in-state tuition increased more than 71% in less than a decade as Medicaid costs increased by \$1 billion each year. Even individuals unpersuaded by eroding health care benefits should be concerned with the potential for health care costs to displace other valuable public projects.").

10. Compare Amy Gutmann, "For and Against Equal Access to Health Care," *Milbank Qtrly.* 59 (1981): 542, 556 ("[A]bove some less-than-maximum level in the provision of opportunity goods, it seems reasonable for people to value what, for want of a better term, one might call 'quality of life' goods: cultural, recreational, noninstrumental educational goods, and even consumer amenities. A society that maximized the satisfaction of needs before it even began to provide access to 'quality of life' goods would be a dismal society indeed. Most people do not want to devote their entire lives to being maximally secure and healthy. Why, then, should a society devote all of its resources to satisfying human needs?"), with Hayry and Hayry, *supra* note 14, at 12 ("[T] here are surely also national budgetary allocations which are by any standards less important than health care. . . . Publicly funded opera houses, for instance, may be culturally highly elevating, but if they are given priority over publicly funded hospitals, decisionmakers are implicitly construing a hierarchy of needs which does not necessarily bear further reflection.")
11. Something like this is suggested in Paul Farmer, "Challenging Orthodoxies: The Road Ahead for Health and Human Rights," *Health and Hum. Rts.* 10 (2008): 5, 8 ("What if we tell those who hold the purse strings that we do not really know how to treat diseases, much less how to prevent them, without promoting basic social and economic rights for the poor? Will the next orthodoxy in public health be that it is acceptable to offer medicines but not acceptable to offer, say, access to microcredit, school fees, or food?")
12. See, e.g., Hayry and Hayry, *supra* note 14, at 14 ("As the [WHO] definition refers to 'a state of complete physical, mental and social well-being', its application in practice could easily give rise to a complete 'medicalization' of social life: poor housing would be a medical problem, economic injustice would be a medical problem, even the price of rice on the world market would ultimately be a medical problem! The earth would turn into one huge hospital governed by medical experts"); Peter Harvey, "Approaches to Population Health Care: The Emerging Context!," *Australian J. Primary Health* 11 (2005): 45, 47 (discussing the "phenomenon of including all things in the causal loop of health" and dubbing it "health imperialism").
13. See *John Rawls, A Theory of Justice*, at 248-50 (describing primary goods as important to life plans); Amy Gutmann, "Children, Paternalism, and Education: A Liberal Argument," *Philos. and Pub. Aff.* 9 (1980): 338, 340 (listing "adequate nutrition, health care, housing, familial affection, and an education adequate to choosing among available economic and social opportunities and to becoming informed, democratic citizens" as primary goods). See also Martha C. Nussbaum, "Capabilities and Human Rights," *Fordham L. Rev.* 66 (1997): 273, 286–88 (delineating a list of central capabilities, including education, health, and political participation, and noting that these abilities "support our powers of practical reason and choice, and have a special importance in making any choice of a way of life possible").
14. Audrey R. Chapman, "Violations of the Right to Health," in *The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights*, ed. Theo C. van Boven et al. (1998), available at <http://www.uu.nl/faculty/leg/NL/organisatie/departementen/departementrechtsgelijkheid/organisatie/onderdelen/studieeninformatiecentrummensenrechten/publicaties/simspecials/20/Documents/20-04.pdf> ("It is not uncommon to invest public money on health interventions of low cost-effectiveness, such as surgery for cancer and organ transplants, while underfunding critical and highly cost-effective interventions, such as treatment of tuberculosis and sexually transmitted diseases"); John Bongaarts and Mead Over, "Global HIV/AIDS Policy in Transition," *Sci.* 328 (2010): 1359 ("The proportion of

- development assistance for health that is allocated to HIV/AIDS reached 23% in 2007, whereas the proportion of deaths attributable to AIDS in the developing world is less than 5%"); Ezekiel J. Emanuel and Colleen C. Denny, "U.S. Health Aid Beyond PEPFAR: The Mother and Child Campaign," *JAMA* 300 (2008): 2038 (similar).
15. See Norman Daniels, *Just Health Care* (1985), at 53 (discussing the "bottomless pit" objection).
  16. See Gostin, *supra* note 8, at 29 ("A merely aspirational right to health that is too broadly defined lacks clear content and is less likely to have a meaningful effect."); Arras and Fenton, *supra* note 13, at 28 (criticizing "the proliferation of many ill-considered and highly controversial rights," including the right to the highest attainable standard of health).
  17. *Office of the United Nations High Comm'r for Hum. Rts., The Right to Health* 27 (2008).
  18. *Id.* at 25.
  19. *Id.*
  20. *Id.*
  21. This issue was raised in American courts in *Abigail Alliance for Better Access to Developmental Drugs v. Von Eschebach*, 495 F.3d 695 (2007), cert. denied, 128 S. Ct. 1069 (2008) (reversing panel decision supporting a fundamental right to access unapproved but potentially lifesaving drugs).
  22. See Jerry Menikoff, "Beyond *Abigail Alliance*: The Reality Behind the Right to Get Experimental Drugs," *Kan. L. Rev.* 56 (2008): 1046; Seema Shah and Patricia Zettler, "From a Constitutional Right to a Policy of Exceptions: *Abigail Alliance* and the Future of Access to Experimental Therapy," *Yale J. Health Pol'y, L. and Ethics* 10 (2010): 1.
  23. Such a tax was recently included in the Patient Protection and Affordable Care Act (PPACA) passed in the USA in 2010. Pub. L. No. 111-148, 124 Stat. 119 (2010), amended by Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010). See also Jon Gabel et al., "Taxing Cadillac Health Plans May Produce Chevy Results," *Health Aff.* 29 (2010): 1 ("Presidents Ronald Reagan and George W. Bush attempted to amend the open-ended tax treatment of employer-based insurance. At the time this is published, President Barack Obama and Senate Democrats, as part of their health reform plan, are considering a 40 percent excise tax on high-cost health plans.").
  24. See Gutmann, *supra* note 18, at 552 ("Without restricting the free market in extra health care goods, a society risks having its best medical practitioners drained into the private market sector, thereby decreasing the quality of medical care received by the majority of citizens confined to the publicly funded sector."). See also J. Paul Leigh et al., "Physician Wages Across Specialties: Informing the Physician Reimbursement Debate," *Arch. Intern. Med.* 170 (2010): 1728 (finding that plastic surgeons in America earn almost twice the hourly wage of family practice physicians).
  25. See Joseph Stiglitz and Arjun Jayadev, "Medicine for Tomorrow: Some Alternative Proposals to Promote Socially Beneficial Research and Development in Pharmaceuticals," *J. Generic Med.* 7 (2010): 217, 221–22 (discussing how regulations like value-based pricing and restrictions on marketing can help increase the cost-effectiveness of pharmaceuticals).
  26. E.g. *Ayotte v. Planned Parenthood*, 546 US 320, 326–27 (2006) (noting that the Supreme Court has "long upheld state parental involvement statutes" and collecting relevant cases). See generally B. Pinter et al., "Accessibility and Availability of Abortion in Six European Countries," *Eur. J. Contraception and Reproductive Health* 10 (2005): 51 (noting parental notification requirements in France, Britain, Hungary, and Turkey); Alan Guttmacher Institute, "Parental Involvement in Minors' Abortions," available at [http://www.guttmacher.org/statecenter/spibs/spib\\_PIMA.pdf](http://www.guttmacher.org/statecenter/spibs/spib_PIMA.pdf) (noting that 36 US states require some form of parental notification).
  27. See Dana McWay, *Legal Aspects of Health Information Management* (2002): 101 and n.26 (discussing circumstances in which it is permissible under US law to withhold health information about individual patients). See also Paul R. Cordts, "Now and Then: Combat Casualty Care Policies for Operation Iraqi Freedom and Operation Enduring Freedom Compared With Those of Vietnam," *J. Trauma* 64 (2008): S14, S16–17 (discussing the United States Army's Release of Actionable Medical Information policy, which censors some medical information that might aid enemy combatants in more effectively attacking U.S. soldiers).
  28. See, e.g., Ronald Bayer and Kathleen E. Toomey, "HIV Prevention and the Two Faces of Partner Notification," *Am. J. Pub. Health* 82 (1992): 1158 (discussing physician disclosure of private health information to third parties in order to protect sexual partners from HIV infection).
  29. E.g., *New State Ice Co. v. Liebmann*, 285 US 311 (1932) (Brandeis, J., dissenting) (arguing that permitting variations in policies between states allows them to try "novel social and economic experiments"); see also Akhil Reed Amar, "Of Sovereignty and Federalism," *Yale L.J.* 96 (1987): 1425, 1428–29 (arguing for the value of experimentation and competition between different states in a federal system).
  30. See O'Neill, *supra* note 3, at 436–37 and n. 14 (criticizing the centralized regulatory system that often accompanies human rights).
  31. S. Kalmanovitz, "Las consecuencias económicas de los fallos de la Corte Constitucional," *Economía Colombiana* 276 (1999), summarized in Rodrigo Uprimny, "Should Courts Enforce Social Rights? The Experience of the Colombian Constitutional Court," in *Courts and Social Transformation in New Democracies*, edited by Roberto Gargarella et al. (Ashgate, 2006), 127, 142 (arguing that the tutela system undermines public health interventions like childhood immunization in order to treat high-profile cases). See also Maria Paula Saffon, "Can Constitutional Courts be Counterhegemonic Powers vis-a-vis Neoliberalism? The Case of the Colombian Constitutional Court," *Seattle J. Soc. Just* 5, no. 2 (2012): 533, 547–48 (noting that the tutela system more than tripled health care expenditures between 1998 and 1999, that the system is unsustainable because of lack of state resources, and that many have criticized tutelas for inefficiently directing money to high-cost interventions, but nonetheless praising the tutela system because it has concretely helped some citizens); Everaldo Lamprea and Tatiana Andia, "Local Maladies, Global Remedies: Rethinking Right to Health Duties," unpublished manuscript presented to the Linda Randall Meier Global Justice Workshop, Stanford University, May 21, 2010, available at [http://iis-db.stanford.edu/evnts/6170/Global\\_Justice\\_May\\_21\\_2010.pdf](http://iis-db.stanford.edu/evnts/6170/Global_Justice_May_21_2010.pdf) (noting that "the cost of health litigation climbed from US\$ 1.48 million in 2001 up to US\$ 344 million in 2008"). See generally Alicia Ely Yamin and Oscar Parra-Vera, "Judicial Protection of the Right to Health in Colombia: From Social Demands to Individual Claims to Public Debate," *Hastings Int'l and Comp. L. Rev.* 33 (2010): 431 (describing the evolution of the tutela system in Colombia).
  32. Fabiola Sulpino Vieira, "Right to Health Litigations: A Discussion on the Observance of the Principles of Brazil's Health System," *Rev. Saude Publica* 42 (2008): 365 (strongly criticizing the Brazilian Supreme Court for issuing rulings guaranteeing access to medicines that ignored resource scarcity and cost-effectiveness); see also Alicia Ely Yamin and Oscar Parra-Vera, "How Do Courts Set Health Policy? The Case of the Colombian Constitutional Court," *PLoS Med* e100032 6 (2009) (observing that "In Brazil, thousands of court cases have been brought since 1992 relating to access to medications—many of which are highly costly and not included in Brazil's national health plan—resulting in distortions of the health budget," and noting similar practices in Argentina and Costa Rica).
  33. *Soobramoney v. Minister of Health (Kwa-Zulu Natal)* 1997 (12) BCLR 1696 (CC); see also Charles Ngwenya, "The Recognition of Access to Health Care as a Human Right in South Africa: Is It Enough?" *Health and Hum. Rts.* 5 (2000): 26, 32–34 (describing the *Soobramoney* case and the reasoning underlying the decision). But see Jeanne M. Woods, "Justiciable Social Rights As a Critique of the Liberal Paradigm," *Tex. Int'l L.J.* 38 (2003): 763 (criticizing the *Soobramoney* decision).
  34. See William M. Sage, "The Lawyerization of Medicine," *J. Health Pol., Pol'y, and Law* 26 (2001): 1179, 1190-91 (noting that physicians, in response to externally imposed limits, "tended to conflate medicine's traditionally broad, normative principles of advocacy with the much narrower, purely instrumental form of advocacy familiar to lawyers," and arguing that "medicine's reorientation toward a lawyerly model not only has made it more difficult for third parties to require scientific justification of professional practice, but also has rendered unreachable any meaningful social consensus regarding the allocation of health care resources.").
  35. See Cesar Ernesto Abadia and Diana G. Oviedo, "Bureaucratic Itineraries in Colombia: A Theoretical and Methodological Tool to Assess Managed-Care Health Care Systems," *Soc. Sci. Med.* 68 (2009): 1153, 1158 (questioning "whether legal proficiency should decide people's health care need," as they believe it does under the tutela system); see also Yamin and Parra-Vera, *supra* note 47, at 114 (noting that "Colombian courts have been awarding health

benefits based on the morally irrelevant category of who has access to justice”).

36. Alicia Ely Yamin, “The Right to Health Under International Law and Its Relevance to the United States,” *Am. J. Pub. Health* 95 (2005): 1156 (“The reference to a ‘highest attainable standard’ of health . . . builds in a reasonableness standard.”).
37. *Id.*
38. *Id.* (“[T]he highest attainable standard will necessarily evolve over time, in response to medical inventions, as well as demographic, epidemiological, and economic shifts.”).
39. UDHR art. 25, <http://www.un.org/Overview/rights.html#a8>.
40. See Attaran, *supra* note 9, at 36 and n. 31 (“‘Maximum’ stands for idealism; ‘available’ stands for reality. ‘Maximum’ is the sword of human rights rhetoric; ‘available’ is the wiggle room for the state.”) (quoting R. Robertson, “Measuring State Compliance with the Obligation to Devote the ‘Maximum Available Resources’ to Realizing Economic, Social, and Cultural Rights,” *Hum. Rts. Q.* 16 (1994): 693).
41. See *supra* note 28 and related text; see also Arras and Fenton, *supra* note 13, at 30 (proposing “a useful criterion of genuineness—only those rights that protect fundamental or basic human interests are real human rights—which can in turn help stem the rising tide of rights proliferation”); Cass Sunstein, “Against Positive Rights,” *E. Eur. Const. Rev.* 2 (1993): 36–37 (arguing that unachievable positive entitlements can reinforce “cynicism about constitutions”).
42. See, e.g., Amartya Sen and Bernard Williams, eds. “Introduction: Utilitarianism and Beyond,” in *Utilitarianism and Beyond* (Cambridge University Press, 1982) (criticizing “Government House Utilitarianism,” in which non-utilitarian theories are promulgated so as to best promote utilitarian aims).
43. See Woods, *supra* note 51, at 783 (criticizing the South African Constitutional Court for “acknowledging that a person’s wealth determined whether he would live or die, yet failing to interpret the constitutional rights to health and life to avoid this outcome”).
44. Cf. Benjamin Krohmal and Ezekiel J. Emanuel, “Access and Ability to Pay: The Ethics of a Tiered Health Care System,” *Arch. Intern. Med.* 167 (2007): 433–434 (describing several objections to tiered health care systems).
45. See Gutmann, *supra* note 20, at 545 (“The restriction upon market freedoms to purchase health care . . . creates a certain discomfiting irony: the equal access principle permits (or is at least agnostic with respect to) the free market satisfaction of preferences for nonessential consumer goods. Thus, the rigorous implementation of equal access to health care would prevent rich people from spending their extra income for preferred medical services, if those services were not equally accessible to the poor. It would not prevent their using those same resources to purchase satisfactions in other areas—a Porsche or any other luxurious consumer good.”); *id.* at 553 (“It is hard to see why one ought to prevent people, rich or poor, from spending money upon health care goods while permitting them to spend money on consumer goods that are clearly not essential, and perhaps even detrimental to health.”).
46. E.g. Gutmann, *supra* note 19, at 557 (“[P]hilosophical argument might establish some criteria by which to judge when the publicly funded level of health care was so low as to be unfair to the least advantaged, or so high as to create undue restrictions upon the ability of most people to live interesting and fulfilling lives. The remaining question of establishing a precise level of priorities among health care and other goods (at the ‘margin’) is appropriately left to democratic decisionmaking.”)
47. E.g. Andreas Follesdal, “Why International Human Rights Judicial Review Might Be Democratically Legitimate,” *Scandinavian Stud. in L.* 52 (2007): 371 (arguing for the desirability of human rights constraints on legislative decisionmaking).

## Social Determinants of Health and the Skeptical Challenge to Universal Health Care

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This past Election Day, I was discussing politics with a colleague who happens to be Canadian. When we got into a discussion about health care and the debates over Obamacare, he commented on how funny it was that so many Americans seemed opposed to universal health care. Sure, the Canadian system was far from perfect and health-related social inequalities persisted despite universal access to care, but it was still better than not having it. My gut reaction was to agree; of course any decent society would have universal health care.

Upon reflection, however, it doesn’t seem reasonable to ignore all the social inequalities that impact health and which health care could not reasonably fix. It is now well documented that social determinants such as poverty, poor nutrition, poor living conditions, poor working conditions, and unhealthy behaviors have more impact on health and life expectancy (in terms of population health) than access to health care.<sup>1</sup> One of the most telling reports that first documented this gap between access to universal health care and health is the Black Report of 1980. The Black Report examined the National Health Service (NHS) in the United Kingdom. It revealed that despite overall improvements in health care, there were still widespread inequalities in health. In fact, since the implementation of the NHS in 1948, the inequalities in health in the United Kingdom actually widened.<sup>2</sup> As the report pointed out, “these inequalities were not mainly attributable to failings in the NHS, but rather to many other social inequalities influencing health: income, education, housing, diet, employment, and conditions of work.”<sup>3</sup>

In his article “Health Risk and Health Security,” Jonathan Wolff identifies this issue and frames it as the following dilemma: on the one hand, universal health care seems like something any decent society would have; on the other hand, health and life expectancy are affected by many factors other than access to health care. As the Black Report and other studies have pointed out, social determinants appear to have a greater influence on health and life expectancy than access to health care.<sup>4</sup> This leads to what Wolff calls the “skeptical argument” against universal health care: “Why should we support universal health care if it is likely to make relatively little difference to health and life expectancy compared to other factors?”<sup>5</sup> That is, why should a society spend its resources on universal health care when the effects on health are so marginal?<sup>6</sup>

Wolff’s skeptical argument seems to present a considerable challenge for any justification of universal health care, especially if we consider the limited resources available to achieve universal health care and all the competing interests for those resources. Here, I’d like to examine the skeptical argument more closely and consider some possible ways of facing this challenge to universal health care. My goal is not

to present a complete refutation of the skeptical argument but to give a critique of Wolff's response to the skeptical argument and to suggest some alternative approaches that may be more fruitful.

Let's start by first clarifying Wolff's skeptical argument and pointing out some of the underlying premises at work. The skeptical argument can be broken down more formally as follows:

Premise 1: "The main value of universal health care is the health benefits it brings"; that is, the goal of health care is health.<sup>7</sup>

Premise 2: Population health is largely determined by social determinants rather than access to health care; that is, health care is not the main cause of health.

Premise 3 [Implicit]: If the effects of universal health care on health are marginal—if population health is largely determined by social factors other than health care—then universal health care is probably not justified.<sup>8</sup>

Conclusion: Universal health care is probably not justified.

So, the real challenge is this: even granting a human right to health (which Wolff argues for elsewhere) there remains a problem of showing why universal health care is justified given that its impact on health is comparatively insignificant.<sup>9</sup> If the goal of universal health care is to promote health then the connection between *health* and *health care* is problematic. It is important to note that these are claims about the connection between health care and population health, not individual health. As Wolff points out, the effects of health care may still be highly significant in terms of health for a particular individual.<sup>10</sup>

Wolff takes on the skeptical challenge by attempting to show that regardless of the complex relationships among health, access to health care, and social determinants, universal health care is still justified because health is not the only goal of health care. In other words, Wolff is questioning the first premise of the skeptical argument, that the goal of health care is health. Health security, Wolff argues, should also be included in the goals of health care.<sup>11</sup> Health security is composed of the following elements:

- (1) Vulnerability: how probable it is (statistically) that an individual will become ill.
- (2) Control: an individual's ability to control health risks.
- (3) Resilience: an individual's ability to "bounce back" after an adverse health event.
- (4) Anxiety: an individual's fear and anxiety of becoming ill or suffering the adverse consequences of being ill.<sup>12</sup>

Wolff then argues that health care significantly improves an individual's health security. For example, the fourth element, anxiety, is directly affected by access to health care: if you

have universal health care then you don't have anxiety over how you will pay for your care. Health care gives you "ease of mind" by reducing anxiety and therefore it promotes health security.<sup>13</sup> If health security is included in the goals of health care along with health then the effects of universal health care are not marginal; when we consider both health and health security then universal health care significantly improves lives.

In addition to health care, the health system also affects an individual's health security. According to Wolff, the *health system* "comprises those elements of a society that can be influenced by government action and are likely to have significant impacts on health."<sup>14</sup> The health system is therefore a broader concept that includes health care and has more of a direct impact on health security. Where health care has little influence, the *health system* plays a significant role. For example, the second element of health security, control, is directly related to many of the social determinants of health, such as poverty and poor housing, which could be influenced by certain government institutions and policies. Control and the other elements of health security are affected by the *health system* even when health care makes little difference.<sup>15</sup>

Wolff thinks that framing the issue in terms of health security will also help us look at the problem of the social determinants of health more holistically and more realistically. As he concludes, "understanding the notion of health security enriches our understanding of the causal frameworks in which health and health care stand. We can begin to see how other types of government action impact positively and negatively on health and how the availability of health care impacts well being."<sup>16</sup>

Wolff is right that we have to consider the role social determinants play in determining health when thinking about universal health care and that the problem of universal health care needs to be looked at from a more holistic perspective if we are to deal with it realistically. However, Wolff's main line of argument in response to the skeptical argument—that is, his argument for health security just outlined—has some significant weaknesses.

Wolff points out that universal health care is usually justified by the fact that it brings us something we value: health. As previously noted, there is an additional assumption that health is not only valuable but we also have a right to it, and as a result, universal health care is justified.<sup>17</sup> This is the reason why the skeptical challenge is so difficult to overcome. Even if we have a right to health, universal health care may not be justified if it fails to bring us health. Wolff claims health security is a beneficial effect of universal health care; however, he never provides a clear justification for the moral value of health security—that is, why we have a right to health security (like we have a right to health) that could then provide support for universal health care.<sup>18</sup> In defining health security, Wolff discusses the ways in which health security may be valuable because it improves lives. But there are many things that people value that would improve their lives to which they don't necessarily have a moral claim. For example, having my student loans paid off would significantly improve my life, but this does not automatically imply that I therefore have a right to have my debts forgiven or a right to

a free college education. Even if we grant that health security is morally valuable, Wolff still needs to explain why it should then be included in the goals of health care. Wolff needs to convince us that he is not simply altering the goals of health care in order to find a justification for universal health care. If the only reason provided for including health security among the goals of health care is because it supports universal health care (and there are no independent reasons for including it) then his argument begs the question.

Wolff attempts to show why health security is a goal of health care by establishing the strong conclusion that universal health care will *significantly* improve health security. However, all Wolff shows is that some elements of health security, mainly anxiety, will be *directly* affected by access to health care. According to Wolff's own arguments, the rest of the elements of health security (vulnerability, control, and resilience) are primarily impacted by social institutions and policies other than health care, what he calls the health system. Since only some elements of health security will be affected by universal health care, he ends up unintentionally supporting the skeptical argument: Why focus on health care when it only has marginal effects on health security? As a result, Wolff fails to provide sufficient evidence for his claim that universal health care will significantly improve health security (even if we accept it as a goal of health care).

There are ways Wolff could probably respond to these weaknesses (although I won't consider them here). What these criticisms of Wolff illustrate, however, is that any response to the skeptical argument that focuses on redefining the goals of health care will likely face similar problems. It is difficult to provide independent reasons, unrelated to the type of health care that should be provided, for redefining the goals of health care to include or exclude certain things. As a result, it would be better to approach the problem from a different angle and consider a possible alternative approach to dealing with the skeptical argument that doesn't simply question the goals of health care.

Even if the effects of universal health care on health are marginal, universal health care may still be justified. The skeptical argument assumes that the only important aspect of an argument for universal health care is outcomes—it only considers the ends of health care—health—and makes no consideration of the means by which health is achieved or why access to universal health care may be valuable *independent* of outcomes. Thus, another way to take on the skeptical challenge is to question the third premise, the claim that if the effects of universal health care on health are marginal then universal health care is probably not justified.

The question of universal health care is often seen in the context of what justice demands of a society. Thus, there is a larger theoretical question about which theory of justice is correct. I will not attempt to defend what that theory of justice should be, but only to point out that a theory of justice plays a significant role in dealing with the skeptical argument's third premise ("if the effects of universal health care on health are marginal then universal health care is probably not justified"). And, if we consider what a theory of justice demands in the context of health care, we may find some reasonable (and even promising) objections to the skeptical argument.

The first approach to consider is Amartya Sen's view of justice since it includes both outcomes and non-outcome related considerations. Sen's capabilities approach focuses primarily on a person's capabilities, or real freedoms and opportunities, to achieve valuable functionings (for example, a person's capability to achieve health).<sup>19</sup> As such, Sen's capability approach is often seen as an ends-focused (or outcomes) approach. However, Sen's ends-focused approach makes room for some considerations that look beyond the achievement of those ends. In Sen's discussions about human rights he regularly points out that an adequate theory of justice must consider two aspects of freedom: the capabilities and opportunities aspects of freedom (ends focused) and the fairness of the process aspect of freedom (means focused).<sup>20</sup> According to Sen, the fairness of processes considers "the freedom of citizens to invoke and utilize procedures that are equitable."<sup>21</sup> Sen further points out that "[i]t is important to recognize that both processes and opportunities can figure powerfully in the content of human rights. A denial of 'due process' in being, say, sentenced without a proper trial can be an infringement of human rights (no matter what the outcome of the fair trial might be), and so can be the denial of opportunity of medical treatment, or the opportunity of living without the danger of being assaulted."<sup>22</sup> Here, Sen considers part of John Rawls's second principle of fair equality of opportunity since process fairness involves fair and equal opportunity by "demanding that positions and offices be open to all."<sup>23</sup>

Sen applies this concept of process fairness to health care. Health care and the distribution of health are primarily issues of process and procedural fairness and thus go beyond health achievement and the capability to achieve health—the concerns go beyond the outcomes of health care.<sup>24</sup> If we continue with this line of reasoning, then fair access to health care could justify universal access. Everyone should have the opportunity for medical treatment regardless of race, class, or gender similar to the way that everyone should have access to a fair trial.<sup>25</sup> This does not guarantee the outcome of health for all, but the opportunity to have access to health care. Sen only briefly mentions the issue of health care in his broader discussion of health equity, but this line of thinking is promising; it provides justification for universal health care independent of the outcomes while not entirely ignoring outcomes either.

Norman Daniels presents another approach that defends universal health care in terms of process fairness by extending Rawls's concept of equality of opportunity to include health and health care. Generally, Daniels argues that individuals are entitled to health care (and in more recent works, health) based on the contribution that good health makes in preserving their fair share of opportunity. Health care and health are important or special social goods. Considerations of fair process occur at the institutional level, where decisions are made about what gets included in the basic package of universal health care.<sup>26</sup>

In light of the effects of social determinants on health, however, Daniels provides a modified version of his argument for fair equality of opportunity.<sup>27</sup> Allocating resources to mitigate the effects of various social determinants on health may be necessary; however, people still have health issues (and need care) independent of the social determinants. In

other words, even if all the effects of social determinants on health were removed people would still get sick. As Daniels points out, “we cannot prevent all illness and we still owe those who are ill protection of their opportunities.”<sup>28</sup> As a result, universal coverage for health care is still justified; considering the social determinants changes what gets included in that basic package of health care but not whether or not universal health care is required. Daniels’s approach seems to tackle the “marginal benefits” element of premise three—even if these effects on health are marginal relative to the other social determinants, they are still morally important.

Of course, these arguments by Sen and Daniels are not the only arguments to consider. And, of course, there are arguments against these types of approaches to justice. But my main purpose has been to illustrate that moving the focus of the response to the skeptical argument away from the goals of health care is a more promising way of dealing with this challenge. Instead, universal access to health care might be justified in terms of fair equality opportunity or process fairness, which does not directly consider the goals of health care. Even though establishing a justification for universal health care in light of social determinants is a difficult task, it is not entirely impossible. As Wolff points out, facing the skeptical argument reveals the need to focus on the social determinants of health but not to give up on universal health care—if health is morally valuable then we have to work on reducing these social inequalities in addition to establishing universal health care.

## NOTES

1. See Daniels, “Justice, Health, and Health Care”; Wolff, “Health Risk.”
2. Black et al., *Inequalities in Health*; Wolff, “Health Risk.”
3. Gray, “Inequalities in Health.”
4. Wolff, “Health Risk,” 72. It is important to note that Wolff provides a broad definition of health based on the UK’s National Institute of Health and Clinical Excellence’s EQ-5D. Health, according to Wolff, is not just the absence of illness, disease, and disability but also mobility, self-care, usual activities, pain/discomfort, and anxiety depression. Additionally, Wolff cites the U.N. Declaration of Human Rights Article 25, Human Right to Medical Care, as a reason to take universal health care as something any civilized society would have.
5. *Ibid.*, 72.
6. *Ibid.*, 75.
7. *Ibid.*, 78.
8. *Ibid.*, 72.
9. See Wolff, *Human Right to Health*, for his arguments on a right to health.
10. Wolff, “Health Risk,” 72–75.
11. *Ibid.*, 74–75. Wolff mentions another response to the skeptical challenge that he does not develop—he argues that if we consider the impact of universal health care on individual health (rather than population health) then universal health care does have a significant impact. However, since Wolff does not focus on this argument I will not consider it here.
12. *Ibid.*, 75.
13. *Ibid.*, 77. And, since anxiety leads to stress that impacts one’s immune system, it also directly affects health.
14. *Ibid.*, 73.
15. *Ibid.*, 75.
16. *Ibid.*, 78.

17. Although Wolff does not present an explicit argument for a right to health when developing his argument for health security, he presents the skeptical argument as a challenge to those who already accept a right to health (or health care). And, as noted earlier, Wolff does develop an argument for a right to health in his recent book, *The Human Right to Health*.
18. Wolff’s defense for a right to health is not equivalent to an argument for a right to health security since his whole point in introducing the concept of health security is to present a separate (even if closely related) concept from health; it’s an *added* benefit of universal health care.
19. Sen, *Inequality Reexamined*, xi.
20. Sen, “Theory of Human Rights,” 336–37. See also Sen, “Human Rights and Capabilities,” 155–56; Sen, “Why Health Equity?,” 660.
21. Sen, “Human Rights and Capabilities,” 155–56.
22. *Ibid.*, 153.
23. *Ibid.*, 156.
24. Sen, “Why Health Equity?,” 660.
25. Sen, “Human Rights and Capabilities,” 153.
26. Daniels, *Just Health Care*; Daniels, “Justice, Health, and Health Care.”
27. See Daniels, “Justice, Health, and Health Care.”
28. *Ibid.*, 29.

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## A Narrow Fellow in the Glass

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A narrow fellow in the glass  
Is what I yearn to see—  
But much I must forgo, alas  
To make a slimmer me—

No cookies, brownies, cake, or pie—  
I may become unstrung.  
The pleasure healthful foods supply  
Is zero at the tongue.

## Can Cost-Effectiveness Analysis Accommodate the Equal Value of Life?

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For decades, cost-effectiveness analysis in health care (CEA) has been criticized for unfair discrimination against the disabled and chronically ill.<sup>1</sup> This allegation about CEA is arguably, in the United States at least, one of the driving forces behind political rejection of using CEA to prioritize health services. In conventional CEA, life extension is measured in life-years, and for good reasons within CEA's conceptual structure, those years are discounted for diminished quality of life. Thus, additional life-years for those in disability or chronic illness are discerned to have less value than for persons in full health.

In constructive response, a number of economists and philosophers have acknowledged that the claim of equal value of life (EVL) between the healthy and the disabled or chronically ill must in some important sense be sustained. They have then defended CEA, however, by distinguishing the different roles in CEA that can be played by individual utility (IU) and social value (SV).<sup>2</sup> The result has been to carve out another kind of CEA, cost-value analysis (CVA), separable from the conventional CEA that amounts to cost-utility analysis.<sup>3</sup> Life-years can readily be of equal value in CVA, where the EVL claim is about social value, though they do not have equal individual utility value. Modified in this way, CEA can allegedly escape the charge of denying EVL.

In this paper I explain such a defense of CEA but then argue that it fails. It fails because the claim of EVL is compelling as a claim not only about social value, but about individual utility. As a result, I argue, CEA continues to face the same challenge to its conceptual structure that EVL posed for it initially.

I will first briefly describe the methodological context for this debate and the precise nature of the threat to CEA from EVL, including the conundrum of the "QALY trap." After articulating why distinguishing IU from SV may provide an escape from this trap, I argue that the escape is an illusion since EVL is a persuasive claim about IU as well as SV.

### THE METHODOLOGICAL CONTEXT

The aim of CEA is to discern, through comparison of the value of health benefits gained from treating (or preventing) *different* sorts of disabling and health diminishing conditions, what investments produce the largest health benefits. To achieve this aim it will not do just to compare various treatments and preventions for a given disease or condition, nor will it do just to compare one sort of health benefit (like life extension) for different conditions. For full CEA, what is needed is a common unit of health benefit in terms of which different sorts of health gain can be compared. Such a unit must bridge at least the two most fundamental sorts of health benefit, life extension and improvements in health-related quality of life (QOL).<sup>4</sup> Without such a common unit, one could not compare, for example, kidney dialysis and its lifesaving benefit with hip replacement and its QOL improvement. The most commonly used unit of benefit that

health economists have constructed to do this is the quality-adjusted life year (QALY).<sup>5</sup>

The most plausible approach to constructing the QALY uses trade-offs people are willing to make between life itself and QOL. Such an approach makes good sense: How else but by discerning willing trade-offs between life itself and QOL improvement could a *common* unit for their value be constructed? One such trade-off method is time trade-off (TTO): How much shorter a life in full health does one think preferable to living longer with disability or chronic illness? Suppose the response of people with paraplegia, on average, is a willingness to trade away 10 percent of remaining lifetime to regain full limb function. They have then rated their QOL as 0.9 out of a possible 1.0.<sup>6</sup> Saving such a person for ten years of life would achieve a 9.0 QALY gain. Restoring her to full function for ten years would achieve a 1.0 QALY gain (a 0.1 gain for each of ten years).<sup>7</sup>

### EQUAL VALUE OF LIFE AND THE "QALY TRAP"

The fact that in such conventional CEA, the life-years of the disabled and chronically ill have lower value than the life-years of those in full health offends widespread convictions that each person's life has equal intrinsic value. A case can be made, though, that CEA and the non-equal values of life implied by QALYs are not only plausible but fair. Within CEA, saving a person with paraplegia produces less health benefit than saving someone for the same number of years of full health, and this does indeed disadvantage people with paraplegia in competing for lifesaving resources. But suppose that in the procedures used to elicit QOL values, TTO questions are put not to members of the general public asked to imagine themselves having no use of their legs, but to people actually living with paraplegia. Then the assessment of life with paraplegia as only 90 percent as valuable as life without disability is a judgment by the very sort of person who ends up being disadvantaged in competing for lifesaving resources. Why would people with such conditions disadvantage themselves in this way by supplying a TTO response that implies a less than 1.0 QOL?<sup>8</sup>

An answer lies in noticing the "QALY bargain"<sup>9</sup> that is an inherent part of QOL assessment. Relative to a higher QOL response, for example, expressions which generate a 0.9 rating for paraplegia expose people to greater risk in competing for lifesaving resources, but they give them an advantage in competing for quality improving care. That's the "bargain" people with disability and chronic illness are involved in when their society uses QALYs to help prioritize health services. The value of their own lifesaving diminishes, but the value attributed to care that improves their QOL back toward full health increases. It is arguably a plausible bargain, so one could claim that CEA does not disadvantage the disabled and chronically ill after all. And therefore it does not discriminate against them despite unequal values of life.

Though plausible, however, this argument for the fairness of CEA and conventional QALYs still contradicts deep rooted convictions for EVL. It does not change the fact that for persons in all but the most difficult and despairing conditions of disability or compromised health, *life itself*—the very business of being alive *at all*—has intrinsic value equal to what life has for those in full health.<sup>10</sup> Defenders of CEA may dismiss such claims as not facing up to the realities of the toll

that illness and disability take on human well-being. Support for EVL, however, can be found right within the very trade-off expressions that are used in CEA to generate QOL ratings less than 1.0.

If we look carefully at what people are really saying about the relative value of different lives when they express willingness to trade time in life for cure, we see that the disabled and chronically ill have not expressed any lower *comparative* value of life. To be sure, the person with paraplegia has said that saving her life for an additional ten years has the same value to her as nine years of additional life would have if her paraplegia were alleviated. But in saying this, she has *not* said that her life itself,<sup>11</sup> as it currently is, has any less value for her than life itself has for *another* different, fully healthy person. Moreover, not only does *she* contend that life itself for her is as valuable as the other person's very life is for them, but all the rest of us, too, can quickly come to see her point and agree. It does not take much reflection on our part to see the disabled person's point: for her, life, as compared to the nothingness of death, has as much value as it does for any of us who are not disabled. Genuine willingness to trade some of one's own longevity to gain full health-related QOL simply does not imply that the lives of other, fully healthy people have greater value.<sup>12</sup>

But this poses a huge problem for CEA, for EVL seems impossible to sustain within the conventional QALY framework. If the value of these different lifesavings is equal, then by the essential trade-off framework for a unitary measure of health benefit, the value of alleviating chronic illness or disability must drop to zero. Within any framework in which the value of life extension and of quality enhancement *come under a common unit of value*, one must choose: either (a) stick with EVL and relinquish the value of cure, or (b) relinquish EVL and retain value for cure. Disabled or chronically ill persons will not relinquish either. They will insist on both EVL and significant value for QOL improvement. And if we were in their shoes, would we not insist on the same? And even staying in our own shoes while understanding their point, won't we, too, insist on both EVL and significant value for QOL improvement? It seems, then, that we all buy in to the EVL claim and believe that restorative cures have significant value. But this is the "QALY trap":<sup>13</sup> within the QALY framework, one cannot accommodate equal value for lifesaving while retaining value for restoration to full health from disability or chronic illness. One cannot, if one is going to have a common unit of health benefit, which CEA needs.

### THE UTILITY/SOCIAL VALUE DISTINCTION

At this point the proposed solution that relies on carefully distinguishing *individual utility* (IU) from *social value* (SV) surfaces.<sup>14</sup>

Individual utilities convey information about the welfare of an individual. They focus on the well-being of the individual whose utility they are, not any relational value between persons or well-being of a community of persons. By contrast, social values are preferences or evaluative claims about a relationship between or aggregate of persons.<sup>15</sup> The distinction is not that IU judgments are made by individuals and SV judgments not; SV judgments, too, can be made by individuals. The difference resides in what they are judgments about.

In the conventional QALY calculation process, rating QOL constitutes a judgment of individual utility. Time trade-off preferences, for example, are about the welfare of the individual expressing the preference. When the person with paraplegia says that her preferential equilibrium is that nine years of life with full limb function restored are equal to ten years of life with paraplegia, she is making a judgment about her own individual welfare.

In the previous examination (six paragraphs previous) of what, exactly, such a TTO respondent is saying about the value of life lies a hint of another sort of value. In her TTO responses the person with paraplegia did not say that her life itself had any less value for her than the life itself of *another person*, without paraplegia, had for that person. She would still contend that life itself is for her as valuable as non-disabled persons' lives are for them. This claim, however, the approach that employs the IU/SV distinction explains, is not about individual utility. It is an expression of social value: *when carefully compared with each other*, the different lifesavings have equal value.

In the revised version of CEA generated by those who emphasize the IU/SV distinction, social value elements are explicitly and formally accounted for by a method of preference elicitation, Person Trade-Off (PTO), that is very different than TTO: How many persons' lives would Program A for people with a certain disability or chronic illness have to save to make it equal in value to Program B that saves the lives of one hundred people for full health? Reflecting on where society should stand on the relative value of different persons' lives, people tend to say that to be equally valuable, Program A needs to save very few, if any, more lives than B. In responding thus, people are expressing a social value, not making an individual utility judgment. Though non-equal values of life emerge from methods like TTO, equal values for lifesaving tend to emerge from PTO questions addressed to the same respondents.<sup>16</sup> This is not inconsistent; the questions simply measure different sorts of value.

And this, it is claimed, gets CEA out of the QALY Trap. In conventional CEA the implicit assumption is that the *sum* of the value of what is done in (a) saving the life of a less than 1.0 QOL person and (b) raising another person from that QOL to full health, must equal (c) the value of saving the life of a person with otherwise full health. Call this the A+B=C assumption. If the IU/SV distinction is employed, however, this assumption needs qualifying. A+B=C holds for IUs, but not for a mixture of IUs and SVs. EVL is a claim of social value. Because they are apples and oranges, so to speak, the equal 1.0 social value for different persons' life-years and the 0.1 individual utility present in each year of restorative cure do not have to total 1.0. To be sure, precisely how to incorporate SVs generated by PTO into a framework of CEA that also uses QOL ratings generated by TTO is then a further challenge.<sup>17</sup> Here it is sufficient to note that making the IU/SV distinction allows CEA to qualify its A+B=C assumption and thereby not be trapped when EVL is acknowledged.

### WHY THIS STRATEGY FAILS

Unfortunately for CEA, this strategy to preserve coherence fails. The equal value of life is broader and more stubborn than the strategy allows. Life can be convincingly claimed to

have equal value not only as a matter of social value, but as a matter of individual utility, too.

When a disabled/chronically ill person says that her life itself (compared to her death) has no less value for her than the life itself of another person without paraplegia has for that person, both of the values of life she claims are equal are individual utility—the value of life *to her*, and the value of the other person’s life *to that person*. One of the reasons reflective people without disability or chronic illness readily come to agree with disabled/chronically ill persons’ claim that the value of their respective lives is equal is that they have little trouble imagining themselves in disabled/ill persons’ shoes, standing before death just as they themselves might stand before death.<sup>18</sup> It does not take much imagination for people to do this. In such reflection they are not then expressing some matter of social principle about living by EVL being ethically preferable in the larger collective. People find it easy to buy into EVL by simply imagining what the value of life itself is *for these other persons*. Understanding what the individual welfare in another person’s life means to that other person constitutes *their own reiteration of the EVL claim as a matter of individual utility*. To be sure, EVL can be a judgment of SV, but it is also compelling as a claim about IU.

But then CEA is right back in the QALY Trap. If EVL holds even at the level of IU, then how, within the QALY framework, can value be retained for curing such disabling/chronic conditions? The framework’s very way of calculating QALYs, relying as it does on willingness of people to make trades between life extension and QOL improvement, seems to say that a life-year with paraplegia, for example, does not have the same value as a life-year in full health. If a person with an impairment is willing to sacrifice some life in their less than full health to be cured of their condition—and we have to ask people to express something like such trade-offs in order to measure what relative value cures have—then how can uncured life have the same individual utility value as life in full health? Yet, in the very face of death, it seemingly does.

One query to press at this point is whether the equal life values explained in this way really are a matter of individual utility. The defender of CEA might claim that what is harbored in the immediately previous explanation of EVL as a claim about IU is a comparison between different persons, and that this renders the equality asserted a matter of social value, not individual utility.

But it does not. The initiating fact for this whole discussion is that people who give time-trade-willing responses to TTO questions still claim that their paraplegic life—their life itself—is as valuable to them as anyone else’s “better” life is to that other person. Grant, for the moment, that this is a judgment of SV because it makes a comparison with another’s life. But consider a subtle adjustment in stating the equal-value claim that keeps it clearly a matter of IU. Shift to this unquestionably *intra*-personal version of the trade-off question, couched here in the first-person: Do I claim that compared to death, saving my life with continued disability or chronic disease has the same value for me as saving my own life back to full health *would* have if I were in otherwise full health? I would, of course, prefer both to remain alive and to get back to full health-related QOL. Yet when that is not possible, and when I think about my current very life and its value for myself,

and also about life’s value to myself if I were not disabled, I can plausibly claim that each of these two savings of my life—one more real, the other more hypothetical—has equal value. Now, this slightly adjusted EVL claim is clearly about individual utility. But then transform the more hypothetical one of the two lifesavings involved in this adjusted claim into the life of another person, saved for her real life in full health, and we have the original comparison that led us to think that EVL is a claim about IU. If the adjusted EVL claim is about individual utility, the other one is, too.

As a different last line of defense, CEA defenders might simply claim that EVL is false: QOL differentiation just does indicate differences in the individual utility value of life.<sup>19</sup> Emerging as it has within a longstanding utilitarian tradition that emphasizes the moral relevance of quality of life, CEA’s defenders can insist that the individual utility value of life just is discerned this way.

But why still insist on this in the face of the detailed explanations given previously that the person who is willing to rate her QOL by TTO as less than 1.0 is not for one minute admitting that in the face of death, her life has less value individually to her than the life of a fully healthy person has to that person? Equal value of life does not at all wither in the face of a conception of the value of life that focuses so exclusively on QOL.

#### WHERE NOW FOR CEA?

Thus, EVL still threatens the coherence of the very structure of CEA. I will end, though, in a somewhat more constructive vein, noting two possible ways in which CEA might develop to meet this challenge. I say “might,” for they have either not yet been well developed, or not yet developed at all.

(1) Accept EVL for lifesaving but still retain value for cure: count virtually all life-years saved as 1.0, yet continue to count the value of quality-improvement measures as in conventional CEA, using TTO, etc., to discern the proportion of a fully healthy life-year that a given restoration constitutes.<sup>20</sup> Such a pragmatic, “live with it [EVL]” response is undoubtedly not conceptually satisfying, and it encounters particular objections in the rare cases where lifesaving can follow quickly after QOL improvement.

(2) Within the value of life, distinguish two sorts of value: the value of lifesaving, where EVL reigns, and the value of life more generally, where it does not. People do, after all, speak of the value of their lives relative to living in full health, not just of the value of life in the absolute, life-itself sense provoked by the comparison with death. The idea that there are two fundamentally different sorts of the value of life is at this point completely undeveloped. It is also not clear whether or how CEA could incorporate both sorts of value into a framework that would appear to require a common, integrated unit of value for all health benefit.

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NOTES

1. An early example is John Harris, "QALYifying the Value of Life," *Journal of Medical Ethics* 13 (1987): 117–23. His title refers to a unit of value measurement used in CEA, the Quality Adjusted Life Year (QALY).
2. Also sometimes referred to as "societal value." Definition of SV to distinguish it from IU is provided later in this paper. Among the first health economists to use the distinction were Erik Nord, Jeff Richardson, and Kelly Macarounas-Kirchmann, "Social Evaluation of Health Care vs. Personal Evaluation of Health States," *International Journal of Technology Assessment in Health Care* 9 (1993): 463–78; Paul Dolan, "The Measurement of Individual Utility and Social Welfare," *Journal of Health Economics* 17 (1998): 39–52; and Erik Nord, *Cost-Value Analysis in Health Care: Making Sense of QALYs* (Cambridge University Press, 1999).
3. The "value" element in "CVA" is understood to be broader than individual utility. It incorporates social value, though the two may not be equivalent. See Erik Nord, "The Trade-off Between Severity of Illness and Treatment Effect in Cost-Value Analysis of Health Care," *Health Policy* 24 (1993): 227–38, for the first clear articulation of CVA in health economics, and a few years later his much more comprehensive articulation (1999), *supra* note 2.
4. I will refer to such health-related quality of life as just "QOL" and not use the more accurate and explicit "HRQOL."
5. For a superb summary of the QALY, see Milton C. Weinstein, George Torrance, and Alistair McGuire, "QALYs: The Basics," *Value in Health* 12, Supplement 1 (2009): S5-S9.
6. The 0.9 QOL rating used here for paraplegia is hypothetical, but not unrealistic. Many people may think it unrealistically high, believing that were they to become paraplegic, they would be willing to sacrifice considerably more than 10 percent of their remaining time in life to be cured. Something in the range of 0.9, however, is not at all an unrealistically high expression to expect from persons actually with paraplegia. Typically they have adapted to their condition and realized that it is likely the only life they have. Subsequent discussion will reveal that 0.9 for paraplegia may even be low.  
  
Obviously one of the issues here is whose expressed ratings should be used to discern QOL in a given condition. If what we claim to be dealing with is the real subjective individual utility value of life in that condition, it is arguably those who actually have the condition who should be asked. Admittedly the matter is complex, but strong considerations lean toward consulting persons with the condition. See Menzel, "Utilities for Health States: Whom to Ask," *Encyclopedia of Health Economics*, ed. Anthony Culyer (online, Elsevier, Inc., forthcoming January 2014), doi: 10.1016/B978-0-12-375678-7.00508-3.
7. In full CEA, of course, costs get included, too. An example would be to compare hemodialysis with hip replacement, as economist Alan Williams famously did in the course of a larger study, "Economics of Coronary Artery Bypass Grafting," *British Medical Journal* 291 (August 1985): 326–29. If dialysis patients express something like a 0.8 QOL, the \$40,000-a-year treatment which extends their lives ten years then gains each of them 8.0 QALYs. That cost-benefit ratio of \$50,000 per QALY is worse than the \$15,000 per QALY ratio for hip replacements if hip replacements improve a likely fifteen years of remaining life from 0.9 QOL to 0.99 (a 1.35 QALY gain for \$20,000). Efficient policy would call for expanding hip replacements before expanding dialysis, or even reducing the current volume of dialysis to reroute resources to hip replacements.
8. Some are not willing to sacrifice any life expectancy to relieve their condition. See F. J. Fowler, P. D. Cleary, M. P. Massagli, et al., "The Role of Reluctance to Give Up in the Measurement of the Value of Health States," *Medical Decision Making* 15 (1995): 195–200. The challenge this constitutes for CEA is noted by Erik Nord, Norman Daniels, and Mark Kamlet, "QALYs: Some Challenges," *Value in Health* 12, supplement 1 (2009): S10-S15, at pp. S10-S11.
9. The term is used by Paul Menzel in "Measuring Quality of Life," part of *Strong Medicine: The Ethical Rationing of Health Care* (Oxford University Press, 1990), 86.
10. The challenge for CEA posed by EVL is noted by Erik Nord, Norman Daniels, and Mark Kamlet (2009), *supra* note 8, at pp. S10-S11.
11. That is, her life compared to death.
12. The EVL judgments explained here are not suspiciously tactical, as might be suggested by the previously mentioned "QALY bargain" point. The person who expresses a willingness to trade time in life to

gain a cure can still insist that this does not imply that life itself is any less valuable to her than life itself is to another person in full health.

13. A phrase first used (to my knowledge) by Peter Ubel, Erik Nord, Marthe Gold, Paul Menzel, Jose-Luis Pinto-Prades, and Jeff Richardson, "Improving Value Measurement in Cost-Effectiveness Analysis," *Medical Care* 38, no. 9 (2000): 892–901.
14. The distinction was well known in economics long before it was used in health economics in the 1990s. Nord's 1999 book-length defense of cost-value analysis used it (*supra* note 2; see p. 120 in particular, where he used it to defend EVL). Among others who have used the IU/SV distinction in defending CEA are Dolan (1998), *supra* note 2; Paul Menzel, "How Should What Economists Call 'Social Values' Be Measured?" *The Journal of Ethics* 3, no. 3 (1999): 249–73; Menzel, Marthe Gold, Erik Nord, Jose-Luis Pinto-Prades, Jeff Richardson, and Peter Ubel, "Toward a Broader View of Values in Cost-Effectiveness Analysis of Health," *Hastings Center Report* 29, no. 3 (1999): 7–15; and Ubel et al. (2000), *supra* note 13.
15. Some theories of social value centrally feature individual utilities—most prominently, utilitarianism, where maximum aggregate individual utility constitutes the highest social value. In and of themselves, however, no IU or set of IUs is a social value.
16. See Erik Nord, "Health Status Index Models for Use in Resource Allocation Decisions: A Critical Review in the Light of Observed Preferences for Social Choice," *International Journal of Technology Assessment in Health Care* 12, no. 1 (1996): 31–44. See also the valuations reported in Christopher Murray and Joshua Salomon, "A Multi-Method Approach to Measuring Health State Valuations," *Health Economics* 13, no. 3 (2004): 281–90.
17. For a specific proposal about how to use TTO and PTO values at different levels of analysis in CEA, see Peter Ubel, Jeff Richardson, and Paul Menzel, "Societal Value, the Person Trade-Off, and the Dilemma of Whose Values to Measure for Cost-Effectiveness Analysis," *Health Economics* 9 (2000): 127–36.
18. Death—comparison with death—is the great equalizer. It is exactly the requisite comparison for discerning the value of life itself.
19. Alistair Norcross, who commented on this paper at the March 2013 Pacific APA meeting, voiced something close to this view.
20. The recommendation to count all life years gained by the disabled and chronically ill as 1.0 (except where QOL ratings approach "not worth living"), while still retaining significant value for quality improvements, was made by Erik Nord, Jose-Luis Pinto, Jeff Richardson, Paul Menzel, and Peter Ubel, "Incorporating Societal Concerns for Fairness in Numerical Valuations of Health Programmes," *Health Economics* 8, no. 1 (1999): 25–39, at p. 36. That proposal was criticized by Magnus Johannesson, "Should We Aggregate Relative or Absolute Changes in QALYs?" *Health Economics* 10 (2001): 573–77, and in turn defended by Erik Nord, Paul Menzel, and Jeff Richardson, "The Value of Life: Individual Preferences and Social Choice. A Comment to Magnus Johannesson," *Health Economics* 12 (2003): 873–77.

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## TRIBUTE TO BERNARD GERT

### *An Introduction to Bernard Gert's Thoughts on Human Nature*

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At the time of my father's death, he was working on a book on human nature. That is, this book had become the main focus of his energies. He had, in fact, been working on it in one way or another for over forty years. For him, a book on human nature is not a book that discusses one topic among others, but rather a book that covers almost everything philosophical there is to say about human beings qua human beings. His manuscript discusses psychological states of every kind: personal identity, free will, the nature of knowledge, and—of course—rationality and morality.

Bernie's thoughts about these topics were strongly influenced by four thinkers—Ludwig Wittgenstein, Thomas Hobbes, Sigmund Freud, and Charles Darwin—and he had a great deal to say about each. There's an important sense in which Wittgenstein's influence on Bernie's thought is the most foundational of these four. He provides a way of understanding much of the language in which Bernie discusses, and thinks we must discuss, these topics. So for the purpose of this essay I will confine myself to discussing some of Wittgenstein's influence.

Before I go into this aspect of Bernie's manuscript, though, I'll begin with a few of his thoughts on human nature that are more likely to be familiar to this audience. For instance, the harms on his list (death, pain, disability, loss of pleasure, and loss of freedom), as well as his list of goods (consciousness, ability, freedom, and pleasure) are central to any proper understanding of human nature. Among other things, he says that it's part of human nature to want to avoid the harms, for ourselves and for those we care about, and that human nature discourages avoiding these goods.

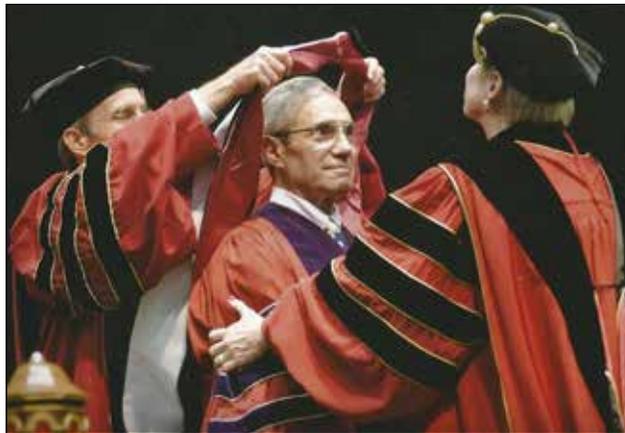
What is the significance of Bernie's claim that it's part of human nature to want to avoid harms? One thing it means is that human beings the world over share the relevant vulnerabilities. It makes sense to try to avoid pain, disability, etc., only if we're vulnerable to them. It also means that we human beings (perhaps not literally all of us, but people everywhere and just about all of us) choose what to do with an eye towards avoiding serious risk of death, substantial pain, disability, and so on. Because of this we can make pretty good predictions about what someone will do if we know his estimation of the risks he'd be taking. And that estimation isn't just based on a correspondence. When I say that what you've asked me to do is likely to get me killed, disabled, or hurt, that counts an explanation of why I'm not going to do it. Other influences on behavior may be more ideosyncratic, but Bernie's harms influence everybody.

So, for instance, knowing that Aunt Betty is making her famous spinach lasagna might motivate Chuck to *accept* her dinner invitation, and Sonya to *decline*. There's nothing odd about that. But it would be weird, to say the least, if the fact that anyone who gets in a car with Aunt Betty is risking death were what motivated Chuck to accept her offer of a ride. If he really needs a ride, he might decide her offer is the best of a set of bad options—the risk of harm if he declines could be even worse—but the risk of death itself cannot motivate him, or any anyone else. Or, better, the likelihood that it's the risk of death that motivates him is vanishingly small, and if it does people everywhere would say he had a serious psychological problem. This illustrates two tightly connected aspects of human nature: it's human nature to prefer to avoid situations that substantially increase your risk of the harms

on Bernie's list, and it's human nature to think of anyone who doesn't do that as having a serious psychological problem. Perhaps apart from college sophomores, human beings don't see avoiding death, pain, disability, and loss of freedom or pleasure merely as a matter of taste.

These aspects of human nature ground Bernie's moral theory, too. If it's human nature for me to see avoiding harm to *me* as a reason when I'm thinking about what I'm going to do, it's human nature to think of it as a reason for Chuck, too. I mean, he has a good reason to avoid harming *me* (and others), not just to avoid harming himself. Whether or not he's as motivated as I am to refrain from actions that might harm me, it's still a reason for him to refrain. And protecting me from harms is a reason for him to do something, just like it's a reason for me. So the fact that encouraging Aunt Betty to get behind the wheel puts all of us at risk is yet another reason for him to decline Betty's offer.

For the rest of my time today I want to talk about an aspect of Bernie's thoughts on human nature that's probably less familiar than what he says about morality and rationality. It will be somewhat more slow going, and depends quite a bit on his interpretation of aspects of Wittgenstein's later thoughts about emotion terms. So that's where I'll begin.



Bernie Gert received an honorary degree from his alma mater, the University of Cincinnati, in 2006.

Much of what Wittgenstein writes about emotion terms addresses a debate between those philosophers who hold that an individual's knowledge of psychological states begins with what he knows about his own, and behaviorists of various stripes who insist that whatever we talk about when we talk about psychological states, it must be something public—because we obviously manage to talk about it *together*.

The first of these sorts of philosophers hold that, really, what we know about fear or pleasure, the experience of hearing a harp or of seeing purple, we know by introspection. Maybe we manage to apply what we know to other persons, perhaps by inference to the best explanation, or something like that. Or maybe we don't. But either way, our real knowledge of psychological states comes from introspecting our own, and thus—these philosophers say—what we mean by the words that refer to those states is entirely determined by what we find when we introspect. So there isn't any mystery about how the words that refer to these states become meaningful. The only mystery is how we manage to coordinate what we mean. So they say.

The second type of philosopher, behaviorists, are more impressed by the fact that we communicate using these terms and learn them from one another. Behaviorists insist, therefore, that whatever these terms refer to must be accessible to multiple persons. Adults teach a child the word "angry" when they see a child exhibiting angry behavior—or when the child and adult together witness someone else

behaving that way. Adults point at pictures of kids smiling to teach “happy,” and at pictures of kids crying to teach “sad.” So, say such philosophers, what these words really refer to are the public behaviors we’re pointing out when we teach and learn them.

Unfortunately, neither option is overly attractive. As likely as not what leads a philosopher to accept one is problems with the other. But Wittgenstein points out that we needn’t choose either. These views look like the only alternatives because of a mistaken presupposition they both share: they both accept, without defense, that the meaning of a psychological term has to be determined by whatever a person is attending to when she learns the term, or what we’re pointing at when we test her knowledge of it. The first sort of philosopher begins with the realization that a psychological term refers to a private state and concludes that children learn the word by attending to that state. Alternatively, the behaviorist notes that we can teach these terms only if teacher and child attend to the same thing—some sort of public behavior—and concludes that psychological terms refer to public behaviors, together with public circumstances.

But what if the thing we’re directing our attention to when we learn a psychological term doesn’t have to be its referent? Wittgenstein argues that this is precisely what differentiates psychological terms from terms referring to physical objects. In the beginning we have to learn words for physical objects and their properties in their presence. In the beginning, if you want to test whether a child knows which word refers to a particular physical object you show her the object and ask its name. She’ll graduate to using pictures and other representations amazingly quickly, but she can’t do all her language learning that way. Also, what a physical object word means is largely determined by the nature of its referents—even when what they’re like isn’t obvious to casual inspection. Whales aren’t fish, despite their superficial resemblance to fish. And it turns out that we were originally making a mistake with our word “jade”; what we thought was one kind of stone was really two. There are certain rules for using physical object words for stones and animals and such, and according to those rules underlying structure matters—even when we’re not aware of it.

Psychological terms are different. Underlying structure isn’t what matters, and it isn’t possible to make the same kind of mistakes we made with “jade” and “whale.” Thus, as Wittgenstein points out, the way these terms are taught is importantly different, too. Behaviorists have to be right when they say we use publicly observable behavior and circumstances to teach children how to use psychological terms. What else can we possibly do? We talk with children about the pains they’re feeling *when they’re exhibiting pain behavior*, and *when we see they’ve hurt themselves* (circumstances). And we talk with them about someone else’s pains when both of us see the other person crying, or wincing (behavior), or see her injury (circumstances). Adults teach kids to talk about being happy or excited when the kids are acting happy or excited, and when they see someone else acting happy or excited. And so on.

But Wittgenstein’s genius was to point out that *it simply does not follow* from the fact that we have to learn “pain,” “happy,” and “excited” in the presence of publicly observable

behaviors and circumstances that these behaviors and circumstances are what we’re referring to. He points out that learning a term is learning how to use it, and even though basic psychological terms must be taught in the presence of certain public phenomena—what he calls “criteria”—learning how to use them simply isn’t learning that their application counts as true whenever those phenomena are present.

Thus, for instance, it’s a significant difference between terms that refer to psychological states and terms that refer to physical objects that children need to learn both first- and third-person ways of using the former, while there’s nothing like that for the latter. So even though children first learn psychological terms in the presence of public behaviors and circumstances, one of the things they have to learn is that they should generally accept first-person attributions of psychological states even when those criteria are absent. If a child—like a behaviorist—refuses to accept this, then she simply hasn’t learned how to use psychological terms. That’s how they’re used. In fact, once it’s clear that a child can describe her experiences when the relevant criteria are present, she is authorized to use the same psychological terms to describe her experiences when they aren’t; we should believe her when she says she’s mad, even though she’s controlling her behavior and isn’t acting mad. If she couldn’t use the term that way, if she couldn’t use psychological terms to describe her own psychological states without first checking to see how she’s behaving, that would signal a significant problem—either an inability to be in the relevant state, or a misunderstanding of the term. But that’s not how things are with the third-person use of psychological terms. No matter how much of an expert he becomes, the child has to accept that his third-person attributions aren’t justified unless the appropriate criteria are present: the person he’s talking about must be exhibiting the relevant public behavior, or be in the right sort of public circumstances; or, of course, she might have described herself that way. He’s also got to learn that the same thing goes for everyone else’s third-person attributions of psychological states; they’re justified only in virtue of the same sort of public stuff we use to teach and test the terms, or when there’s been a relevant first-person claim.

What Wittgenstein says, then, is that the very possibility of using psychological terms depends on the behaviors and circumstances he calls criteria. Without public criteria we couldn’t teach or test the use of psychological terms, and although first-person attributions are legitimately made without attending to criteria, even experts aren’t warranted in their third-person attributions unless these criteria are present. (Whether such attributions are *true*, on the other hand, as opposed to *justified*, doesn’t depend on criteria.) All this means that there is a *conceptual*, and not merely a contingent, connection between psychological terms (or states) and their associated public criteria. But it still doesn’t mean the terms refer to these criteria. Psychological phenomena get classified together because of their association with public criteria, but those phenomena are still private. You have a good deal of authority when it comes to knowing whether the psychological state you’re in—*in any individual instance*—is of a particular psychological kind. But the word you’re using can refer to members of that kind only because of the associated public criteria.

Interestingly, if we accept something like Wittgenstein's picture of how psychological terms work—as Bernie did—it turns out that the broader psychological kind (emotion, sensation, etc.) to which a specific psychological term refers (pride, pain, for instance) depends on the role criteria (behavior and circumstances) play in how we use that term. Some psychological terms have both behavioral and circumstantial defining criteria, some have only behavioral defining criteria, and some have only circumstantial defining criteria. More specifically, terms referring to emotions (envy, pride, and jealousy, for instance) have both types of criteria, terms referring to the psychological states Bernie calls "feelings" (for instance itches, pains, and anger) have only behavioral defining criteria, and the terms that refer to perceptual sensations (a lemony taste, the visual sensation of purple, etc.) have only circumstantial defining criteria.

### EMOTIONS AND HUMAN NATURE

Finally, we have arrived at the point when we can begin looking at some of Bernie's thoughts about what he calls "principles of human nature." If Wittgenstein is correct, or if Bernie's interpretation of Wittgenstein is correct, then the only way to learn basic psychological terms is in the presence of the public criteria. In particular, as I've noted, there are two types of public defining criteria (behavior and circumstances), and that what Bernie calls "feelings" have only behavior as their defining criteria, while emotions have both behavioral and circumstantial defining criteria.

Thus, being angry, which is a feeling according to Bernie, has only behavioral defining criteria. But being jealous, which is an emotion, has both behavioral and circumstantial defining criteria. In particular, the defining behavioral criteria for being angry are the same as the defining behavior criteria for being jealous. In both cases they are things like stomping and shouting, and certain sorts of familiar facial expressions. That doesn't mean everyone who is correctly described as angry or jealous behaves like this, but anyone who is angry or jealous *feels like* stomping and shouting and so on. In fact, according to Bernie, being angry just is feeling like doing those sorts of things. And being jealous is feeling angry—feeling like shouting and stomping, etc.—in a particular type of situation, a situation in which one's exclusive love interest is threatened, or something like that. Much the same is true about the feeling of happiness and the emotion of being proud. Happiness is a feeling, so its defining criteria are behavioral; they are behaviors such as smiling, walking with a light step, and so on. And being proud is feeling happy—feeling like smiling, walking with a light step, etc.—in a particular type of situation. A person feels proud if she feels that way when she or someone she cares about or identifies with has behaved in a praiseworthy way. Again, people who are happy or proud don't always smile, but they feel like smiling.

Bernie suggests that it's plausible that some emotion words, presumably "jealousy" and "pride," among them, appear in every, or virtually every, language. If that's so, then even without Wittgenstein we might say that jealousy and pride are universal human emotions, and that's a claim about human nature. After all, how would all languages come to have these words unless people everywhere needed them for talking about these emotions. Making use of Wittgenstein, however, Bernie notes that we're in a position to say something more.

If there are words that translate as "jealousy" and "pride" in every, or virtually every, language, that tells us that people everywhere are inclined to exhibit *these* behaviors in *those* sorts of situations. This is what Bernie calls "a principle of human nature." If the word "jealous" is found in all languages, that's good reason for believing it's a principle of human nature that persons stomp, shout, hit, make certain sorts of faces, and so on, when an exclusive love interest is threatened. If the word "pride" is found in all languages, that's a good reason for thinking it's a principle of human nature that we smile, and exhibit related behaviors, when we ourselves, or those we care about, behave in praiseworthy ways. Thus, Bernie hypothesizes that we can discover that it's a principle of human nature to behave in this particular way in that sort of context by making the empirical discovery that all around the world people learn an emotion word with these defining criteria. If people everywhere use a word that could only have been learned where such-and-such behaviors (including facial expressions) are typically exhibited in this sort of context, that shows that people everywhere exhibit those behaviors in those contexts—a principle of human nature. Conversely, if we discover that a given emotion term cannot be translated into many languages, that's good evidence that the behaviors and circumstances that serve as its defining criteria are not conjoined in all societies—that behaving that way in these contexts is not a principle of human nature.

So universally used emotion words give us reason for saying it's a principle of human nature that people behave in particular ways in particular contexts. But what does it mean to say that it's a principle of human nature? Here are a few brief thoughts.

Most obviously, to say behaving this way in that context is human nature is to say that people tend to act that way in those sorts of contexts. But when we say that this is a principle of human nature we mean more than that these contexts and behaviors are correlated. Bernie notes that to say that a person is in such a situation can be accepted as an explanation for why she's having a particular emotion and, what comes to the same thing on this view, why she's behaving as she is. (What we tend to think needs explanation, it turns out, is why a person *isn't* behaving the way people typically do in that context!) Thus, a perfectly natural answer to the question, "Why is Gina smiling?" is "She's watching her daughter graduate." It's true that it may be natural to add, "And she's very proud of her." According to Bernie's view, though, that last remark doesn't add much. If I know she's smiling as her daughter graduates, and that that's why she's smiling, I will already assume she's proud. Adding "she's proud" merely makes mention of the principle of human nature that Gina, like the rest of us, smiles and exhibits other happy behavior when those we love are praiseworthy. In normal human beings events of this kind provoke behavior of that kind. Similarly, a natural answer to the question, "Why is Kevin scowling? And why are his answers to the guy he's talking with so clipped?" is "Because his girlfriend across is the bar talking with her previous boyfriend, and he's jealous." (Maybe he isn't stomping and shouting, but his behavior seems to be the result of holding himself back, of refraining from such behavior.) In the real world, citing the fact that the woman Kevin loves is paying attention to a man he considers a threat to their relationship just does serve as an explanation

for his behavior, and once we know about the context and the behavior, all else being equal, it's redundant to add, "and he's jealous." Our very use of "jealous" depends on the fact that people in Kevin's situation tend to act the way he's acting. Of course, we might wonder why such events make humans proud or jealous, why they tend to provoke these behaviors. And for answers to questions of that kind we might look to Darwin, or Freud, or to Bernie's interpretation of them. Nonetheless, we needn't go looking for further explanation of why Gina and Kevin react as they do. That's just human nature.

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## BOOK REVIEW

### *Bad Pharma: How Drug Companies Misdemean Doctors and Harm Patients*

Ben Goldacre (New York: Faber and Faber, 2013). 448 pages. ISBN 978-0865478008.

Reviewed by Deborah Barnbaum  
 KENT STATE UNIVERSITY

Ben Goldacre's *Bad Pharma* comes on the heels of many books about the sins of the pharmaceutical industry. Jerome Kassirer's *On the Take*, Marcia Angell's *The Truth About Drug Companies*, and Daniel Carlat's *White Coat Black Hat* detail the perils of the current drug development, testing, approval, and marketing processes. So some of Goldacre's extensively researched and very up-to-date book is familiar. Bioethicists, especially those well-trained in research ethics, will nod in appreciation as Goldacre discusses me-too drugs, surrogate end-points, and the perils of direct-to-consumer marketing. He is on target here. He also does an excellent job proposing small practical ways of changing the system. It is where he proposes a novel, large-scale solution to the mess we've gotten ourselves into that he stumbles.

And a fine mess it is. Goldacre convincingly argues that most of what we think we know about prescription drugs is mistaken. First off, the sponsors of the clinical trials (most often pharmaceutical companies) don't publish the findings of all the trials that are run. A significant portion of study results are buried. Of course, the results that do see the light of day are those that report positive results. Thus, the data available to the medical community, and the public, is skewed in favor of the pharmaceuticals. Goldacre returns to this problem again and again, viewing the missing data as the greatest scandal in modern medicine. He rightly points out that if a single scientist engaged in this behavior—throwing out the data that doesn't prove his hypothesis, only reporting the data that he wants to report—we would call these practices research misconduct and throw the book at him. However, despite the enormous scale on which this is practiced by pharmaceutical companies, we strangely look the other way.

Second, the studies themselves are based on biased methodologies. Drugs are too often tested against placebos in these industry-controlled studies, ultimately gaining approval on the strength of the claim that they are better

than nothing. Drugs are found to meet surrogate end-points (cholesterol numbers go down, tumors shrink), without meeting a goal that patients actually care about (fewer heart attacks, longer life). Primary end points in trials are switched, half-way through trials, when it becomes clear that the drug will fall short in one area but might appear to succeed after the goalposts are moved. Studies are "stopped early," not because they have genuinely fallen out of clinical equipoise, but because the results look better when they cover a shorter period of time. Studies are "stopped late," reporting data from too long a period of time, thereby making drugs look better than they are by watering down initially bad outcomes. Subjects in many studies are not representative of the populations who will most likely take the drugs once they are approved; study subjects are often healthier, without multiple medical problems. Data is often reported only from those subjects who stay in the trial for the duration—some may drop out of the studies due to an inability to tolerate side-effects, but we don't hear enough about those patients, or the side-effects that drove them out of the study. The approval process is compromised, with underpaid regulators looking to curry the favor of the pharmaceutical companies, so that regulators can one day cash in by working for those whom they used to regulate. Data is withheld from approval hearings by industry. Conflicts of interest abound.

Finally, once approval is granted, drugs are marketed both to physicians and to patients in unscrupulous ways. Goldacre spares neither the hard sell of direct-to-consumer marketing and celebrity endorsements, nor the soft sell of swag at medical conferences or charming drug reps wandering the halls of the hospital. Goldacre's examples are numerous and he recounts many stories with the pacing of a thriller.

Goldacre doesn't merely tell us how bad things are, though. His mission is to make things better. Thus, he presents lists in each chapter as to what one can do to improve the situation. Some activities are appropriate for patients and/or research subjects (ask whether as a participant in a clinical trial you will be given a copy of the results, ask whether your physician has taken industry money), some for healthcare practitioners (refuse to take money from pharmaceutical companies, refuse to have your name on ghost-written articles that are effectively thinly-veiled promotions written by drug companies), medical students (continue to fight the good fight against pharmaceutical companies' handouts of free food, travel, etc.), or journal editors (declare industry income to your journal, refuse to publish studies that switched their primary endpoints). These are small but eminently practical pieces of advice that one hopes will make a difference over time.

However, when Goldacre attempts to promote a large change, in a chapter entitled "Bigger, Simpler Trials" at the center of his book, he runs into trouble. Recall that given the myriad problems he details above, his conclusion is that most of what we think we know about prescription drugs is mistaken. However, there is a solution to this problem. If there were large, widespread clinical trials that were well regulated, starting now, then in short order we would have the information we need to make responsible choices about medicine. What we need is methodologically sound, randomized trials. And since the current state of affairs is prescription in the absence of knowledge, what we should

do is *enroll every patient into a randomized trial, as part of routine care*. Patients are practically being randomized into trials anyway, since our knowledge is so imperfect. If patients were routinely randomized into trials as part of clinical care, then we could quickly learn what was working and what wasn't. We'd determine which adverse events result from the drugs, and aren't merely swept under the rug. Goldacre's book was first published in the United Kingdom, so his solution capitalizes on large databases in the United Kingdom and throughout Europe found in universal healthcare systems. The data is already being tracked. We just need to randomize people so that the data can be examined and we can determine once and for all what works.

Let's not get hung up, Goldacre insists, on onerously long informed consent documents for these routine trials. Patients don't read, and barely understand, twenty-page consent documents. Approval from an ethics committee isn't necessary either. Routine care as practiced today is no more than randomization by another name, given that we are all operating in the dark when it comes to prescription medicines. So the ethics committees, who weren't really doing their jobs anyway, can be dispensed with. Consent documents can be pared down dramatically.

Here, Goldacre seems to have made two significant mistakes. First, he commits a black-and-white fallacy: Either we have perfect knowledge—or even good enough knowledge—of what is going on with these pharmaceuticals, or we have no knowledge at all. Only if we had *no knowledge* would it make sense for every patient interaction to be routinely transformed into clinical trial-like randomization with minimal informed consent. If we had some knowledge—imperfect as it is—then patients or the physicians might have a well-grounded preference among two competing therapies, and a failure to allow patients to act in keeping with those preferences would be a violation of both autonomy and beneficence. For example, imagine a woman who after treatment for breast cancer is considering taking either tamoxifen or raloxifene to prevent reoccurrence. Let's grant that we have imperfect knowledge about these drugs. We don't know enough about the long-term side effects, we don't know enough about which will best prevent a reoccurrence of cancer. But we do know some things: tamoxifen is connected with a higher risk of uterine cancer than raloxifene. Raloxifene is connected with a higher risk of certain types of blood clots—deep vein thrombosis, lung clots, retinal vein occlusions—than tamoxifen. Maybe the patient had previously had a hysterectomy, and thus uterine cancer isn't a concern, but the blood clots are. Isn't this a reason for the patient and her physician to choose tamoxifen over raloxifene? One would think so, but for Goldacre such considerations don't amount to much. Since we don't have

perfect, or good enough knowledge, then it must be the case that we have no knowledge. Only having no knowledge at all would justify routine randomization.

Now imagine that the patient was randomized into the raloxifene arm, as part of Goldacre's routine randomization. After a few months the patient starts getting pain and spasms in her legs. This could be a precursor to blood clots. The patient calls her physician and reports the side-effects. At this point, one course of action could be to switch the patient from raloxifene to tamoxifen, moving her from the drug that is more likely to cause the side effect she is actually experiencing to a drug that doesn't have that side effect. But the problem is, the patient has been randomized into an arm of a study, and recall that one of Goldacre's objections to the current state of clinical trials is that patients drop out due to side-effects and we never learn enough about adverse events. So to solve this problem, we shouldn't let the patient switch drugs! We're dealing with *zero knowledge*, after all, and thus we need to keep the patient on raloxifene, even though she would prefer to take something else. Goldacre would force the patient to stay in the raloxifene arm, despite the fact that this not only violates autonomy but is a failure to practice nonmaleficence, given what little knowledge we have.

Goldacre would probably respond that I am being unfair to him—of course he would allow the patient to switch from raloxifene to tamoxifen. But to do so raises Goldacre's second problem: His "solution" of randomizing all patient care, and then breaking randomization once adverse events occur, ends up *replicating some of the very problems that he is trying to avoid*. One of the methodological shortcomings of current clinical trials is that patients are dropping out due to side-effects, making the drugs look better than they are. Had the patient not been allowed to drop out, we could learn whether those horrible adverse events—lung clots, retinal vein occlusions—happen with a given frequency or not. Either Goldacre bites the bullet and admits that his solution doesn't do what he claims it will, or he is forced to engage in some pretty unethical practices so as to gain the scientific knowledge we sorely need.

Goldacre proves himself to be an excellent writer, a thorough researcher, and an acute observer of medicine as practiced in the twenty-first century. He isn't an ethicist or a philosopher, and when he tries to take on those roles, that overreach results in the weakest chapter of the book. Had he stuck to what he knows best, he would have written a safer book. But safer isn't always better. He tried something pretty novel and it failed. Most people don't bother trying and are content with the small-scale changes he peppers throughout the book. It is well worth your time to read the less safe book and examine his argument for yourself.