

# *Medical Humanities Report*

This Issue: Health Care Justice

Winter, 1996

## **Just Caring: The Moral and Political Challenge of Health Reform and Health Care Rationing**

by Leonard Fleck, Ph. D.

For most of the past fifteen years my academic research has been focused on what I refer to as the "Just Caring" problem. That problem is best summarized in these three questions: (1) What does it mean to be a "just" and "caring" society when we have only limited resources to meet virtually unlimited health care needs? This is the "just caring" problem at the macro-level. (2) What does it mean to be a "just" and "caring" hospital, health insurance plan or managed care plan when you have only limited resources to meet the disproportionate needs of those for whose health you have some responsibility? This is the "just caring" problem at the meso-level. (3) What does it mean to be a "just" and "caring" physician, nurse or social worker when you have only limited resources to meet the needs of your patient? This is the "just caring" problem at the micro-level.

Implicit in the "just caring" problem are the following claims:

(1) How health care is distributed in our society is fundamentally a moral and political problem, and only secondarily an economic, managerial, or organizational problem.

(2) The need for health care rationing is

inescapable.

(3) The fundamental moral value at stake with respect to the problem of health care rationing is that of justice.

(4) What is most morally problematic about health care rationing as it occurs now is that: (a) it is done invisibly, in ways that are hidden from either individual resistance or public scrutiny, and (b) it typically involves the healthy, wealthy and politically powerful imposing decisions on the sick, poor and the politically powerless.

(5) The key to correcting the moral problems identified in (4) is to devise social policies and practices that implement health care rationing in ways that are public and self-imposed, that is, through a process of rational democratic deliberation.

(6) The judgments that emerge from this process of rational democratic deliberation will be non-ideal, but they will be morally justified to the extent that they represent a moral improvement over the status quo, and are a product of free agreement among the rational social contractors affected by these judgments.

(Continued on page 2)

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(7) In a resource-constrained environment, such as a managed care plan, the key to extracting physicians from an apparently unsolvable moral dilemma -- the obligation to be both gatekeepers of social resources, and loyal advocates of their patients -- is to have rationing processes that their patients have collectively and freely agreed to.

The seven propositions above capture the core argument of the book that I am writing. This is an ambitious book. My goal is to articulate a coherent and comprehensive theory of health care justice that will contribute to the fair resolution of the numerous practical problems of justice that afflict our health care system. In this regard my work is very much in the spirit of the American pragmatist, John Dewey. That is, the theory will be complex and highly nuanced because it must be very sensitive to the empirical dimensions of our health care system and policy. I reject more simplistic, ideologically-tainted theories that either markets and individual choice, or the recognition of a universal "right to health care" will resolve the moral problems of health reform and rationing.

Here is a short list of the sorts of problems that an adequate theory of health care justice must have the resources to solve. Is it just for a hospital to deny very expensive life-prolonging medical interventions (e.g. heart transplants or autologous bone marrow transplants) to individuals who have no ability to pay and who would make large claims on the charity budgets of hospitals. Is it unjust for hospitals to create charity care budgets by overcharging their paying patients? Alternatively, are large managed care plans that extract large discounts from hospitals unjust because they substantially diminish the capacity of these hospitals to provide charity care? More broadly, who ultimately should be morally responsible for meeting the health care needs of the 43 million Americans currently without health insurance?

How should just and caring managed

care plans establish health service priorities within their plan? How can we judge whether specific cost-constraining incentives aimed at shaping the behavior of physicians or consumers are just?

Is it unjust to deny individuals above a certain age access to absolutely scarce life-saving medical resources, such as transplantable hearts or ICU beds? Given the disproportionate demands placed on the health care system by the current generation of the elderly (who make up 13% of the population but consume 35% of health resources), and the graying of the "baby boom" generation, what sorts of policies for health care rationing would be just and caring?

Is it unjust to permit the healthy in our society to purchase excellent health services at affordable prices by segregating themselves into insurance pools that exclude those with the greatest health care needs? Is there anything unjust about the federal policy that permits the middle class to have tax-free health insurance through their employers (a 40-45% subsidy of the cost of that insurance) while denying any such assistance to the uninsured working poor in our society? This subsidy represented about \$70 billion in foregone revenue to the federal government for 1995, and about \$600 billion over seven years. This is \$100 billion more than the savings Congress wants to extract from the Medicare and Medicaid programs over the next seven years. If Medicare and Medicaid represent federal subsidies to the poor and elderly, and if the need for health care rationing is inescapable, is there any moral justification for not making the middle class give up a share of their health care subsidies?

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What is most distinctive of the account of health care justice that I will offer is that it is rooted in rational democratic deliberation. As a society we have failed to create social practices that would support such broad civic deliberation. But such practices are feasible; this is not a vain utopian hope. In the field of health care the managed care plans now rapidly emerging and likely to dominate the future represent the organizational matrix within which such deliberations must be nurtured. Managed care is where the nitty-gritty problems of fair health care rationing will have to be worked out.

A major presupposition of this account is that no philosophic principles have the capacity to solve our concrete problems of health care justice "all the way down." Theory alone will not yield morally preferable or rational solutions to our concrete problems of health care justice. To address specifics we need to turn to rational democratic deliberation to achieve moral agreement on what health care policies are "just enough." These conversations are rational and morally legitimate to the extent that they are a product of "public reason."

Public reason can be thought of in two modes. In its theoretical mode public reason is responsible for the construction, interpretation, specification, and adjustment of what I refer to as "the constitutional principles of health care justice." I refer to these principles, using a legal/political analogy, as constitutional principles of health care justice because they circumscribe the "space" of just rational democratic deliberation. Democratically determined rationing policies and practices that violate these boundaries are by that very fact unjust. We might be tempted, for

example, to have as a rationing protocol in our managed care plan denying expensive life-prolonging medical care to AIDS patients who have less than a 10% chance of surviving another year. Such a proposal, however, would be presumptively unjust unless some morally compelling account could be given as to why AIDS patients should be marked out in this way. In contrast, we could rationally and democratically approve in our managed care plan a rationing protocol that would deny expensive, life-prolonging medical care to all terminally ill individuals who have less than a 10% chance of surviving another year.

Public reason also has a practical mode. In this mode public reason in rational democratic deliberation is responsible for the construction and adjustment of social policies and practices for

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resolving the difficulties associated with health care rationing at the concrete level -- e.g. in a clinical setting, managed care plan or legislative arena. Examples of such issues would include: What are the just claims to expensive, marginally beneficial, limited health care resources of the terminally ill? the elderly? the hyper-elderly (over age 85)? the chronically ill? the seriously mentally ill? individuals in a persistent vegetative state? individuals with end-stage dementia? individuals seriously physically disabled? infants born under 700 grams, 23 weeks gestation or with other gross brain anomalies? infants doomed to a very early death (less than 7 years) as a result

of a serious genetic defect? individuals whose serious health problems are largely a result of their own less-than-responsible choices?

How can we determine what counts as a just allocation of health care resources to medical research? Are desperate individuals treated unjustly if they are denied access to publicly-funded research trials (which represent their only chance of being saved) because the totality of their medical problems are such that they would not yield "clean data" as research subjects?

What criteria should be used for determining who has the most just claim to the "last bed in the ICU"? Should medical effectiveness be the dominant criterion? Would the application of such a criterion result in the unfair treatment of those who were afflicted with some serious disability? Would it be unjust to remove individuals from the ICU when patients who are more likely to benefit from ICU treatment also need access? Or should all candidates for an ICU bed have an equal chance of obtaining that bed on the grounds that all should be accorded equal moral rights?

Are there some types of health care services that are justly distributed on the basis of ability to pay? Should, for example, transplantable organs ever be distributed on the basis of ability to pay? It is likely that we will see the development of a Totally Implantable Artificial Heart (TIAH) by the year 2000. We may potentially need 350,000 such devices annually at a cost of \$150,000 each (in 1994 dollars). Because more than 70% of these would go to individuals over age 65 the potential cost to the Medicare program would be \$35 billion per year. If it was not a Medicare covered benefit, only the wealthy elderly could afford it. Would it be unjust to deny TIAHs to Medicaid beneficiaries or the uninsured in our society, or to allow individual employers to determine whether or not it would be a covered benefit in their health plans?

The genetic endowment that each of us has at conception is usually taken as a moral given, something that may be a matter of good

fortune or misfortune, but not a matter of justice or injustice. However, future genetic research and technological breakthroughs, especially in the form of embryonic genetic therapy, will call this assumption into question. There is the potential for altering radically what would count as fair equality of opportunity in our society. If we assume that such genetic embryonic therapy might be very expensive, say, \$50,000 per embryo, what would be the just claims of all future parents to such benefits for their future children? Would it be just to make such interventions available only to those who can pay? On a scale of health care priorities where would such a therapeutic intervention fit? Would this be more important from the perspective of social justice than funding the development and dissemination of the TIAH, or some expensive anti-cancer therapy?

I have provided a very long list of issues here for several reasons. First, it is important to recognize the diversity and complexity of problems of justice that an adequate theory of health care justice must be able to address. Second, these problems are very often intimately connected to one another and their solution requires a comprehensive vision of the domain of health care justice.

Third, our settled moral judgments in one area of health care justice may become suddenly unsettled as a result of technological advances. For example, from a moral point of view TIAHs are not just another addition to our transplant armamentarium. They change dramatically how we need to think about the problem of justice with regard to organ transplants. For now we can accept as tragic and unfortunate the limited numbers of transplantable organs that become available. There is little we can do to change that supply. But the development of artificial organs eliminates the natural limit to the number of TIAHs that we could produce and implant. Assuming that economic considerations or clinical judgment would create reasonable limits for the dissemination of such technologies would

be a grievous moral mistake unless we had compelling arguments for the claim that such allocation mechanisms were most likely to yield a just distribution of these life-prolonging resources. I do not believe there are such arguments; we must face directly the health care justice problem of how many artificial organs a just and caring society must produce.

Fourth, emerging problems of health care justice will force us to constantly reflect on and revise our theoretic framework of constitutional principles of health care justice. For example, we may have a reasonably settled sense of what commitment to protecting fair equality of opportunity means with respect to the problems of health care justice, until something like embryonic gene therapy comes along. The precise meaning and application of that principle may need to be revised in the light of the concrete

## **Poverty, Sickness, and the Medical Humanities**

by Judith Andre, Ph.D.

The poorer people are, the more likely they are to be sick. I suppose few readers are surprised to read that. But most Americans see the link between poverty and health in terms either of lifestyle (the poor don't eat right, don't exercise) or of access to health care. The link is deeper and tougher than that, and we in the medical humanities need to be talking about it.

Everyone should be able to see a doctor or nurse when they need to; yet insuring that would make less difference than one might think. England has had a highly egalitarian health care system for 50 years, yet the difference between the health of the rich and that of the poor remains great. What about eating right and exercising? Sociologists Nancy Krieger and Elizabeth Fee report that the relative risks imposed by poverty

moral judgments we make with respect to embryonic gene therapy.

In concluding, we can ask again the question "Why rational democratic deliberation?" The short answer is that the moral problem of health reform cannot be adequately resolved by health care economists, organizational theorists or health professionals, nor by insurers, politicians or moral philosophers. At bottom, the problem of health reform involves a conflict of social values that is reflected within each of us as we consider the issues raised above. A philosophic account of just rational democratic deliberation is intended to provide a workable framework for such social deliberation. What we need in addition is social effort to devise practical models of how such a conversation might be organizationally implemented.

are about double those of diet, exercise, alcohol, and cholesterol. Poverty *as such* is a health risk.

How? Being poor means not having money, not having the single most crucial tool for controlling the circumstances under which one lives; many studies have documented the health value of having a sense of control. More than that, poverty is a position on a scale; it is having less money than others. In a society which believes that individuals create their own destinies, it is hard for the poor not to see themselves, and be seen by others, as failures. Poverty threatens self-esteem, and that too affects health. Recent studies find chronic emotional distress (hostility, anxiety, pessimism, depression) doubling the likelihood of serious disease, making emotional distress a stronger risk factor than smoking. Despair doubles one's chance of a heart attack. (Media reports of these studies, interestingly, focused on the way individuals should learn to relax, to handle hostility, etc. No

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## Andre (cont.)

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one mentioned that these results help explain the connection between socioeconomic status and health.)

Poverty as status (i.e., as inequality) is particularly interesting. "The developed countries with the highest average life expectancy are not the richest ones but those with the narrowest differences between rich and poor . . . . Increased wealth regardless of inequalities is so far from being salutogenic for the population as a whole that if you control for the incomes of the poor, national infant mortality rates actually rise as the rich get richer."<sup>1</sup> That is, as the rich get richer, the poor get sicker -- even if they do not get poorer in absolute terms. The difference itself is damaging. One must speculate about the causal mechanism: perhaps it is a lessening of the "sense of coherence" that Aaron Antonovsky found crucial for maintaining health. Or we might recall John Cassel's classic paper about the damaging effects of social disruption. Among animals, for instance, an unpredictable and uncontrollable environment elicits "profound neuroendocrinal changes . . . presumably . . . permanent alterations in . . . hormones and autonomic nervous system arousal."<sup>2</sup>

Just as poverty can cause sickness it can make it difficult to deal with sickness. All the psychological elements just described come into play, as well as fundamental practical limitations. Again, this is separate from issues of access to health care, even separate from the cost of medication. Take, for instance, diabetes. Diabetics have circulation problems and can lose their feet to gangrene. What does it take to keep your feet warm? Sturdy shoes, for one thing; more fundamentally, a home. What does it take to maintain insulin levels? Again, a home: where hypodermics will not be stolen, where insulin can be kept refrigerated. For poverty less dire, imagine holding down two jobs and trying to arrange for child care, while maintaining a complicated medication schedule; or keeping your feet warm when your car heater has broken

down, or as you stand in the snow waiting for a bus.

To all of this add the dimension of time: Suppose that poverty is all one has known, and all one expects. Suppose it has been internalized, as part of one's self-concept, not just of one's circumstances. David Hilfiker describes the contrast between his own situation and that of his inner-city patients: "There are privileges of birth and upbringing I could never renounce, even if I wanted to. I could give away all of my money, but none of my education. . . . I would always have the possibility of returning to the mainstream and beginning again . . . . Were I ever in desperate need . . . [my family] or my church community or my friends (all with solid, middle-class resources) would be present to bail me out. . . . I would still have a lifelong sense of entitlement to fall back on . . . [and] confidence that I was able to handle whatever came to me in life. . . ." <sup>3</sup> Even Mother Teresa's sisters, he writes, who take strict vows of poverty, have "the abiding knowledge of having given their lives direction."

It can be overwhelming to think about poverty in America; one wants either to ignore it, or to be told how to help. In this essay I will make no practical suggestions, but not because nothing can be done. Other industrialized democracies have much less disparity between rich and poor than we do; our situation is not inevitable. What makes it seem inevitable is not only the depth of the misery, the thirty years of fitful and under funded efforts to address it, and our increasing economic polarization, but more basically our ideological blinders. American discourse focuses overwhelmingly on the rights, the obligations, and the promise of individual's choices about their own lives. We think less deeply, less clearly, and less willingly about the structures which constrain and shape those choices.

There have been two honorable exceptions to that in the medical humanities: we ask about justice in the health care system, and we

ask about the ethical implications of managed care. We need to continue those inquiries *and go beyond them*. If we care about health and healing and wholeness, we will also turn our minds to the death-dealing poverty around us. Unless we do, I am afraid, we will be helping divert the nation's attention from its gravest problem.

<sup>1</sup> Richard G. Wilkinson, Letter to Editor, The Lancet 343 (Feb 26, 1994) 538.

<sup>2</sup> John Cassel, "The Contribution of the Social Environment to Host Resistance," American Journal of Epidemiology 141:9 (1995) 798ff. Reprinted as a "Historical Paper," the essay first appeared in the same journal in 1976 (Vol 104, no 2).

<sup>3</sup> David Hilfiker, Not All of Us Are Saints, NY (Hill and Wang 1994) 78.

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## Announcements

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The Center welcomes Libby Bogdan-Lovis. Libby began as an Academic Specialist in December. Her primary duty is to provide assistance in the planning and administering of academic activities of the Center, but she will also coordinate educational conferences and serve as a liaison to other academic units. She is currently helping the Center in the development of a mission statement. In addition to her work at the Center, Libby will continue as Coordinator of the College of Human Medicine's Medical Scholars Program.

Leonard Fleck did a workshop, "Just Caring: Hospital Trustees, Health Reform, and Health Care Rationing," for hospital trustees in the Upper Peninsula at Marquette General Hospital on November 4, 1995.

Leonard Fleck spoke to social workers at the Henry Ford Hospital on the topic "AIDS and the Duty to Warn" on November 29, 1995.

On December 5, 1995 Leonard Fleck addressed home health nurses and social workers at Saginaw Cooperative Hospital on the topic "Ethical Issues in High-Tech Home Care."

On December 12, 1995 Leonard Fleck gave a workshop for managers and administrators of Lutheran Social Services of Michigan in Detroit. The title was "Just Caring: Emerging Moral Challenges in Our Changing Health Care System."

Tom Tomlinson spoke to the American Organ Procurement Organization on the "Ethics of Organ and Tissue Donation: Separation of Care for the Dying and the Dead -- How Absolute?" on January 12, 1996.

Howard Brody will present "The Gatekeeper Role" at the Ethics Symposium, Bon Secours Hospital, Grosse Pointe, February 7, 1996.

Howard Brody will present "Ethical Issues in Managed Care," to the Ingham County Medical Society, February 20, 1996.

Howard Brody will give the keynote address, "Ethical Controversies at the End of Life," to a symposium at the Cleveland Clinic, March 20, 1996.

Howard Brody will present "Managed Care and Professional Integrity," for the University of Michigan medicine grand rounds, April 1, 1996.

Howard Brody will present "The Saving and Preserving of Life," as part of "The Goals of Medicine," sponsored by the Hastings Center, Detroit, May 10-11, 1996.

The Center now has a new e-mail address. Electronic correspondence can be sent to [Center@pilot.msu.edu](mailto:Center@pilot.msu.edu).

# Coming Events

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*The Center for Ethics and Humanities is an academic unit whose faculty teach, write, and consult about bioethics and the other medical humanities. Staff members frequently conduct public discussions about a variety of such topics and we encourage our readers to attend and participate in these forums.*

**Thursday, February 8: Brown Bag Lecture.** Leonard Fleck will present "The Moral and Political Challenges of Health Care Reform and Health Care Rationing" from 12:00 to 1:00 in E4 Fee Hall.

**Friday and Saturday, April 21-22: Medical Ethics Resource Network of Michigan Annual Meeting.** The conference theme is Ethics in the Continuum of Care. Keynote speaker James Nelson, Ph.D. of the Hastings Center will give a presentation entitled, "Judgement Difficult: On Clinical and Moral Judgement." The Marriott Inn, East Lansing, MI. For brochure call Jan Holmes at The Center for Ethics and Humanities in the Life Sciences (517) 355-7550.

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