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Last Chance Therapies: Can a Just and Caring Society Do Health Care Rationing When Life Itself Is at Stake?

Leonard M. Fleck, Ph.D.*

What does it mean to be a just and caring society (or a just and caring hospital or managed care plan) when we have only limited resources to meet virtually unlimited health care needs, and the need before us now is a person faced with death in the near future unless she or he has access to a very expensive medical intervention that offers only a relatively small chance of a relatively small gain in life expectancy? Such medical interventions are what Norman Daniels and James Sabin refer to as “last chance therapies” because patients who need them have no other medical options to forestall death in the foreseeable future.¹ It is difficult to imagine a more psychologically and morally burdensome decision than whether to offer a last chance therapy.

This Article attempts to determine how such last chance therapy rationing decisions should be made within the broad structure of the U.S. health care system—a very fragmented, public-private system for financing health care that is dominated by a variety of managed care options intended to control health care costs more effectively than the indemnity insurance system.² The focus of this Article can be interpreted in two ways: First, what moral norms should be used in making these last chance rationing decisions? Given all of the health care needs that exist in our society, and given limited resources to meet those needs (limits ultimately determined by taxpayers or members of a managed care plan), what priority should access to various last chance therapies have relative to all other health needs that make presumptively just claims on health resources? Second, what should be the political-philosophical framework of managed care plans responsible for making these last chance rationing decisions? That is, would we be more likely to get morally defensible last chance rationing decisions if the political philosophy that shaped the functioning of our managed care plan were libertarian, communitarian (Ezekiel Emanuel’s vision³), or liberal (in the Rawlsian sense)?

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I will argue that limited solidarity and limited community (the “caring” part of the “Just Caring” problem) can be adequately protected under a liberal conception of health care justice, and such a limited notion is sufficient to protect these values as much as they ought to be protected. Going beyond these limits will threaten both the liberality and the justness of our society as far as health care is concerned. I will also argue that the first virtue of our health care system, and of managed care plans within that health care system, must be the virtue of justice. My intent is to reject the views of both libertarians, who would assign value preeminence to unequal liberty, and communitarians, such as Michael Sandel,⁴ who would relegate justice to the status of a minor remedial virtue of social institutions. Finally, I will argue that the best approach to resolving fairly the last chance therapy problem will be through a form of rational democratic deliberation, which I describe below. Such an approach will yield rationing decisions when life itself is at stake that are “just enough,” that protect “just liberty” adequately enough, and that sufficiently maintain the bonds of a liberal pluralistic community.

The practical implication of the philosophic claims I advance above is that we want our managed care plans to be Rawlsian-like liberal political communities on a small scale.⁵ This would mean that members of these plans would not necessarily share with one another any comprehensive vision of the good (or even a vision of the good as it related to health care). Instead, they would share a commitment to a certain set of liberal virtues and liberal social practices, the most important of which would be a commitment to rational democratic deliberation as the primary method through which social conflict within the plan would be addressed (i.e., problems such as the last chance therapy rationing problem).

Health care rationing decisions need to be made communally, if they are to be made fairly. There is no practical way for individuals as individuals to make rationing decisions for themselves of the range and complexities required by our current health care system and still preserve overall fairness. But we also readily recognize that rationing decisions need to be made freely and autonomously if they are to have moral and political legitimacy. After all, rationing (as used in this Article) is about denying individuals what all would agree is beneficial health care—albeit what is judged from some larger social point of view to be marginally beneficial, non-costworthy health care.⁶ Still, it will sometimes be the case, as with last chance therapies, that marginally beneficial care is what might make the difference between life and death for a given individual (if only for a relatively brief period of time). Given the significance of an outcome like this, in a liberal society such a decision should be endorsed at some level

by the individual who will bear the burden of that decision. Otherwise, we would need a compelling moral argument for the claim that there is someone else who has the moral authority to impose such a decision on this individual. It is not obvious what such an alternate source of moral authority might be that would still be liberally defensible.

I. FRAMING THE PROBLEM OF LAST CHANCE THERAPY RATIONING

A. Last Chance Therapies: Some Examples

For the sake of clarity, I call attention to four concrete examples of last chance therapies to focus and illustrate the problem. First, Herceptin therapy is for the 25% of women with metastasized breast cancer (roughly 12,000 women per year in the United States) who have HER-2 receptors, which unfortunately hasten the progression of cancer.⁷ Second, the left ventricular assist device (LVAD) is for patients with end-stage congestive heart failure—about 550,000 new patients suffer from this problem each year in the United States.⁸ Third, the totally implantable artificial heart (TIAH) is for patients with end-stage heart disease. This device is in the earliest stages of clinical testing,⁹ but it would offer hope of prolonged life to about 350,000 individuals per year in the United States who would otherwise die from their heart disease.¹⁰ Fourth, total parenteral nutrition (TPN) can be used for infants, usually born prematurely, who do not have a functioning gut, and hence, do not have the capacity to process food in the normal way. About 4,000 such infants are born each year in the United States.¹¹

The common features of last chance therapies that create our moral problem are the following: First, the cost of the therapy itself is very high at the individual level. In the examples above, the costs per person range from \$100,000 to several hundred thousand dollars. In the case of infants with necrotic small bowel syndrome, the costs of TPN range from \$50,000 to \$200,000 per year, and these infants can now survive for four years.¹² A medically and morally troubling fact about TPN is that the therapy that prolongs the infants' lives also destroys their livers.¹³ Liver damage will cause their deaths unless we provide them with liver transplants at a cost of about \$200,000 each.¹⁴ A liver transplant might only yield an extra two years of life, and the next alternative, being an experimental total bowel transplant, would cost \$600,000.¹⁵

Second, the aggregate cost of treating all who are in similar medical circumstances is very high and grossly disproportional to what would seem to be a reasonable share of total health resources. In the case of the TIAH, for example, we could be looking at annual increases in health care

expenditures of about \$52 billion in an economy in which we currently spend a little more than \$1.3 trillion on health care.¹⁶ If we were looking at only a few hundred or a few thousand of these high-cost interventions, the moral reality would be that we could afford such interventions, and we might be fairly judged indecent and uncaring if we failed to provide them. But the potential aggregate demand is very great and essentially unavoidable as a moral problem.

Third, the terminal prognosis itself is unaltered by all of the above interventions. There is no reasonable medical expectation that any of these interventions will bring about a medical miracle and provide an individual with an open-ended life expectancy. Each of these interventions promises some gain in life expectancy with an acceptable quality of life, but nothing more than that.¹⁷

Fourth, the gain in life expectancy will vary considerably from one individual to another, and from one therapeutic intervention to another, often depending upon a mix of factors that will not be well understood at the individual level; but fifth, from some larger social perspective the general judgment will be that the gains in life expectancy are mostly marginal. The clear case of that is Herceptin therapy where the average increase in life expectancy (compared to conventional therapy for women with metastasized breast cancer and HER-2 receptors) is five months.¹⁸

By way of contrast, treatment of HIV-positive patients with protease inhibitors and combination therapy in the later stages of that disease, or renal dialysis for patients with end-stage renal failure, both cost less and produce longer life expectancies. Costs for protease inhibitors are about \$20,000 for each year of life gained,¹⁹ while costs for dialysis are about \$45,000 for each year of life gained.²⁰ Individuals in these medical circumstances might be described as being “terminally ill” because their diseases represent the most likely causes of their future deaths, but their life expectancies are actually much more open-ended and indefinite, stretching out for a couple decades or more in the case of many dialysis patients. For this reason I think of them as being in a different category for purposes of moral analysis than the last chance category I am delineating here.²¹

Finally, all the patients I have in mind as last chance patients want access to these expensive, marginally beneficial therapies. The painful acuity of our moral problem would be significantly diminished if these therapies generally offered prolonged life filled with substantial pain and suffering. We, societal or institutional decision-makers, could then convince ourselves that the truly right and compassionate thing to do would be to expend substantial effort to persuade these patients to reject

these interventions as therapeutic mirages. This would allow us to avoid having to think of ourselves as making a rationing decision that would bring about the “premature” death of an individual. However, the medical reality is that this source of solace is generally not available in these circumstances.

B. Last Chance Therapies: Distinctive Moral Features

A number of morally relevant considerations seem to put last chance therapies into a distinctively weighty moral category, and, in addition, make rationing decisions with respect to such therapies an exceptional psychological burden.

First, it is partly for monetary reasons that we are motivated to deny an individual access to life-prolonging technology. It is for reasons of “fiscal scarcity” rather than “absolute scarcity” that we deny an individual this medical intervention.²² If we had only so many transplantable organs, we would still feel regret that we had to deny a certain individual one of those organs, but we would know that some number of individuals would be denied those organs no matter what. In the case of money, however, especially in a \$9 trillion economy, we can always imagine some other source for funds that would lift this burdensome decision from our shoulders.

Second, it is ultimately an identifiable individual who is denied this expensive life-prolonging care, someone with a name and face who will elicit our natural sympathies. It seems uncaring, cold-hearted, disturbingly calculating, and violative of the core virtues essential for any civilized community to have a medical intervention at our fingertips that offers some small hope of life prolongation an individual desperately wants, but still our intent is to deny that individual access because it is not cost-effective from a larger, abstract social point of view. Another way of making the same point is to say that it involves “putting a price on human life,” making the judgment that some lives are not worth saving. That judgment may be morally and psychologically tolerable when we are talking about “statistical lives,” but it seems intolerable when we are talking about an identified person. If, for example, we were aware of miners trapped 1,000 feet below the surface, climbers trapped in a storm on a mountain peak, or a physician in Antarctica at risk for pancreatitis, then we would never call off a rescue effort because some speedy fanatical accountant calculated that the rescue effort would cost a minimum of \$6 million with no guarantee of success (and this was really an economically irrational use of resources).

Third, we can debate about whether there is a right to health care, or

whether we have a societal moral obligation to be responsive to the health care needs of all. We can argue about precisely how we ought to define a health “need” or how encompassing the domain of health care needs ought to be. But in the last chance therapy situation I have in mind, it is unambiguously clear that if there is anything that can be called a health need, and if such a need ever generates a moral obligation to be responsive, then this is a paradigmatic situation where there is an obligation to provide access to a medical intervention that offers an individual’s only hope to forestall death for some period of time. We might interpret this as an obligation of justice (these are people whom Rawls would classify as being among the “medically least well off”) or we might interpret it as an obligation of beneficence. In either case, the operative word is “obligation,” the intent being to suggest that it would be especially inapt to consider making rationing decisions with regard to patients in these circumstances.

C. Last Chance Therapies: Why Rationing Is Inescapable

To avoid confusing the reader, I emphasize that the material in the prior section should be read as an uncritical description of the moral phenomenology associated with last chance therapies and rationing. The practical conclusion one is supposed to draw from that analysis is that decisions to deny individuals last chance therapies are just plain morally intolerable. But I reject that conclusion. The need for health care rationing in general is really inescapable. Some may be tempted to argue that getting rid of waste and inefficiency in the health care system is the real moral imperative, and those matters must be addressed completely before any rationing decisions receive a moral seal of approval. At a general enough level, I would agree with this view. But, among other things, closer inspection often will show that one person’s “waste and inefficiency” is another person’s chance at life-sustaining medical care.²³

Still, a critic might insist that if rationing is inescapable, then we should make all our rationing decisions around care where life itself is not directly at stake. Unfortunately, the fact of the matter is that we could not possibly save enough money that way to avoid the more difficult sorts of rationing decisions associated with last chance therapies.²⁴ The general line of argument, which my last chance therapy examples above are intended to illustrate, is that the proliferation of expensive life-saving and life-prolonging medical technologies has become so expansive (and has resulted in the proliferation of what we categorize from a moral perspective as “health needs”) that not even a society as affluent as our own can afford to provide these technologies to all who have the relevant

medical needs. Further, it is generally the case that these emerging technologies result in both prolonging lives and adding to the total burden of costly chronic illness in our society. Thus, providing 350,000 artificial hearts per year will substantially reduce heart disease as “the” cause of death in our society while increasing the number of people who will die from various cancers, strokes, or Alzheimer’s disease, after they have generated substantial costs for the treatment of these additional disorders. Artificial hearts do not confer eternal life on anyone. We should conclude, as I argued in an earlier article,²⁵ that we cannot avoid “putting a price on human life,” that is, accepting that there are some lives and some life-years that are too expensive to save. The real moral challenge then is to determine what our understanding of health care justice permits or requires in the way of making these rationing decisions.

In short, solving the problem of health care rationing requires that we come up with a rationally compelling moral account of what it means to be a just and caring society when we have only limited resources for meeting virtually unlimited, extremely heterogeneous health needs. It also requires a rationally compelling political/economic account of what will count as costworthy health care from a point of view that is both social and sufficiently respectful of individual judgments of costworthiness. Finally, we need a rationally compelling account of health care rationing and the social mechanisms required to implement it that is congruent with our liberal and democratic political traditions.

D. Last Chance Therapies: Why Justice?

What should be the central moral or non-moral considerations that determine how society, managed care plans, or employers make rationing decisions with respect to last chance therapies? Should the ability of individuals to pay for the therapy be that determining factor? In some circumstances, as I explain below, that is the correct answer to give. However, I hastily add that the appropriateness of those circumstances has to be shaped by certain judgments of health care justice. I reject the view that health care should be thought of as nothing more than another commodity in the market to be distributed entirely on the basis of individual ability to pay (with apologies to Tristram Engelhardt²⁶) since that view almost entirely ignores the complex problems of health care justice, which I will argue need to be addressed. To my mind, the most serious of those problems would be the failure of such a libertarian health care system to meet the health care needs of the most seriously chronically ill, who will often find themselves unemployed, uninsured, and entirely dependent upon the vagaries of local health care charitable impulses.²⁷ I

find Daniels' arguments in support of the view that health care is "morally special" quite compelling.²⁸

Our social practice is also worth noting. For example, as a society we passed the 1972 End Stage Renal Disease (ESRD) amendments to Medicare, which underwrite the costs of either renal dialysis or renal transplant for anyone in end-stage renal failure no matter what his or her work or economic status. We found it morally intolerable that a society as affluent as our own would simply allow people to die because they could not afford the cost of dialysis (roughly \$45,000 per year at present²⁹), which will often mean many extra years of life. In the year 1999, that program cost in the aggregate about \$14 billion and sustained the lives of more than 300,000 individuals.³⁰

We can argue, of course, as to what precisely was the moral motivation for that decision. I would assert that it was a matter of health care justice. Others might say it was no more than a charitable impulse expressed societally. However, I find that explanation open to serious moral criticism. Specifically, if it were no more than a charitable impulse, then it would have to be morally unobjectionable if we were to decide as a society to withdraw that funding for the indefinite future, with the result that literally tens of thousands of those individuals would likely die in the space of a year because they would be unable to afford dialysis. There is something obligatory about our continuing that funding, unlike in a situation in which I have contributed \$25,000 to cancer research for each of five years and then decide to donate no more. But someone could add that the obligation is not necessarily a matter of justice; it could be better characterized as an obligation of beneficence. That response strikes me as being ethically incomplete. Other individuals, such as hemophiliacs needing Factor VIII to sustain their lives, something that can be more expensive than dialysis, can justly complain that there should be a national program to fund their needs as well. After all, public resources are being used to fund the dialysis program. It may not be morally necessary to show that justice requires funding the dialysis program, but some argument must be made to show that it is not unjust to fund it. At least in that respect, considerations of health care justice must come into play. That minimal point is all I wish to make for now.

I want to call attention to a very provocative argument made by Allen Buchanan that deserves broader notice.³¹ He points out, contrary to popular belief, that managed care plans are for the most part immune to moral criticism, so far as matters of justice are concerned, as long as they meet their contractual obligations to subscribers, and as long as they observe basic understandings of procedural justice in the plan ("treat like

cases alike, so far as providing or denying benefits are concerned"). This is because there are no substantive social agreements regarding what should count as a basic or minimally decent package of health benefits that should be guaranteed to all in our society, nor regarding what should count as reasonable approaches to health care rationing/cost control with regard to health benefits provided to subscribers, nor regarding what should count as the level of quality of health care to be guaranteed to all subscribers within a plan. With regard to these latter points, there is no agreement among plan members, or in society at large, about what the relevant substantive values or conceptions of justice would be that could identify morally objectionable rationing judgments or morally objectionable quality deficiencies. The only reference points for such judgments are the exaggerated expectations of plan members. Buchanan writes: "Because no authoritative standard has been determined for what constitutes the types and quality of care to which everyone could be said to be entitled, complaints that patients are treated unethically when they are denied care or when they receive care of less than the highest quality are groundless."³² He also concludes that because we have no authoritative standard for the care to which everyone is entitled there is no benchmark for determining what a physician's fiduciary obligations are.

If Buchanan's analysis is correct as an empirical moral description,³³ as I believe it is, then this should be very unsettling for the average middle-class American in managed care. It means that each year I, for example, invest about \$6,700 in this health care game of chance. The rules of the game that determine when there is a payoff are less than perfectly clear, and they are subject to sudden change or definitive interpretation by two other very powerful players in the game (my employer and the insurer/managed care plan), both of whom have strong interests in denying me a payoff. I know that for small bets there are frequent and reliable payoffs, but I find that to be of small comfort. When I and/or a family member are faced with a very serious and potentially very expensive health crisis, then I most want certainty that the payoff will be there. But it seems then that there is the greatest uncertainty, and I have the least ability to control the outcome of any bargaining or adjudicative process because I have little political or moral power. Further, it would be small comfort to be told that my managed care plan is committed to formal justice, that all plan members will be treated alike in similar circumstances.

We can imagine any number of virtues that we would like to see our managed care plan display in these very difficult circumstances. But all these virtues would be nothing more than shifting in uncertain sand if the policies and practices of that managed care plan were not rooted in

explicit, substantive, and well-defined understandings of health care justice. Imagine, for example, a managed care plan that advertised itself as “caring and compassionate” and that exemplified those virtues every now and then by “investing in” an expensive life-prolonging last chance therapy for one of its plan members. Such sporadic displays of exemplary behavior would hardly assuage our own anxiety as to whether we might be the beneficiaries of such behavior in the future were we to face a life-threatening medical crisis. Further, we could not help but note the fact that it is “our money,” our premiums, that are being used to underwrite that generous response (and might not be there in the future, were we in need of a similarly generous response).

Perhaps this would not be a practical problem if our managed care plans were those single-minded idealized communities that some communitarians would like to see more generally disseminated. But, for the most part, we are moral strangers to one another in managed care plans, which is why we need a rationally defensible basis for knowing when we or others are entitled to draw on the common resources of the plan to meet health needs. Shared understandings of health care justice articulated through a shared process of rational democratic deliberation are needed, the details of which I sketch below. The virtue of such shared understandings achieved through a shared deliberative process is that they constrain morally objectionable arbitrariness by plan administrators, shift the power to make rationing decisions to those directly affected by those decisions, and protect our liberal commitments to value pluralism.

E. Last Chance Therapies: Why Non-Ideal Justice?

Though some philosophers with a more rationalistic bent might believe that our philosophic theories are capable of yielding uniquely right and uniquely rational responses to complex problems of health care justice, this belief is excessively utopian. The empirical complexities associated with our health care system and emerging medical technologies, the uncertainty with respect to medical interventions, the possibilities for trade-offs with respect to very complex mixes of rationing options—all of the factors that Rawls tries to capture under the rubric of the “burdens of judgment”³⁴—defeat the hope that philosophy would have the resources to yield complete resolutions to the justice problems associated with health care rationing.

Daniels and I agree that no theory of just health care will prove adequate to address the moral challenges alluded to above. As Daniels puts it: “The general distributive principles appealed to by claimants as well as by rationers do not by themselves provide adequate reasons for choosing

among claimants: they are too schematic.”³⁵ Ultimately, rationing decisions come down to the level of individuals, and often those individuals will be able to appeal to plausible distributional principles that would justify their not being denied some type of health care that they need. If this is true, if we have conflict and incoherence among distributional principles at the level of individuals, and if what is at stake for these individuals is access to health care that is perceived to be of great import (i.e., a last chance therapy), then this is not a state of affairs that is morally or socially tolerable. There would be enormous opportunity here for arbitrary or discriminatory judgments to be made, as Buchanan has reminded us. Here Daniels takes note of the move made by Rawls to deal with indeterminate distributive principles, namely, an appeal to fair democratic procedures to resolve the indeterminacy. Daniels, however, is not satisfied with this. He finds that there are some strong moral objections that can be lodged against this move to fair democratic procedures, which I discuss below.

The large view I defend is this: First, we should view health care as a distinct “sphere of justice,” as Michael Walzer³⁶ uses this phrase. There are features of health care in our society that make it distinct enough as a social good that it requires its own principles of distributive justice.³⁷ Three broad areas would have to be addressed by these principles: fair access, fair financing, and fair rationing/priority-setting/cost containment.

Second, the most we can hope to achieve would be a morally defensible conception of non-ideal health care justice.³⁸ We are faced with the extremely complex moral problem of coming up with a framework for fair health care rationing that can address “justly enough” the concrete problem of last chance therapies, as well as several related rationing problems at a slightly more general level. These are often referred to in the literature as the “ragged edge” problem, the “Rule of Rescue” problem, and the “priorities” problem. These are not merely philosophical problems of health care rationing; rather, these are problems that policy-makers (private or public) in our society must address. We have no reason to believe that there is any uniquely and perfectly rational, or uniquely and perfectly just, theory of health care rationing that can address all these problems. Rather, there are numerous trade-offs among competing moral considerations and among competing considerations of health care justice that will yield a pattern of rationing outcomes that will be “just enough.” Within the framework of non-ideal justice (as I conceive it) our objective is to come up with recommendations that will bring about more just policies, practices, and patterns of health care rationing than currently exist. At the very least we want to identify those features of our current rationing practices that are clearly unjust. Within managed care plans we want to

identify policies and practices with respect to health care rationing, trade-offs of various sorts, that are “just enough” and not illiberal.

Third, the theoretical underpinnings for rational democratic deliberation as an approach to just health care rationing are to be found in a theory of public reason, as articulated by Rawls.³⁹ The more theoretical side of rational democratic deliberation, that is, the construction, interpretation, specification, and mutual adjustment of the constitutional principles of health care justice, should be thought of as a matter of wide reflective equilibrium, as Rawls and Daniels would understand it.⁴⁰ The more practical side of rational democratic deliberation, that is, the construction and mutual adjustment of social policies and practices for fairly, rationally, and democratically resolving the indeterminacies, trade-offs, and priorities associated with health care rationing at the level of concrete social practice, should be thought of as a matter of public reason or democratic legitimation, as understood by Daniels and Sabin.⁴¹

The practice of reason-giving must be integral to our process of policy-making, whether in the public sphere or in private managed care plans. In addition, following John Dewey, the theoretical and practical dimensions of public reason must not be separated from one another for purposes of constructing a fair approach to health care rationing. The precise shape of the domain of practical rational democratic deliberation will change as a result of how effective resolution of concrete problems of health care rationing brings about a refinement and specification of our broad principles of health care justice. We see precisely this happening in our legal practices of constitutional interpretation as our understanding of privacy or free speech or other such broad matters evolves as a result of our grappling with emerging social problems in these areas.

Fourth, rational democratic deliberation has moral legitimacy as an approach to health care rationing because it best captures what respect for individual autonomy is about in the rationing context. Rationing decisions that involve the healthy, wealthy, and politically powerful imposing rationing protocols on the sick, the poor, the vulnerable, and the politically powerless are presumptively unjust. By way of contrast, rationing protocols that we impose upon our future selves as a result of rational democratic deliberation are presumptively just. There are, of course, alternative approaches to health care rationing besides rational democratic deliberation. These include markets/individual incentives, bureaucratic rule-making, expert medical or technical judgment, or administrative decision-making in a hospital, insurance company, or managed care plan. But I have argued elsewhere⁴² (and I take Emanuel and Emanuel to be making the same point⁴³) that all these alternative approaches are seriously

flawed as primary mechanisms for health care rationing, either from the perspective of justice or from the perspective of respect for individual autonomy. To be sure, there are appropriate places for the functioning of all these alternate mechanisms in a scheme of health care rationing, but the overarching framework for that scheme must be rational democratic deliberation.

II. LIBERAL COMMUNITARIANISM: A CRITICAL ASSESSMENT

Should we embrace the communitarian vision of managed care presented by Emanuel⁴⁴ rather than liberal rational democratic deliberation for fairly addressing rationing issues? Emanuel wants to permit, maybe encourage, managed care plans to be defined in terms of some sort of comprehensive vision of a health good. What he rejects in the liberalism of Rawls, Dworkin, and their philosophic brethren is the notion of liberal neutrality. He sees this as a sham because liberalism itself represents a fairly definite set of value commitments, which may be congenial to many comprehensive visions of the good, but which may be uncongenial to others—very often religiously based comprehensive visions. Emanuel contends that there is something fundamentally wrong with a political society that would force an individual to choose between being a good liberal citizen and being a good Catholic, a good Amish person, or a good Orthodox Jew. Thus, if we were to have some sort of national health insurance, and if abortion services, physician-assisted suicide, or embryonic genetic analysis and selection were funded benefits, then some individuals who are deeply opposed on moral/religious grounds to any or all of these practices would find themselves contributing tax dollars/premium dollars to support these practices. This strikes Emanuel as being illiberal and dishonest.

Emanuel sees the managed care movement as a way of escaping these problems that is both protective of our liberal political traditions (minus the neutrality commitment) and protective of the integrity of distinctive religious/philosophic communities. He sees managed care plans as possibly forming around differing organizational perspectives, including religious commitments. He would give each family or citizen of our society a voucher that would have a precise economic value sufficient to purchase a very good package of health care benefits. Individuals could use these vouchers to join whichever managed care plan they found congenial to them in terms of a comprehensive vision. There would then be no nationally required set of specified health care benefits/services. Instead, members of each plan would decide among themselves the precise content of their benefit package, up to whatever limit was allowed by the value of

the vouchers, plus whatever private resources they were willing to add to a common pool of resources for purchasing health care services. Emanuel says the vouchers might be “graded,” increased in value to reflect the likely health needs of individuals with those vouchers so as to minimize any risk of economic discrimination against older or chronically ill individuals.⁴⁵ Otherwise there would be a serious justice problem. However, we would then need a national decision-making mechanism to do the grading. That is, someone would need to decide which medical problems, with what degree of severity, and with what likelihood of being responsive to various more or less costly medical technologies, ought to be considered for purposes of assigning a value to a particular voucher for a particular individual.

Whose vision of the good would be operative at the national level for this purpose? This is supposedly the problem that prompted Emanuel to devise his proposal in the first place. But it looks like he still has that problem, at least if he remains committed to protecting the overall justness of the system. Could those religious managed care plans object that they do not want their tax dollars spent, or the value of their own personal health vouchers reduced, to accommodate what they regard as the perverse health needs of the HIV-positive population, just as many object to the use of federal money for the funding of abortions? If the federal government were to respond positively to this challenge, then we would have de facto discriminatory outcomes that are both illiberal and unjust.

If protecting pluralism is important, which means in political terms protecting the right of individuals to form many kinds of communities around many conceptions of the good, then a liberal government will have to be neutral among different (sometimes competing) conceptions of the good. That neutrality will be in the “justificatory” mode rather than the “consequentialist” mode. In other words, in justifying any particular law or policy, a liberal government will have to show that it is justified by appeal to “thin” values and interests that can be reasonably construed as being supportive of the general good of liberal citizens as liberal citizens in a liberal society. That is, these are interests that transcend (but are also necessary to support) the much thicker and more specific conceptions of values that define the multiplicity of communities that comprise our society as a whole. Our conception of justice, as Rawls articulates it, is intended to be the most important value embraced by a liberal society, in part as a way of protecting the stability and peacefulness of our society. I emphasize that Rawls is a moral and political constructivist: The conception of justice (or any other basic social value) is not simply “out there” to be discovered; rather, it is constructed through rational

democratic deliberative processes, the resources of public reason, as we struggle with emerging social problems, such as health care rationing.

Let us now apply this general framework to the last chance therapy problem. Imagine that we have Emanuel-like managed care plans organized around a core value such as “sanctity of life” or “maximum healthy living.” Those committed to the sanctity of life ideal may want everything medically possible done to sustain their own lives or the lives of their loved ones; thus they will want access to Herceptin, LVADs, TIAHs, or TPN, all at plan expense. By way of contrast, those who are committed to the ideal of maximum healthy living may adhere to the belief that most of the chronic illnesses characteristic of contemporary Western society results from bad lifestyle choices that “weak-willed” individuals in society make. They want nothing to do with paying for the medical costs of this “weak-willed” misbehavior. What they want funded with their health dollars is an indefinitely large array of health-promoting practices and herbal supplements, for example. Both sets of these individuals define strong morally legitimate health needs from the perspective of their comprehensive visions of the good.

How can individuals with such radically different visions of legitimate health needs co-exist in the same health plan? This problem generates Emanuel’s vision of separating out into distinct managed care plans adherents of all these different comprehensive visions. However, this move does not solve any moral or practical problems. As noted above, if there is some sort of national commitment to “necessary health care for all,” and if that is expressed through giving health vouchers to all, then some economic value will have to be attached to the vouchers, and that value cannot be fairly or reasonably determined by reference to what adherents of different comprehensive visions judge to be their health needs. To address that problem we will need some thin conception of health care justice that can be the focal point of an overlapping consensus.⁴⁶

A more telling point, however, is that this very same problem would exist in each of these philosophically distinctive managed care plans we have postulated. This is because there are, as a psychological and sociological fact, indefinite degrees of commitment to the core vision of the good that would define any of these plans by individual members of these plans. Some members of the “maximum healthy living” plan will be ultra-health enthusiasts (and demand health resources to achieve their ultra-health goals) whereas others will be only “excellent” or “very good” or “near average” health enthusiasts (still a couple standard deviations beyond the minimal level of commitment to health promotion of the average American). The same will be true in the “sanctity of life” managed

care plan where some will enthusiastically endorse sustaining at all cost the lives of Helga Wanglie and others in a persistent vegetative state, while other plan members would see that as a wasteful and inappropriate use of limited plan resources that ought to be directed to more support for last chance therapies.

To resolve such possible conflicts within any of these plans appeal would have to be made to some conception of health care justice, and a method for justifying that conception, that is independent of the more radical and less radical commitments of plan members to their central value conception. If such a conception and method can be worked out within these plans to prevent destabilizing and fractious bickering among plan members, then the same conception and method can be appealed to for purposes of resolving conflicts among these plans with respect to how at the national level we ought to determine the value of health vouchers that would be given to all. And if it is possible to achieve that to a sufficient degree, then there is no need to try to organize health plans around differing comprehensive visions, for we would then have the resources that allowed individuals with very different deep comprehensive visions of the good (health-related or not) to function fairly in relation to one another within the bounds of liberal generic managed care plans.

My contention is that something akin to Rawls' liberal conception of justice and something akin to the version of rational democratic deliberation I describe below are necessary to achieve these objectives, while at the same time preserving the value of community and solidarity to the limited functional extent that is possible. Within the domain of health care justice, Daniels has provided a helpful approach to addressing this problem of diverse comprehensive visions with his fair equality of opportunity account for identifying and prioritizing health needs⁴⁷ since it is fundamentally neutral among competing comprehensive visions. It is a "thin" enough, but still substantive enough, value that it can address many rationing problems, including some parts of the last chance therapy problem.

III. JUST HEALTH CARE RATIONING: CRITICAL CHALLENGES

Daniels identifies four unsolved broad rationing problems.⁴⁸ I will add several more. My ultimate objective will be to show that rational democratic deliberation provides us with a reasonable approach for addressing all of these problems more fairly than any alternative. This includes the last chance therapy problem. Daniels uses the Oregon priority setting process as background for his critical observations.⁴⁹ Both Daniels and I agree that the Oregon process is seriously flawed as a model of what

rational democratic deliberation ought to be. Nevertheless, I have argued that useful moral lessons can be drawn from that policy-making effort for purposes of designing morally preferable examples of rational democratic deliberation for health care rationing.⁵⁰

The first problem Daniels identifies is the “fair chances/best outcomes” problem. At the micro level we have Alice and Betty. Both will die in a week without an organ transplant; both are the same age; both have been waiting in line for the same period of time. Alice is expected to live two years with the transplant while Betty will live twenty. What does fair treatment require in terms of determining who gets the transplant? From a best outcomes perspective, certainly not unfair or unreasonable, Betty would get the transplant. From a fair chances perspective, recognizing that those two years are of ultimate importance to Alice, there ought to be a lottery, which Alice demands. Both are plausible moral principles. How can we reasonably decide which principle ought to prevail in our managed care plan?⁵¹

Alice and Betty are merely abstract ciphers that hardly elicit compassion. In the real world there are millions of individuals with assorted disabilities who would fear a discriminatory outcome if our consistent commitment were to best outcomes, especially if those outcomes were measured by Quality-Adjusted Life Years (QALYs).⁵² If, for example, access to Herceptin therapy at plan expense were only available through clinical trials, then most individuals with significant disabilities would be excluded from such trials. If we wanted all women with metastasized breast cancer to have fair access to limited slots in these trials, then the likely result would be less reliable trial data. Is the desire for more reliable clinical data (best outcomes) sufficient to justify denying individuals with potentially confounding disabilities access to these trials and to the possibility for prolonged life represented by Herceptin?

Daniels’ second problem is the “priorities problem.” Should we give higher priority to those who need treatments that will yield greater net benefits, or to those who are medically worse off, even if doing so does not result in greater net benefits? The relevant moral intuition at stake here is the Rawlsian Difference Principle—if inequalities are inescapable, then institutions should be structured in such a way as to make the least well off as well off as possible. Daniels asks us to imagine people with Condition 1 who are more seriously impaired by their disease/disability than people with Condition 2. Treatments 1 and 2 will yield the same net gain in benefits for either group. This suggests that priority would be given to neither treatment. But Daniels says most of us would be inclined to treat Condition 1 because these individuals were worse off to begin with, and

this would be especially true if treatment still left these individuals somewhat worse off than individuals with untreated Condition 2. But our judgments in this matter would be less confident if those with Condition 1 ended up better off after treatment than those with Condition 2, who were denied treatment. Daniels continues that if Treatment 2 yielded greater net benefit for those with Condition 2, then we would still likely favor those who were worse off to begin with. But if the worse off could gain only a very modest improvement from Treatment 1, and those with Condition 2 were denied the opportunity for very great improvement, then Daniels contends we probably would not award strict priority to the worst off.⁵³ In the context of our last chance therapies, for example, we could ask: Could a just and caring managed care plan or Medicare program deny the TIAH to individuals who had both end-stage heart disease (likely to kill them in six months) and a terminal cancer (likely to kill them in two years) so that the TIAH would be more available for individuals likely to gain at least five years of additional life from it?

Daniels' third problem is the "aggregation problem." How do we determine whether various aggregations of health benefits are just or not? For example, if we can save one life or provide computerized functional assistance to a quadriplegic that will significantly improve quality of life for that person, which allocation would be more fair? If we make these one-to-one comparisons, then we may be able to make judgments in which we are morally confident. But if we have a fixed sum of money and we can either save one life with that money or provide to ten quadriplegics that quality-of-life/functionality-enhancing computer assistance, then which of these allocations is more just, all things considered? There are some aggregation principles that are strongly morally justified, but there is no clear, well-ordered account of how various aggregation principles might be related to one another, or how they might be fairly applied in practice to deal with numerous problems of health care rationing. In the context of last chance therapies, we might pose this question: In the Medicare program is it more important from the perspective of health care justice to fund approximately 200,000 TIAHs (at an annual cost of about \$35 billion) or to fund a Medicare drug benefit with a ten-year projected cost of about \$310 billion (roughly 60% of total drug costs for the elderly)?⁵⁴ All of the TIAHs would be needed to sustain lives while only a relatively small fraction of the prescription drugs would be necessary for that purpose.

Daniels' fourth unsolved rationing problem is the "democracy problem." Daniels calls attention to the fact that in Oregon, vasectomies were given a higher priority than hip replacements for health funding. *Prima facie*, this ranking is indefensible. But if this ranking did reflect

community values and the outcome of a fair democratic process, then we ought to abide by it. On the other hand, if we are morally confident that this ranking is mistaken, then we obviously have a substantive reference point for the conclusion that calls into question the moral legitimacy of appealing to fair democratic procedures to do fair health care rationing. Obviously some concrete rationing problems ought to be entrusted to fair democratic procedures while others need to be adjudicated “by appeal to some prior notion of what constitutes a fair outcome of rationing.”⁵⁵ But what moral methodology do we have for determining which to choose in a non-arbitrary way?

Here are some additional challenges to any approach to fair health care rationing. I start with Callahan’s “ragged edge” problem,⁵⁶ which challenges the fundamentals of the Oregon priority-setting process, specifically, the reliance on medical condition/medical treatment pairs. If, for example, you have a failing heart or a failing kidney, and a treatment is available to address your health problem, then Oregon’s Medicaid program will pay for it if it has high enough priority. But there are indefinitely distinguishable degrees of failing hearts and failing kidneys for which essentially the same treatment will be available, but with results that will range from minimally to extraordinarily beneficial. In its early years dialysis yielded impressive results, at least for significant prolongation of life. However, this was an artifact of the restrictions placed on acceptable candidates when dialysis was scarce.

Today very old, very sick, very near to dying individuals are routinely candidates for dialysis, though the costs will be large and the benefits small. Why is this a routine judgment? Because there is no sharp edge, morally speaking, that will permit us to judge confidently that a given patient has a just claim to dialysis while another patient does not. In our managed care plan, what would be a just enough and liberal enough approach to addressing this problem? I earlier put dialysis outside the last chance therapy category. My comments above suggest the need for qualification. There are a significant number of cases where dialysis will prolong life for a brief period (weeks or months), and in such cases I contend we should think of it as a last chance therapy for purposes of moral assessment.

Another example pertains to TIAHs, of which we now have a working model. The cost of transplantation is around \$160,000 each.⁵⁷ What is known statistically is that each year there might be 350,000 individuals who could benefit with five extra years of life expectancy from access to this device. About 70% of those individuals would be over age sixty-five.⁵⁸ How many of these devices should a just and caring society produce each year?

If we did have some form of national health insurance, specifically, something like the competing managed care plans envisioned by the Clinton Administration, would justice require that the TIAH be a covered benefit in every one of those plans? Would justice require that it be a covered benefit for Medicare and/or Medicaid? Would it be just to allow each employer to decide to cover it or not? Would it be fair enough if we allowed individual ability to pay to determine the distribution of TIAHs? This is one dimension of the ragged edge problem with respect to TIAHs. The other dimension, as in the dialysis case, is whether we could deny a TIAH to individuals whom we knew with near certainty would be dead in slightly more than one year. The critical moral problem raised by these ragged edge examples is this: How can we justifiably create sharp moral edges for health care rationing when there are only ragged edges in reality? We might be tempted to say that the morally safer course is to provide access to such technologies whenever they offer any benefit at all. But that denies (unjustly) the reality of the “Just Caring” problem. Resources are scarce. Money spent to fund very marginal TIAHs is money not available to meet stronger just health needs.

Our next health care rationing problem is the “medical innovation/dissemination” problem. As a society we want medical innovation, though what we have gotten for our investments thus far are a lot of halfway and ten-percent-of-the-way technologies. Recall the controversies that surfaced in the recent past regarding autologous bone marrow transplants (ABMT) for breast cancer or testicular cancer. This technology is very expensive—somewhere in the vicinity of \$100,000 to \$150,000 per case.⁵⁹ Reported results in the early 1990s initially suggested projected three-year survival rates of 10%.⁶⁰ There are more than 44,000 women each year in the United States who will die of breast cancer.⁶¹ A more recent study has shown the positive results with ABMT are illusory, that ABMT does no better than available conventional therapies.⁶² As is common in the United States, this experimental technology had become semi-disseminated, resulting in extremely arbitrary (morally speaking) inclusion and exclusion of women relative to the technology. Given the original situation with ABMT, should all women who have Stage IV breast cancer, and who have failed standard chemotherapy, have an equal chance for access to ABMT, when the initial positive results seem very marginal?

This same scenario is being replayed with Herceptin today (though the cohort of women is much smaller). But the experimental medicine angle adds another dimension to both the ABMT and Herceptin problems. The additional question that needs to be posed is whether it would be just if Herceptin were available at social cost only through approved clinical trials

and only to individuals who are deemed most “fit” for those clinical trials. That is, these individuals would not have comorbidities that could confound the results of the trials and thereby diminish the reliability of the medical knowledge society would hope to gain. Our capacity to do clinical trials efficiently, and to gain genuine medical knowledge to make both more informed personal and policy choices, was substantially undermined by the premature dissemination of ABMT. This may be happening with Herceptin as well.

We turn next to the “Rule of Rescue” rationing problem. A good society ought not allow individuals to die when it has the capacity to rescue them and money alone prevents their rescue. More dramatically, we should never “put a price on human life.”⁶³ This problem is also referred to as the “identified life” versus “statistical life” problem. Coby Howard in Oregon is the perfect illustration of this (the Lakeberg conjoined twins provide another illustration).⁶⁴ Coby was the eight-year-old boy with leukemia who needed a \$100,000 bone marrow transplant for any chance at survival, but Oregon Medicaid refused to pay for it. A public example of health care rationing like this usually elicits expressions of moral outrage, often followed by funds that will give an individual access to that expensive “life-saving” medical technology. Most often, the dismal predicted results occur, with or without the funding.

Assertive middle-class women have often been successful in forcing insurance companies to pay for ABMTs for their breast cancers. They are successful because they are willing to make themselves visible as individuals in desperate need of rescue.⁶⁵ Saying to these women that it is just not worth it from a societal point of view to save their lives seems insensitive and cruel. But, as noted earlier, a defining feature of health care rationing is that *individuals* must ultimately bear the burden of rationing. If all such individuals could make themselves visible victims of rationing in need of rescue, it would subvert all just schemes of health care rationing, including last chance therapies. The Rule of Rescue is a morally feasible rule so long as its required uses are small in number. Given rapid advances in numerous, expensive forms of life-sustaining medical technology, the application of the Rule of Rescue becomes ubiquitous. In the United States, the vast majority of us are likely to require multiple such medical rescues before we die.

Two moral problems are raised at the societal level by this Rule of Rescue. One is the conflict between what justice requires of us in maintaining fair rationing practices and what compassionate caring requires of us when faced with individuals threatened with death for whom there is “some chance” they might be saved, though at very great cost to

society or to our managed care plan. The other moral problem involves a conflict between a “slice-of-time” conception of justice and a “course-of-life” conception of justice. Do we have any principled basis for distinguishing rationing situations in which one rather than the other conception of justice applies? To be clear, there may be some circumstances in which a rationing decision is made most fairly by only considering present circumstances; past use of expensive health resources would be regarded as entirely irrelevant. But there are other circumstances where past access to expensive life-prolonging medical care might justly limit present access to marginally beneficial, very expensive, life-prolonging medical care. Imagine a future situation, perhaps twenty years from now, for HIV-positive individuals whose lives were first prolonged by protease inhibitors, then integrase inhibitors (or other successor medications) at \$20,000 per year (aggregated to \$400,000 for twenty years). Could we justly deny such patients access to another life-prolonging intervention costing \$100,000 that would extend their lives for six more months, part of the moral justification being that we had provided the prior twenty years of life-sustaining care?⁶⁶

IV. JUST AND LIBERAL MANAGED CARE: KEY ELEMENTS

We cannot reasonably expect to bring about perfectly just or perfectly liberal managed care plans. This has nothing to do with a recalcitrant reality or sinful citizens. Rather, there are numerous reasonable values and numerous considerations of health care justice that pertain to the practical problems of choosing fair rationing policies and protocols, and there are an indefinite number of trade-offs among these competing considerations that will yield policies and practices that are “just enough” and “liberal enough.” Any that are in fact chosen need to have both moral and political legitimacy. There are two primary sources for that legitimacy. One is that these decisions are made in bounded political space, space defined by what I refer to as constitutional principles of health care justice.⁶⁷ These society-wide principles protect society-wide justice. But they also create expansive democratic space in which there can be a plurality of morally legitimate policies and practices regarding health care rationing, which would be reflected in different managed care plans. Such space, however, cannot be devoid of justice-related structures. At this local level there must also be a pattern of public reasons that shapes democratic deliberations about health care rationing and protects to a large extent the moral legitimacy and the fairness of the outcomes.

That brings us to the second source of moral and political legitimacy: The actual trade-offs made are a product of rational democratic

deliberation that all who might be affected by specific rationing policies or protocols have had a fair opportunity to shape or endorse. At the very least that means that all these rationing policies or protocols, and the reasoning that would justify them, are public or visible. This is required by what Rawls refers to as the “publicity condition,” an element he sees as central to our shared conception of justice.⁶⁸ When decisions are just, nothing is or need be hidden. This means that rationing decisions that are invisible, hidden from public recognition or scrutiny, are presumptively unjust.⁶⁹ Further, if it can be honestly said that our rationing protocols are a product of public democratic deliberations open to all, then it can be justifiably said that these rationing protocols are freely and autonomously imposed by individuals upon themselves. In the course of explicating rational democratic deliberation it is important to respond to Daniels’ objections, especially the “democracy problem.”

Several moral lessons can be learned from the Oregon experience of health care rationing.⁷⁰ I will recall two of them. First, justice requires that there be limits to the claims that health care makes on total societal resources and that these limits are expressed in the form of hard budgets. The moral virtue of hard budgets is that they make clear and visible necessary trade-offs among competing health needs and services. Second, hard budgets give structure and coherence to a process of prioritizing health needs and services. A process of prioritizing and actual priorities that are explicit, rationally determined, and freely agreed upon protects fairness against special pleading by individuals or health interest groups.

Do terminally ill individuals really have a just claim to last chance therapies? If we ask this question in a perfectly abstract way, as a free-standing moral problem devoid of any further context, then no morally or rationally secure answer is available. But, if we ask this question in the context of a fixed health care budget, and if we have talked and thought through our health priorities with one another in a communal framework over a substantial period of time, and if we want to achieve as much health good as possible within the constraints established by certain basic considerations of health care justice, then we will be able to distinguish between just health claims by the terminally ill for life-prolonging resources, and those other claims requiring an empathic response but otherwise generating no just moral obligations. Again, the key to preserving the overall fairness of this system is that we are all part of this community over the course of a life. It is, of course, unlikely that many of us would be part of any single managed care plan over the course of a life. But we will likely be part of a society that has endorsed the broad constitutional principles of health care justice that will shape/constrain all

managed care plans that we might join over the course of our lives in that society.

We know we will die and that our dying could be a prolonged and expensive affair. A key moral concept for understanding what a just liberal community is all about is the notion of reciprocity and fair terms of cooperation. Do I believe I have a just claim to a half-million dollars worth of health resources at age eighty for six extra months of a reasonable quality of life? Again, there is no reasonable answer to this as an isolated question. We must also ask whether we would be willing to spend the additional taxes and insurance premiums required over the course of our own lives to sustain the lives of an indefinite number of strangers in our community in those same medical circumstances. If I say that they have had ample opportunity to live a full life, that other more important health needs or social priorities make a stronger claim on those dollars, or that I wish to satisfy other personal preferences with those dollars, then clearly I have no just claim to those communal resources at age eighty because I too am a moral stranger to the rest of the community.

Talk of moral strangers will strike some as disheartening and dehumanizing. It looks like a moral world surfeited with justice but devoid of compassion. If this is the moral community implicit in Oregon's efforts, then this is not a moral community worthy of national emulation. David Eddy, however, offers us an insightful way of looking at Oregon's approach to health reform, or managed care reform, that allows us to see both justice and compassion.⁷¹ He asks us to consider the case of a fifty-year-old woman with metastatic breast cancer whose only hope for survival is an ABMT at a cost of \$150,000. There is only a 5% chance of long-term survival. Should a compassionate and caring community provide her with that transplant? If that community has unlimited resources, then failing to provide the transplant would be indecent. But no community has unlimited resources. Something else always must be given up; and a just and rational community will inquire carefully about what is given up.

Eddy asks us to imagine one thousand women, relatively young, working at a factory.⁷² They have an extra \$1.5 million that can be spent over the next ten years for health benefits. They are concerned about breast cancer. Eddy asks whether they would want to spend this money on ten ABMTs or on annual screening mammograms for those thousand women. The basic math is easy. Do nothing: Thirty-six of those women will die of breast cancer over ten years. Buy ten ABMTs: Thirty-five women will die. Buy the screening mammograms: Twenty-nine women will still die. If a reasonable, prudent, and just goal is maximizing lives saved or life years saved in this situation, the choice is obvious. It seems that from every

reasonable perspective the process is fair. No one has any unfair advantage. All are behind what is a real world version of Rawls' "veil of ignorance." All know that twenty-nine women will die of breast cancer no matter what. All know they could be among those twenty-nine, and that they have denied themselves a small chance of extra life years by agreeing to this trade-off. All twenty-nine of those women will have names and faces in the future and could command our compassion. But they would not have a moral right to invoke the Rule of Rescue as a moral basis for access to an ABMT, arguing that this is their last and only chance for therapy. If such a rule had ultimate overriding moral authority, little money would be left over for any less urgent health needs. If someone needed pain relief for his or her cancer, and if there were any other opportunity to spend money for a small chance to prolong life for someone else, then this latter option would always win. Such a choice is flawed from the perspectives of prudence, fairness, compassion, and cost-effectiveness. Given this, it seems unimaginable that any rational democratic deliberative process would endorse such a choice.

Imagine that one of these twenty-nine women, Abby, was able to gain some media attention, hoping to use it to pressure the managed care plan to make an exception for her. Such pressure is often sufficiently successful. To recall Buchanan, the institutional reality in many managed care plans is that no considered judgments of health care justice shape rationing, prioritizing, and cost containment decisions within the plan. Administrators make decisions that appear to plan members and the public, if there is any awareness of them, as largely arbitrary, or driven by self-interested economic considerations alone. A woman in that situation really is alone against the plan. She likely deserves public support.

But then imagine this same woman in my deliberative version of Eddy's managed care plan. She can no longer claim that she is "alone against the plan." She made an agreement for a certain trade-off with 999 other women who "are the plan," and this was a fair agreement. If she reneges, if she gets \$150,000 in plan resources for her ABMT, if the plan subsequently stopped covering screening mammograms for a year, then the result will be that one more woman will end up with a deadly metastatic breast cancer who should otherwise have survived. We will not be able to identify her as that woman who should not have died. But her death could only be described as unjust, while the other twenty-nine are correctly described as unfortunate. In this managed care plan there has been a complex set of rationing protocols, health care priorities, and precedent-setting commitments rationally agreed to by plan members for purposes of fairly sharing the risks and controlling the costs associated with

meeting their health care needs. Abby might complain that she had not agreed to this particular rationing protocol. If so, the moral and rational burden would be on her to explain what the rational basis was for her reservations. It is difficult to imagine what that might be, and what might persuade other plan members that they made a mistake in this regard, which they should now reconsider. Further, we can imagine Abby has been part of this plan for years and has benefited from its rationing protocols. That is, the burdens and risks associated with those protocols fell upon other plan members, thereby freeing up resources for meeting Abby's health needs. This too undercuts any moral basis for Abby's request for an exception.

If we all belong to a managed care plan offering a comprehensive package of health benefits, as proposed by the Clinton Administration in 1993, where "all belong" means that (1) there is no morally objectionable sorting of individuals according to socioeconomic status, health status, or race; (2) a single health budget is used to purchase all needed health services; (3) the budget cannot possibly cover all likely needs for health services; (4) the budget is limited through a priority-setting process and mutually agreed upon rationing protocols that apply equally to all plan members; and (5) we are all largely ignorant of our future health care needs (which is mostly true), then the likelihood is that the rationing protocols and health priorities that emerge from a rational process of democratic deliberation will be "just enough" or "fair enough."

We must concede there will be future Coby Howards (the eight-year-old denied a bone marrow transplant for his cancer by the Oregon Medicaid program), or our dear Abby, that is, individuals who will die "prematurely" because they will have been denied the only medical intervention that promised them some additional opportunity for prolonged life for no better reason than that it was the informed and impartial judgment of the community that the benefits promised by these interventions were too small, too costly, and too uncertain. Still, the essential fairness of the process is secure because any member of that community, given the right combination of circumstances, could have a child that was Coby Howard or could themselves be in circumstances comparable to Abby.

We can imagine potentially biasing factors that might undercut the impartiality of the deliberative process. For example, given emerging genetic testing technology, some individuals are likely to know that they are at elevated risk of Alzheimer's disease. But what will necessarily follow from that? They will likely be tempted to give more priority for funding research and treatment related to Alzheimer's disease. If they are

reflective, however, they will realize that trade-offs have to be made within the context of hard budgets, that Alzheimer's disease occurs late in life, and that they are likely to have many other health needs they will want adequately met before they have to worry about Alzheimer's disease.

All of us are to some degree rationally self-interested, but we are also concerned about the health welfare and general well being of others—our children, parents, spouses, siblings, friends, co-workers—all of which considerably dilutes the biasing potential of our personal health concerns and increases our reliance on more rational considerations in the process of public deliberation that yields health priorities and rationing protocols. This feature of our social life protects the overall impartiality and fairness of the priority-setting process within a managed care plan. It does not require of us any heroic moral commitments. A basic sense of justice, commitment to respect fair terms of cooperation freely and mutually agreed to, is all that is necessary, along with average abilities to process rationally, medically relevant information.

A brief aside may be helpful for illustrative purposes. I have witnessed many public conversations about health care rationing under the rubric of the "Just Caring" project.⁷³ Personal responsibility for one's health elicits strong reactions. I pose this issue: Should individuals faced with very high end of life costs due in part to unhealthy personal choices, such as smoking or high-fat diets, be denied costly medical interventions at social expense because they have been irresponsible, and it is unfair that we should have to pay for their irresponsible choices?

The first responders are typically those who strongly agree, most often for the reasons suggested in the prior sentence. With a little supportive prompting the next individuals to speak are those who have some reservations. A sampling of responses would be the following: (1) How "irresponsible" must someone have been with their health to merit denial of expensive life-prolonging care? If they smoked for twenty years but have given up smoking for the past ten, would we still be justified in denying them life-sustaining care? What if during that ten-year period they relapsed four times for several months each time? How many fast food meals would one have to consume per year to be subject to this denial? And who would be keeping track? And who would judge which sorts of anti-health behaviors, such as speeding on a rain-slick highway, would result in this penalty? (2) How would a rationing protocol such as this change the professional role of physicians? Would we have to label some physicians as "prosecutorial physicians" and others as "defense physicians" so that patients would know with whom they could be candid about their health history? Would we have "Fifth Amendment rights" with respect to our

health history? (3) How would we factor in our genetic endowment in making judgments about responsibility for our health circumstances? Some people have genes that result in very high levels of the “bad cholesterol” (and early heart attacks), even if they eat what would appear to be a reasonably healthy diet. (4) And what about individuals who have been victims of abuse, who have taken up less than healthy behaviors (e.g., smoking or over-eating) in connection with that abused behavior?

This is a compact list of some considerations that emerge in this dialogic process. Further, these considerations are often quite effective in getting those who strongly agree with the suggested rationing protocol to change their minds, or at least to express much less confidence in the rightness of their moral judgment. This happens quickly, in part because individuals have not thought carefully about their views, in part because most people are more reasonable and less rigid than we expect. On a small scale, this suggests that rational democratic deliberation can be successful in the real world; it is not just a philosopher’s utopian thought experiment.

We return now to Daniels’ “democracy problem.” If we see rational democratic deliberation as a matter of pure procedural justice, then there is no correcting of results that seem counterintuitive. On the other hand, if it can be corrected by an appeal to some prior notion of what counts as a fair rationing outcome, then we wonder what the point of the democratic process is. Then there is Daniels’ “fair chances/best outcome” problem, which is related to the democracy problem. Recall Alice and Betty who both need a transplant, are the same age, and have spent the same period of time waiting for a transplant. Both will be dead in a week without the transplant. Alice will live only two years, while Betty will live twenty. Who should get the transplant? We get the best outcome, maximum number of quality-adjusted life years saved, by saving Betty. But Alice wants a lottery, arguing that each has an equal right to life. Both have reasonable and morally compelling considerations on their side. Oregon’s democratic deliberations favored the net benefit approach. Does Alice have a moral right to be aggrieved at this result? Has she been harmed in a morally significant sense? Does this undermine the moral authority of the democratic deliberative process for yielding just results?

I believe my model of rational democratic deliberation can respond to Daniels’ challenges. We assume that no matter how fine-grained a conception of health care justice we develop, it will never be fine-grained enough to generate a uniquely correct complete set of just rationing protocols. There are innumerable reasonable, morally permissible trade-offs that might be made in the course of articulating some set of rationing protocols. This moral space is “the domain of just democratic decision-

making.” Again, within this space we cannot identify the “most just” set of rationing protocols possible for our society or our managed care plan. Many possible trade-off patterns will be “just enough,” all things considered, especially when we recall that other values besides justice are a legitimate part of the overall moral equation.

Note that two critical conditions elicit the need for a democratic deliberative process and morally justify that appeal. The first is that we cannot simply allow individual liberty to operate with respect to the resolution of this particular rationing decision. For if we did allow medical, administrative, or consumer discretion to be ultimately and pervasively determinative, then there would be the potential for unjust, arbitrary, and discriminatory results, though I emphasize again that there is a domain beyond justice where such individual discretion, along with social beneficence, is morally permissible.

Imagine, for example, that our managed care plan must decide whether to use high osmolality contrast agents (HOCAs), as opposed to low osmolality contrast agents (LOCAs) for CT scans. HOCAs cost \$10 per dose while LOCAs cost \$180 per dose.⁷⁴ There is one chance in a thousand that the less expensive drug will cause anaphylactic shock, which can be reversed by health professionals who know they must be prepared for such events. The cost difference seems relatively small for any individual case. However, given the millions of CT scans done each year in the United States, we would add at least \$2 billion to total costs if we used only LOCAs, with proportional results in any managed care plan.

It is easy to imagine a health plan choosing the less expensive drug through the sort of democratic deliberative process we envision. If it meant saving \$2 billion per year that could be used to meet what plan members judged to be higher priority health needs for themselves, then that is both rational and just. But nothing is obviously wrong with choosing the more expensive drug. However, if the choice of drug were left to medical or administrative discretion, then it is easy to imagine more knowledgeable and assertive patients demanding the more expensive drug, or physicians permitting daily subtle biases associated with friendship and social class to affect their decisions. This would clearly be unfair. In this case we could allow wealthier consumers to purchase the more expensive drug with their own private resources (unsubsidized by tax deductions); and this would not be unfair because the benefits are very marginal, the majority of other plan members have traded off their access to that drug for other health benefits they judge more important, and other plan members are not harmed by private purchases.

Our second condition for appealing to the rational democratic

deliberative process is that there are plural choice possibilities, all of which have prima facie moral and political legitimacy, but none of which are unequivocally superior from a moral, political, or rational perspective. “Prima facie moral and political legitimacy” means that the constraints represented by our constitutional principles of health care justice are not violated. This is the situation regarding Alice and Betty. A good case can be made for going with a decision rule that might favor a lottery in this situation, or going with net benefits. Any number of complex decision rules might be adopted, especially if we vary morally relevant case facts, such as age of the individuals, likelihood of survival for each, morally permissible quality of life considerations, and so on. What is morally important is that whatever decision rule we adopt through the democratic deliberative process must be applied consistently over time to all members of the society/health plan. So long as that decision rule is in place and was, in fact, approved by both Alice and Betty, or their democratic representatives, when they did not know their future medical circumstances, neither one will have just cause for moral complaint, no matter what the outcome.

Again, individual participants in this democratic process are ongoing members of this community so that the trade-offs they agree to, some specific distribution of benefits and risks, is a distribution that they are imposing on themselves. That is, in many cases of rationing, say, with reference to the health care needs of the elderly (our future elderly selves), the distribution of benefits and risks does not occur simultaneously for any individual. It would clearly be unfair for a younger individual to derive the benefits of rationing health care for the elderly and then have the option of exiting that health plan as an older person in order to escape the risks and burdens of rationing for an older individual.

To address Daniels’ democracy problem, in the case of Alice and Betty a number of rational “just enough” decision rules might have been chosen. The deliberative process yields a decision among those options, provides a reasoned account for that decision, and legitimates that decision. In that respect, the process is not otiose. A philosopher or managed care administrator could have made “the same decision,” but it would not have the same moral legitimacy because the democratic deliberative process is an essential part of the legitimacy of the decision itself. This is what makes the decision an autonomous choice for all individuals in the group, even if some disagree with that specific choice. A deliberative decision can “go wrong” in all the usual ways, just as scientific research can “go wrong” in all the usual ways. Any particular deliberative decision might violate one of our constitutional principles of health care justice, just as we argue in our

legal system about whether “hate speech” ought to be protected under our constitutional commitment to freedom of speech. Or a particular deliberative decision might fail to take into account relevant scientific facts about Herceptin or the artificial heart or other medical technologies that might be the focus of a rationing decision. Or a particular deliberative decision may fail to give due weight to the pattern of reasons and prior considered judgments of health care rationing within the managed care plan, thereby creating a kind of moral incoherence that would threaten the legitimacy of the decision. In all such cases, the necessary corrective, as in the scientific enterprise, would be more democratic deliberation since no other ultimate authority exists for an appeal.

Two other points must be made briefly with respect to understanding the moral and political legitimacy of rational democratic deliberation. The first is that our constitutional principles of health care justice have emerged and will continue to emerge through the same process of moral discourse that has generated contemporary medical ethics. This means that these principles are modified, refined, and specified through their use in the deliberative process in addressing a broad range of concrete rationing problems. This is analogous to the decision-making process of the U.S. Supreme Court. The adequacy of any particular set of constitutional principles of health care justice will be determined from the perspective of wide reflective equilibrium, which is to say there are coherence considerations among the principles that would have to be worked out, as well as coherence considerations between the principles and proposed sets of rationing protocols within a given managed care plan. In addition, we would have to account for the actual empirical consequences of putting a particular set of rationing protocols in place, plus other empirical considerations related to emerging medical technologies and other aspects of medical practice.

Coherence considerations should not be overstressed. “Rough coherence” among our rationing protocols in a particular managed care plan will be “just enough.” There is no moral necessity of having perfect consistency among various rationing trade-offs that have been rationally democratically approved. Again, to address Daniels’ concerns, the constitutional principles of health care justice provide normative reference points for critically assessing the process and outcomes of our democratic decision-making process; but clearly they are incapable of yielding the outcomes that are needed from the process itself, which is to say that they do not render the process itself otiose.

My second point is this: While these principles and the democratic deliberative process together comprise the domain of health care justice,

there is also this domain beyond justice, a domain of individual freedom and social beneficence. This domain provides moral space in which individuals can use their own private resources to purchase health services not required by just health care policies, and various social groups can choose to be differentially beneficent in ways that reflect their specific comprehensive visions, which may be shared by only a small subset of the membership of a given managed care plan. That is, a church or social group may choose to raise the funds for, say, Herceptin therapy for one of their members who otherwise would be denied it because it is not included in the health services package guaranteed to all. In a liberal society this is not obviously unjust.

V. LAST CHANCE THERAPIES AND RATIONAL DEMOCRATIC DELIBERATION

Before concluding, I return to Daniels' other challenges to argue that my model of rational democratic deliberation is capable of meeting those challenges.

First, recall the moral distinction between "slice-of-time" and "course-of-life" issues of just health care rationing. "Slice-of-time" issues mean that the degree to which an individual has used the health care system in the past will be morally irrelevant to judging whether that individual has a just claim now, say, to an expensive form of life-prolonging medical care. The "course-of-life" perspective means that prior use of the health care system may justly constrain meeting current health needs. My claim is that our deliberative process, properly structured, can determine the moral appropriateness of either perspective in particular circumstances. That is, there are no strong moral principles that absolutely require we choose one or the other in specific circumstances. There is ample deliberative space. However, we should also note that the deliberative process as a whole requires a comprehensive "course-of-life" perspective if we hope to have an overall just, stable, effective approach to health care rationing. Isolated, episodic rationing decisions are almost certain to be unjust.

Some of Daniels' challenges under the "priorities" problem or the "aggregation" problem lose much of their moral force when we recognize this. For example, should we fund TIAHs in the Medicare program or a prescription drug benefit? Should we reduce our level of commitment to artificial hearts for middle-aged individuals if we can purchase instead computerized functional assistance for ten disabled persons with the same funds? The apparent moral difficulty of the examples derives from the unstated assumption that individuals are already ensconced in one or another of these groups by virtue of their being afflicted with a specific medical problem. That is, we are looking at these examples from the

current point in time. But if we go back to that prior point in time when we need to join a health plan, and if we have little knowledge of what our future health needs might be, and if we have to make a decision about a fair and prudent allocation of health resources with a limited budget, then our problem looks like simply a macro version of the Alice and Betty problem, or the Abby problem. That is, there might be a number of morally permissible, “just enough,” trade-offs we might make through a process of rational democratic deliberation, none of which are uniquely morally required.

We need to say more about the slice of time/course of life problem of health care rationing. When we are faced with the need to make a costly rationing decision, why do we sometimes consider morally relevant prior use of the health care system and at other times judge it morally irrelevant? A critic might say:

What generates a presumptively just claim to limited health resources is having a health need. A need is a need; it is morally irrelevant how often that need has occurred for a particular individual (as in the case of a serious chronic illness). If it is a genuine health need, then it must be treated consistently as such.

But my contention is that many other morally relevant considerations can come into play at different points in an individual’s life and modify that health need in a way that would justify our giving that “same” need lower priority at one point in time as opposed to another. There are at least six potentially morally relevant variables that could have a bearing on whether we respond to a particular need from a course-of-life perspective or a slice-of-time perspective. These six variables are: (1) quality of life (currently and after treatment), using Daniels’ fair equality of opportunity account to give moral concreteness to this notion; (2) age; (3) probability of survival if the patient has access to expensive life-prolonging intervention; (4) number of additional life-years gained as a result of treatment; (5) cost per extra life-year gained; and (6) prior just democratic rationing agreements.

Space does not permit a long explanation of each variable. But I can offer some helpful illustrative analysis in connection with our “last chance therapy” problem. I argue that age is a morally relevant consideration in making some sorts of rationing decisions.⁷⁵ Fair and prudent individuals, ignorant of their future life expectancy, would likely allocate more resources to relatively younger years than is currently the case in our society in order to maximize the probability of their achieving a normal life expectancy. This view implies we could pick an age beyond which

individuals would not have access to the artificial heart at social expense. If we picked age seventy for that purpose, we would be committing ourselves to producing and paying for about 100,000 of these artificial hearts per year, which is roughly the predicted need prior to that age. Why age seventy and why 100,000? These numbers are somewhat arbitrary. Democratic deliberation could alter these numbers up or down justifiably, depending upon a number of variables. Here are some judgments of which I am morally confident that a democratic deliberative process could justly endorse.

First, it would be unjust if there were no public funding for artificial hearts under any circumstances. This is because there would be thousands of relatively young individuals who would be faced with premature death from cardiac failure and no other medical alternative to significantly prolong their lives. It would be unjust to determine access to TIAH entirely by individual ability to pay or ability to elicit a charitable response from some local community.

Second, it would not necessarily be unjust to exclude access to the TIAH from the Medicare benefit package, thereby leaving access to individual ability to pay. To simplify what are in fact very complex possible policy trade-offs, if secure access to prescription drugs for the elderly at \$30 billion per year or more is what we have to give up as a Medicare benefit in order to cover some number of artificial hearts, then I would argue strong egalitarian, utilitarian, and prudential considerations would all justify choosing the prescription drug benefit instead of the TIAH.

Third, it is expected that on average the TIAH would increase the life expectancy of an individual by five years. I would argue that we could justly make differential distributions of the TIAH in connection with predicted life expectancy in specific medical circumstances through the deliberative process. Thus, if an individual were sixty-eight, and if we did permit access to the TIAH at Medicare expense for those under age seventy, we could have a democratically legitimated rule that such an individual would have to have a minimal predicted life expectancy of more than two years in order to have an actual just claim to the TIAH. Such a rule would not violate any constitutional principle of health care justice. That individual could still purchase a TIAH from his or her own resources, which means that a poorer individual in the same circumstances would not have been treated unjustly if he or she then dies at age sixty-eight because he or she cannot afford the TIAH. But there is another part to this rule. We could justly pay for access to the TIAH for younger individuals, say, age sixty or below, even if they were unlikely to survive two years, as long as it was likely they would survive a year, part of the moral justification being that they

had not had the opportunity to live as long a life as others.

Fourth, we can imagine a fifty-two-year-old individual who is HIV-positive, whose life has been sustained for the past twenty years by protease inhibitors (or their successors) at a total cost of \$400,000, who now has a failing heart, and who might survive no more than two to three years with the TIAH. Such an individual has a presumptively just claim to a TIAH, and our constitutional principle of health care justice regarding the protection of fair equality of opportunity would warrant that presumption. His past use of the health care system would be morally irrelevant to making a fair rationing judgment now. But if we alter this scenario just a bit, then we will get a different result. Imagine that he has moderate to advanced AIDS dementia. Then I would argue we could justifiably deny him the TIAH, appealing to the “current and future quality of life criterion” mentioned above. This is a very complicated area for moral analysis, complicated by potential threats to the rights of disabled individuals. But this issue can be justly addressed.

My goal would be to provide individuals with disabilities whatever resources were available in our society for protecting effectively their access to fair and effective equality of opportunity. We have an array of technologies today—often expensive—for providing to individuals functional equivalents for various disabilities. All other things being equal, we would have a strong moral obligation to provide access to such technologies. However, the most crucial morally relevant consideration is that such access will result in effective functional restoration to a significant degree. If such an individual developed heart failure at age fifty-two, as with our HIV-positive patient, then he would have an equally strong claim to a TIAH at societal expense, and prior societal expenditures on his behalf would be morally irrelevant. Similarly, if he were afflicted with some untreatable serious dementia, as with our HIV-positive patient who developed AIDS dementia, then he could be justly denied access to a TIAH, and this would not represent any form of unjust discrimination against disabled individuals, especially if it were the case that there were rational democratic legitimation of a general rationing guideline that would deny our own possible future demented selves access to expensive life-prolonging medical care under those circumstances. As nearly as I can tell, such a democratically endorsed judgment would not violate any constitutional principle of health care justice. It would not be discriminatory in a morally objectionable sense, nor would it violate the equal moral respect to all persons.

This analysis provides us with a helpful perspective for addressing some specific instances of last chance therapies. Again, these are just

schematic comments. Consider Herceptin. Many of the women faced with metastatic breast cancer will be relatively young or middle-aged. This would typically trigger the judgment that justice requires doing everything medically possible to prolong their lives for as long as they find their lives worth living so that they have an opportunity to achieve a normal life expectancy. However, the background assumption is that the life gained is significant and costworthy. This would be a questionable assumption if the average gain in life expectancy is only five months more than alternative available therapies, and if the cost of achieving that result is more than \$70,000, which works out to a cost per QALY of about \$160,000. Here Eddy's strategy in thinking about breast cancer options is quite apropos.

We must ask ourselves whether there are other investments for health dollars where we can save more high-quality life years at a lower cost. But perhaps a morally and politically better way to ask the question would be to consider whether there are alternate investments in cancer prevention or cancer therapy—especially cancers for which women might be at greater risk—that would reasonably and justifiably command the dollars otherwise to be spent on Herceptin. Again, if we imagine Eddy's thousand women working for a company with a better-than-average (but limited) health benefit package at an earlier point in time deciding collectively and autonomously what to include in that benefit package, it is hard to imagine that they would include Herceptin, given all their other possible health care needs. Thus, women denied access to Herceptin at social expense would not be treated unjustly.

This social judgment has other beneficial effects worth noting. It provides helpful information to women and their families in such circumstances. It says that a thoughtful social judgment has been made that this therapy is marginally beneficial at best and not costworthy, that a family that was tempted to sacrifice access to a college education for their children in order to purchase Herceptin would be making an unwise choice. Similarly, churches and other social organizations hold fundraisers to help underwrite the costs of very expensive medical interventions that offer the only hope for individuals otherwise faced with imminent death. This is the domain of beneficence, charity freely given. We generally applaud such efforts, though if the analysis above is correct, the implication is that there will be times when such applause ought to be withheld.

Though we see charitable responses as something "freely offered," not a matter of moral obligation in most specific instances, this does not mean that thoughtless or unreflective charitable giving should be commended. Again, we need to keep in mind that charitable dollars are limited; few

churches or other social organizations could afford to raise the funds for all expensive, life-prolonging medical care their members might need that are not covered by public or private insurance. Thus, if there is a public, democratically ratified rationing protocol that would deny women with metastasized breast cancer access to Herceptin for the reasons given above, then the implicit message to socially beneficent organizations is that they should not imprudently expend their resources to assist such individuals in unfortunate circumstances to gain access to Herceptin.

This same analysis helps us address the challenges posed by the Rule of Rescue and identified individuals needing access to last chance therapies. Nothing will diminish the psychological difficulty of dealing with these circumstances. The Rule of Rescue in its traditional application is morally compelling, in part, because it rarely needs to be employed, at least outside health care. But given our enormously expanding technological capacity for maintaining life, and focusing on the urgency of the present medical circumstances of an individual, the Rule of Rescue has pervasive applicability. It is wholly without the moral context that originally made it a reasonable moral rule. Applied to health care in this promiscuous fashion, it will completely undermine any fair or reasonable effort at health care rationing and health care cost containment.

Finally, the identified individuals in these urgent, tragic, and unfortunate circumstances are certainly entitled to a caring and compassionate response from our society. There are many ways in which this compassionate response might be conveyed. But the moral requirement of compassion must not be confused with the moral obligations of justice. Providing such unfortunate individuals (women wanting access to Herceptin) with health resources to which they have no just claim, thereby diminishing the pool of resources to which others have a just claim, represents a failure of both compassion and justice.

References

1. Norman Daniels & James Sabin, *Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers*, 26 PHIL. & PUB. AFF. 303 (1997); see also Norman Daniels & James Sabin, *Last Chance Therapies and Managed Care: Pluralism, Fair Procedures and Legitimacy*, HASTINGS CENTER REP., Mar.-Apr. 1998, at 27.

2. I emphasize that I am talking about the structure of the U.S. health care system as it is now (more or less) to make clear that I am not writing a utopian essay. Still, two features of our system make health care justice virtually impossible: lack of universality and the link to private employers. The Clinton health reform plan from 1993 showed that both of these features of our health system could be radically altered and that such alteration was politically realistic. Although the Clinton plan failed, it did not fail because it embraced universal coverage or because it severed the link between health insurance and employment.

3. EZEKIEL EMANUEL, *THE ENDS OF HUMAN LIFE: MEDICAL ETHICS IN A LIBERAL POLITY* (1991).

4. MICHAEL SANDEL, *LIBERALISM AND THE LIMITS OF JUSTICE* (1982).

5. JOHN RAWLS, *POLITICAL LIBERALISM* (1993).

6. Two of the more prominent writers about health care rationing who would endorse this point are David Eddy and Paul Menzel. See generally DAVID EDDY, *CLINICAL DECISION MAKING: FROM THEORY TO PRACTICE* (1996); PAUL T. MENZEL, *MEDICAL COSTS, MORAL CHOICES: A PHILOSOPHY OF HEALTH CARE ECONOMICS IN AMERICA*

(1983); PAUL T. MENZEL, *STRONG MEDICINE: THE ETHICAL RATIONING OF HEALTH CARE* (1990).

7. Dennis J. Slamon et al., *Use of Chemotherapy Plus a Monoclonal Antibody Against HER2 for Metastatic Breast Cancer that Overexpresses HER2*, 344 NEW ENG. J. MED. 783, 783 (2001); see also Brett Chase, *Gene Test Company Soaring*, CHICAGO SUN-TIMES, Sept. 9, 2001, at 41.

8. The total prevalence of congestive heart failure in the United States is 4.7 million. AMERICAN HEART ASSOCIATION, 2001 HEART AND STROKE STATISTICAL UPDATE 19 (2000), available at <http://www.americanheart.org/presenter.jhtml?identifier=1928> [hereinafter HEART UPDATE]. Total deaths from all cardiovascular diseases in the United States in 1998 were 949,619. Total prevalence of all forms of cardiovascular disease in the United States is sixty-one million. *Id.* at 4. See also Mariell Jessup, *Mechanical Cardiac-Support Devices—Dreams and Devilish Details*, 345 NEW ENG. J. MED. 1490 (2001); Eric A. Rose et al., *Long-Term Use of a Left Ventricular Assist Device for End-Stage Heart Failure*, 345 NEW ENG. J. MED. 1435 (2001).

9. *Fourth Abiocror Heart Patient Recovering*, BOSTON GLOBE, Oct. 19, 2001, at A15.

10. Of all deaths from heart disease in the United States, about 220,000 are sudden. HEART UPDATE, *supra* note 8, at 3-4. Of the patients who died from heart disease, half could have benefited from a TIAH if it had been provided before their disease progressed too far. This is a very approximate figure. The reader should know that considerable confusion of medical and political/economic judgments occurs when decisions must be made regarding the number of candidates for the

TIAH. This was also true in the early years of dialysis. At that time, clinically suitable candidates for dialysis were thought to be patients between fifteen to forty-five-years-old. Today the fastest growing cohort of dialysis patients is over age seventy-five. Aaron and Schwartz document that in Britain in the 1980s “medical judgments” of suitability for dialysis masked what were really rationing judgments based on economics alone. HENRY J. AARON & WILLIAM B. SCHWARTZ, *THE PAINFUL PRESCRIPTION: RATIONING HOSPITAL CARE* 34-37 (1984).

11. See Shoo K. Lee et al., *Variations in Practice and Outcomes in the Canadian NICU Network: 1996-1997*, 106 *PEDIATRICS* 1070, 1076 (2000). This study finds that 7% of about 3,800 very low birth weight (VLBW) infants in seventeen Canadian NICUs (which represented approximately 75% of the total Canadian NICU beds) had necrotizing enterocolitis (NEC). That is approximately 300 infants. The U.S. experience is the same, which would mean about 4,000 infants are born each year in the United States with the disorder. See James A. Lemons et al., *Very Low Birth Weight Outcomes of the National Institutes of Child Health and Human Development Neonatal Research Network, January 1995 Through December 1996*, 107 *PEDIATRICS* e1 (2001), at <http://www.pediatrics.org/cgi/content/full/107/1/e1> (finding that 7% of VLBW infants in fourteen NICU sites had NEC). For survival, all of the infants would need either TPN or PN, depending upon degree of intact remaining gut.

12. Jon A. Vanderhoof & Alan N. Langnas, *Short-Bowel Syndrome in Children and Adults*, 113 *GASTROENTEROLOGY* 1767, 1774 (1997).

13. *Id.* at 1774 (“The most common life-threatening problem to face patients

with intestinal failure is the development of total parenteral nutrition-induced liver failure.”).

14. See J.H. Best et al., *Trends in Expenditures for Medicare Liver Transplant Recipients*, 7 *LIVER TRANSPLANT* 858 (2001); J.C. Bucuvalas et al., *Predictors of Cost of Liver Transplantation in Children: A Single Center Study*, 139 *J. PEDIATRICS* 66 (2001).

15. Data on file with author. Also, Vanderhoof & Langnas report that prospects for liver/small bowel transplants have improved over the past several years with one-year survival rates of about 65%. Vanderhoof & Langnas, *supra* note 12, at 1774. Still, five-year survival rates will be smaller because of the many medical complications entailed by this surgery.

16. Stephen Heffler et al., *Health Spending Growth Up in 1999; Faster Growth Expected in the Future*, *HEALTH AFF.*, Mar.-Apr. 2001, at 193, 194.

17. I need to emphasize the phrase “acceptable quality of life.” We are generally not talking about life-prolonging interventions that compromise quality of life to such a degree that most reasonable persons would reject them.

18. Slamon et al., *supra* note 7, at 786.

19. See *Study: HAART Less Costly Than Treatment for AIDS*, *AIDS ALERT* (American Health Consultants, Atlanta, GA), Feb. 1, 2001, at 26, at http://www.ahcpub.com/ahc_online/aa.html.

20. U.S. Renal Data System, *USRDS 2001 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*, Section K, Economic Costs of ESRD, Table K20 2001 at <http://www.usrds.org/adr.htm>. [hereinafter *USRDS Report*]. The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S.

government.

21. There is obvious room for argument here. The boundaries I am suggesting are not perfectly sharp. The TIAH, for example, promises (for the future) average gains in life expectancy of five years. It is unlikely that any of the four patients that currently have these devices will survive that long. But younger patients in the future, with fewer co-morbid conditions, are likely to survive much more than five years, making the device for them look more like dialysis and less like Herceptin.

22. E. HAAVI MORREIM, *BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS* 45-70 (1991).

23. The Helga Wanglie case is one well-known example of this issue. Helga Wanglie was eighty-six-years-old and in a persistent vegetative state for fourteen months before she died. Her care for that period cost about \$800,000. Many, perhaps a vast majority of us, would regard such care as wasteful and inappropriate. But her husband and children did not. Ronald Cranford, *Helga Wanglie's Ventilator*, HASTINGS CENTER REP., July- Aug. 1991, at 23, 24.

24. In this Article I cannot rehearse all the arguments and evidence to support that point. See, e.g., GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* (1978); DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1986) [hereinafter *SETTING LIMITS*]; DANIEL CALLAHAN, *WHAT KIND OF LIFE: THE LIMITS OF MEDICAL PROGRESS* (1990) [hereinafter *WHAT KIND OF LIFE*].

25. Leonard M. Fleck, *Pricing Human Life: The Moral Costs of Medical Progress*, 34 *CENTENNIAL REV.* 227 (1990).

26. H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 375-410 (2d ed.

1996).

27. For more detailed criticisms of Engelhardt's position, see my earlier critical assessment of his libertarian views on health care. Leonard M. Fleck, *Just Health Care (I): Is Beneficence Enough?*, 10 *THEORETICAL MED.* 167 (1989) [hereinafter *Just Health Care (I)*]. See also Ezekiel Emanuel & Linda Emanuel, *Preserving Community in Health Care*, 22 *J. HEALTH POL., POL'Y & L.* 147, 165-69 (1997).

28. NORMAN DANIELS, *JUST HEALTH CARE* 1-35 (1985) [hereinafter *JUST HEALTH CARE*].

29. USRDS Report, *supra* note 20, at Table K20. Per patient cost in 1999 for all end stage renal disease was \$45,286.

30. The number of ESRD patients in 1998 was 323,821, with 85,000 new cases each year, and 63,000 deaths. *HEART UPDATE*, *supra* note 8, at 18. The number of ESRD patients is multiplied by per patient cost to get approximate total Medicare costs.

31. Allen Buchanan, *Managed Care: Rationing Without Justice, but Not Unjustly*, 23 *J. HEALTH POL., POL'Y & L.* 617 (1998).

32. *Id.* at 618.

33. To be clear, Buchanan is not endorsing this as a morally unalterable state of affairs. On the contrary, his goal is to convince middle class members of managed care plans that if there is no just access to health care for the uninsured, then there can be no justice for them either. Secure access to needed costworthy health care requires that the middle class construct explicit socially legitimated understandings of health care justice. *Id.* at 632-33.

34. RAWLS, *supra* note 5, at 54-58.

35. Norman Daniels, *Rationing Fairly: Programmatic Considerations*, 7 *BIOETHICS* 224, 224 (1993) [hereinafter *Rationing*

Fairly].

36. MICHAEL WALZER, SPHERES OF JUSTICE: A DEFENSE OF PLURALISM AND EQUALITY (1993).

37. I explain and defend this point more fully in two of my earlier articles. See *Just Health Care (I)*, *supra* note 27; Leonard M. Fleck, *Just Health Care (II): Is Equality Too Much?*, 10 THEORETICAL MED. 301 (1989).

38. I explain and defend in greater detail what non-ideal justice is in an earlier article. See Leonard M. Fleck, *DRGs: Justice and the Invisible Rationing of Health Care Resources*, 12 J. MED. & PHIL. 165, 165-76 (1987) [hereinafter *DRGs*].

39. See, e.g., RAWLS, *supra* note 5, at 212-54; John Rawls, *The Idea of Public Reason Revisited*, 64 U. CHI. L. REV. 765 (1997); John Rawls, *Reply to Habermas*, 92 J. PHIL. 132 (1995).

40. See NORMAN DANIELS, JUSTICE AND JUSTIFICATION: REFLECTIVE EQUILIBRIUM IN THEORY AND PRACTICE (1996), especially chapters 1-3, 8, and 16. Wide reflective equilibrium is a coherentist approach to moral justification. It rejects the idea of a moral reality "out there" that correct moral judgments must match to be justified. Instead, it relies upon a web of considerations to justify and stabilize our moral judgments. That web includes scientifically established facts about human beings and the world, well-grounded moral theories, and "considered moral judgments" of all degrees of generality that have proven consistently effective in addressing real world moral problems. Justification in the law seems to work in much the same way with appeal to facts about the world, constitutional principles, established law, and case precedent to justify legal judgments made with respect to concrete legal conflicts.

41. Daniels & Sabin, *supra* note 1

(citing both articles).

42. Leonard M. Fleck, *Just Health Care Rationing: A Democratic Decisionmaking Approach*, 140 U. PA. L. REV. 1597, 1617-21 (1992) [hereinafter *Democratic Approach*].

43. Emanuel & Emanuel, *supra* note 27.

44. EMANUEL, *supra* note 3, at 97-244.

45. *Id.* at 185-92.

46. See RAWLS, *supra* note 5, at 133-73.

47. JUST HEALTH CARE, *supra* note 28.

48. *Rationing Fairly*, *supra* note 35.

49. The goal of the Oregon priority setting process was to establish a comprehensive ranking of health care interventions from those most worthy of public funding to those least worthy. A total of 709 medical conditions and associated treatments (called condition-treatment pairs) were so ranked using community values (elicited from community dialogues, polling, and focus groups), expert medical opinion regarding effectiveness, and relevant cost data. The comprehensiveness of the process and the appeal to explicit community values made this a unique social experiment. The fact that the process was limited to a much-expanded Medicaid population (a major goal of the process) opened its backers to moral criticism since Medicaid recipients were under-represented in the process. See Michael Garland, *Oregon's Contribution to Defining Adequate Health Care*, in HEALTH CARE REFORM: A HUMAN RIGHTS APPROACH 211 (Audrey R. Chapman ed., 1994).

50. Leonard M. Fleck, *Just Caring: Oregon, Health Care Rationing, and Informed Democratic Deliberation*, 19 J. MED. & PHIL. 367, 374-80 (1994) [hereinafter *Oregon*].

51. *Rationing Fairly*, *supra* note 35, at 225-27.

52. See PETER UBEL, PRICING LIFE: WHY IT'S TIME FOR HEALTH CARE RATIONING 1-10 (2000). QALYs were introduced by health

researchers to facilitate fine-grained effectiveness comparisons across numerous medical outcomes. A scale of 0 to 1 is used. Earlier discussions had only focused on saving life-years. But it was noted by some that we should not spend as much money on a life year of 0.1 quality as opposed to 0.9 quality. Many see this as threatening to the rights of disabled individuals who need expensive health care.

53. *Rationing Fairly*, *supra* note 35, at 227-28.

54. See Jackie Koszczuk, *Dried-Up Shelves RX Deal; Congress is Unlikely to Expand Medicare*, PITTSBURGH POST-GAZETTE, Aug. 31, 2001, at A17.

55. *Rationing Fairly*, *supra* note 35, at 232.

56. WHAT KIND OF LIFE, *supra* note 24, at 31-68.

57. The cost of transplantation for either the TIAH or LVAD would be approximately the same at \$160,000. See Byron Spice, *Heart Transplant Alternative?; Implantable Pump Lets Some Patients Live Longer, Live Well*, PITTSBURGH POST-GAZETTE, Nov. 13, 2001, at A3.

58. HEART UPDATE, *supra* note 8.

59. See David Eddy, *The Individual vs. Society: Is There a Conflict?* 265 JAMA 1446, 1446 (1991) [hereinafter *Individual vs. Society*].

60. See David Eddy, *High-Dose Chemotherapy with Autologous Bone Marrow Transplantation for the Treatment of Metastatic Breast Cancer*, 10 J. CLINICAL ONCOLOGY 657 (1992).

61. Slamon et al., *supra* note 7, at 783.

62. Edward A. Stadtmauer et al., *Conventional-Dose Chemotherapy Compared with High-Dose Chemotherapy Plus Autologous Hematopoietic Stem-Cell Transplantation for Metastatic Breast Cancer*, 342 NEW ENG. J. MED. 1069 (2000); see also Michelle M.

Mello & Troyen A. Brennan, *The Controversy over High-Dose Chemotherapy with Autologous Bone Marrow Transplant for Breast Cancer*, HEALTH AFF., Sept.-Oct. 2001, at 101.

63. See UBEL, *supra* note 52, at 67-95. Ubel cites social research showing people will often prefer less economically efficient means of saving lives if this means more people will have "a chance" of having their lives prolonged. That is, they categorically reject rules that would exclude individuals from any access to expensive life-prolonging care because their chance of benefit was too small.

64. Coby Howard died at age eight, having fallen short of raising the \$100,000 needed for a bone marrow transplant. Loyola University Hospital in Chicago refused to attempt separation of the Lakeberg twins. The ethics committee of the Hospital argued that this was an unjust use of resources needed to meet the health needs of the poor in the area. The twins were separated in Philadelphia at a cost of more than \$1 million. Since they shared a single six-chambered heart that needed to be reconstructed surgically, one twin was sacrificed in surgery. The other survived almost one year, never having left the hospital.

65. The Christine deMeurers case is a good example of this. See Alex London, *Bone Marrow Transplants for Advanced Breast Cancer: The Story of Christine deMeurers*, in ETHICAL ISSUES IN MODERN MEDICINE 686 (John Arras & Bonnie Steinbock eds., 1999).

66. I discuss precisely this example in my article *Just Caring: Managed Care and Protease Inhibitors*, in ETHICAL ISSUES IN MODERN MEDICINE 679 (John Arras & Bonnie Steinbock eds., 1999).

67. I speak of "constitutional principles of health care justice" in a metaphorical

sense. These are the broad moral principles needed to constrain democratic deliberation about health care rationing by identifying rationing protocols or practices that are inappropriate (i.e., violate one of these principles). In my conception, constitutional principles of health care justice would include the “publicity principle” (putting out of bounds invisible rationing), an “equal respect for persons principle” (putting out of bounds a range of improper discriminatory judgments), and a “fair equality of opportunity principle” (following Daniels in distinguishing health interventions that make stronger or weaker just claims on health resources). See JUST HEALTH CARE, *supra* note 28. I lay out the core of my views in two earlier articles: *Democratic Approach*, *supra* note 42, and *Oregon*, *supra* note 50. Space does not permit a full account of these constitutional principles of health care justice or my model of rational democratic deliberation. This will be found in a book-length manuscript I am now finishing for Oxford University Press titled JUST CARING: THE MORAL AND PRACTICAL CHALLENGES OF HEALTH REFORM AND HEALTH CARE RATIONING (forthcoming 2003). In the meantime I am sympathetic to the work of Gutmann and Thompson, who also elaborate constitutional principles that would constrain democratic deliberation. See AMY GUTMANN & DENNIS THOMPSON, *DEMOCRACY AND DISAGREEMENT: WHY MORAL CONFLICT CANNOT BE AVOIDED IN POLITICS AND WHAT SHOULD BE DONE ABOUT IT* (1996). Finally, a very important essay foundational to my conception of deliberative democracy is Joshua Cohen, *Deliberation and Democratic Legitimacy*, in *DELIBERATIVE DEMOCRACY: ESSAYS ON REASON AND POLITICS* 67 (James Bohman & William Rehg eds., 1997).

68. RAWLS, *supra* note 5, at 66-71.

69. I have argued at great length in two earlier articles for this point against Calabresi and Bobbit, who would defend invisible rationing to avoid the risk of social divisiveness, especially when life itself is at stake, as in last chance therapy situations. *Just Health Care (I)*, *supra* note 27. See also *DRGs*, *supra* note 38; Leonard M. Fleck, *Justice, HMOs, and the Invisible Rationing of Health Care Resources*, 4 *BIOETHICS* 97 (1990). Daniels & Sabin, *supra* note 1 (citing both articles), are equally strong defenders of Rawls' publicity condition and critics of invisible forms of health care rationing. The main problem with invisible rationing, from a moral point of view, is that it subverts both social trust and our capacity for democratic deliberation.

70. *Oregon*, *supra* note 50, at 374-75.

71. *Individual vs. Society*, *supra* note 59.

72. *Id.*

73. The first of these projects was conducted in Goshen Indiana over an eighteen-month period (1985-86) with the help of a grant from the Indiana Committee for the Humanities and the Goshen Hospital and Health Care Foundation. The concern of the hospital (and its community board) at the time was the effect of health care rationing, effected through the then new Medicare DRGs on the elderly. The results of that community dialogue project are summarized in a thirty-two page report. GOSHEN HOSPITAL AND HEALTHCARE FOUNDATION, *JUST CARING: JUSTICE, HEALTH CARE, AND THE GOOD SOCIETY* (1986) (pamphlet on file with author).

74. See David Eddy, *Applying Cost-Effectiveness Analysis*, 268 *JAMA* 2575, 2575 (1992) (noting that LOCAs typically cost ten to twenty times more than HOCAs).

75. See Leonard M. Fleck, *Justice, Age*

Rationing, and the Problem of Identifiable Lives,
in HEALTH CARE FOR AN AGING POPULATION
93 (Chris Hackler ed., 1994); *see also*
SETTING LIMITS, *supra* note 24; NORMAN
DANIELS, AM I MY PARENTS' KEEPER? (1988).