



Disability, Aging, and Rationing: Continuing the Discussion

by Howard Brody

Center for Ethics and Humanities in the Life Sciences

Disability perspectives on bioethics was the focus of the advanced bioethics course sponsored by the Center for Ethics and Humanities in the Life Sciences (CEHLS), MSU and the Medical Ethics Resource Network of Michigan, June 25-26, 2004. We were privileged to have as our guest keynote speaker Adrienne Asch of Wellesley College, noted as both a bioethicist and a disabilities rights advocate. This article is my attempt to extend some of the discussion from that meeting on the difficult moral decisions involved in health care rationing.

Bioethicists, in my view, need to take much more seriously some of the critiques that have been lodged against their work by advocates for persons with disabilities. But does that mean that bioethicists must acquiesce in various arguments put forth by those advocates around issues such as rationing? The question of age-based rationing illustrates these tensions especially well.

Health care resource allocation is an especially contentious topic. Bioethicists routinely state that rationing of one sort or another is inevitable, since a developed, technological society could theoretically devote its entire gross domestic product to health care and still not meet all needs of every citizen. Disabilities advocates typically distrust any call for the rationing of health care. They have far too much experience with the discriminatory stereotypes by which society as a whole devalues the lives of persons with disabilities, and presume that any appeal for "rationing" is likely to be one more exercise in diverting resources away from these vulnerable populations.

Leonard Fleck of CEHLS, as part of an exercise in rational democratic deliberation about rationing, proposed first the general question of whether a just and caring society would provide a totally implantable artificial heart for all who could benefit from it. These devices, now in the late stages of development, are estimated to cost as much as \$250,000 apiece, and might on average extend life by about 5 years; some 350,000 Americans would be potential candidates for this device annually (as sufferers from end stage heart failure). Fleck further asked the group to consider three 80-year-old persons in end-stage heart failure. Imagine that one is quite sound both mentally and physically apart from the heart condition; the second is physically sound but has advanced Alzheimer's disease; the third is mentally intact but is wheelchair-bound.

Fleck claimed that this exercise illustrated the ethical recommendation that any fair scheme of rationing must involve people rationing health care first for themselves and their loved ones (as opposed to morally objectionable forms of rationing where one group votes on limits to health care that will only be imposed on some other group). These hypothetical 80-year-olds all could be our future selves. If we propose to deny one or all of them access to the artificial heart at public expense, then we have to be content to forgo that opportunity for a longer life for ourselves, if at age 80 we end up being one of these three people.

Replying to Fleck's formulations, Adrienne Asch objected to the idea of pitting one patient against another in a rationing scheme, even under the guise of "future selves." She recalled Daniel Callahan's controversial recommendation for age-based rationing in *Setting Limits* (1987). Callahan proposed that once a person had reached the end of a natural life span, which he judged

to be approximately 80 years, the person should have no entitlement to life-extending care, though nothing should be stinted in comfort care and care that improves quality of life. Much as she might dislike age rationing, Asch added, she thought it a more fair approach than rationing based on various levels of impairment.

Others in the audience objected to either age-based or impairment-based rationing, raising the argument that any such scheme is tantamount to denying the full humanity of the individual who is thereby denied health care services. To test out this moral intuition, Fleck proposed that the audience use the computer reply system to vote their agreement or disagreement with the proposal: "The three 80-year-old patients previously described should all have equal access to the totally implantable artificial heart at public expense." At first the straw vote suggested a considerable division within the audience, with almost as many disagreeing as agreeing. Breaking down the vote by self-assigned role, however, showed a striking divergence. Those in the audience who identified themselves as disability advocates overwhelmingly agreed with the statement, while those who had identified themselves in some other role just as widely disagreed with the statement.

What I now want to do is to try to guess what this straw poll might have meant, particularly with regard to Asch's recommendation that the Callahan model of rationing according to a natural life span might be a position that could be consistent with a disabilities perspective.

First, I want to note how strong a statement the declaration of equality in the status of these three patients truly is. Many would argue that the diagnosis of advanced stages of Alzheimer's disease ought to be regarded as a terminal diagnosis. So claiming that the three patients have equal entitlement to a totally implantable artificial heart is tantamount to arguing that a terminally ill 80-year-old should have the same right to that technology as 80-year-olds who are not terminally ill. Perhaps one might object that "terminal" is the wrong label to place on the Alzheimer's diagnosis, and that such a label is just one more example of discrimination against persons with disabilities. That objection leads to further considerations I will discuss below.

Next, let me suggest three possible sets of reasons for the straw vote coming out as it did (given that the time limitations within the conference prevented a full discussion of why different people took the different positions).

(A) Earlier, this same audience had indicated that a majority believed that the artificial heart *should not* be a covered benefit within a national health insurance program for individuals of any age, at least not until other more urgent health care needs had been met. Therefore, it would follow logically that none of the three 80-year-olds would be entitled to an artificial heart; in that regard they all occupied equal moral status with regard to that technology. This would be the most benign interpretation of the straw vote in terms of whether a disabilities perspective could be brought into congruence with Callahan's proposal, as I will explain.

(B) Since this conference was about disabilities, and was a chance for disabilities advocates to speak their piece before an audience interested in bioethics, the advocates could have felt pressure to take a position that reflected their "party line"; in this case that required stating that an 80-year-old with a mental disability and one with a physical disability were just as entitled to "top of the line" health care as one with no disability other than end-stage heart failure. Seen this way the straw poll was more an exercise in rhetoric than in careful moral analysis. Such an explanation allows us to dismiss the importance of the straw vote, but only at the cost of patronizing and demeaning the disability advocates in the audience. (Of course, the others in the group might have been playing a rhetorical game of their own in taking the opposite position. But since those self-identifying as "non-disabilities-advocates" were a much more heterogeneous group, only a few of which would probably have labeled themselves "bioethicists," I think this less likely.)

(C) A final reading of the straw vote is that it demonstrates that the rest of us, at some level, "don't get it" when it comes to social stigmatization and discrimination against persons with disabilities. On this interpretation, the only reason to deny access to an artificial heart for one of the 80-year-olds, but not for one or both of the others, would be some form of invidious discrimination that holds that the life of one is less worth living, or is worth less to society. But this form of discrimination, as the criticism goes, would be tantamount to denying the full humanity of one of these 80-year-olds, which we must never do.

Suppose that C is the "right answer" to what this audience had in mind, and especially to why the disabilities advocates disagreed so notably with the others. What does this imply for Asch's proposal that the Callahan model might be a good way to address the problem of rationing in our society?

It is first necessary to be clear on what the "Callahan model" is. Those inclined to dismiss Callahan focused on the notion of an explicit age cut-off. And indeed any particular age seems arbitrary. We all know some 80-year-olds who seem more like 60 and others who seem more like 100. So to say that the entitlement to life-extending therapy ends at some specific number of years in all cases seems a very crude version of what Callahan was suggesting.

I think a more sympathetic reading of Callahan would show that the core idea is not a number of years, but rather the concept of *aging near death as inevitable decline*. Callahan suggests that at whatever number of years it might be, the "average" life starts to exhibit an inexorable downward trajectory (unless the individual dies suddenly without any anticipatory decline, in which case no tough decisions about life-extending treatment need be made). This decline prior to death has several characteristics. To the extent that a life is characterized by a set of projects that the individual finds important and fulfilling, the person has either completed most of those projects, or else merely extending life by a few more years holds out little hope that the unfinished projects will be completed. Many important relationships in the person's life may have ended or dwindled as the loved ones themselves die off or become incapacitated. Whatever years of life the person can look forward to seem to offer fewer and fewer opportunities to engage in valued or pleasurable activities and instead to lead to steady diminution in function, either mental or physical or both.

Callahan might be read as suggesting that as a matter of public policy, we would refuse to set a specific and arbitrary age cutoff. Instead our culture would slowly change so as to send signals to patients and their families as to what was viewed as socially acceptable and fitting. At whatever age an individual entered into this discernible life stage of pre-death decline, it would simply be the accepted thing to do to cease to request life-extending therapy. As a result, medical research would cease chasing after indefinite life-extension technologies for the elderly, and would turn attention instead to improving chronic illness and palliative care.

So now we must ask: is this more sophisticated version of Callahan's rationing based on a "natural life span" sensitive to and consistent with the disability critique of bioethics?

If my reading "C" of the group's straw vote is the correct one, I would suggest that disabilities advocates could never accept even this more sophisticated version of Callahan's model. This is because the decline due to aging that precedes death is a form of impairment. It is not possible within a disabilities perspective to allow that any health care entitlements could hinge on whether an individual suffers from any impairment. Any such use of impairment status to decide who is entitled to any form of health care is invidiously discriminating and hence dehumanizing.

To expand on this argument a bit more fully: We saw that there were two versions of Callahan's argument. The crude version called for cutting off life-extension resources at an arbitrary numerical age. This, I argued, was too arbitrary. The alternative form said that the decline of aging before death, at whatever chronological age it occurred, would be the criterion

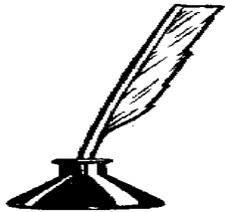
for cutting off access to life-extending medical treatment. But what does this "decline" consist of? It is ordinarily a mixture of things such as the inability to walk unaided, to see well, to remember recent events, and so on. But every one of those deficits could equally be viewed as a "disability." Therefore, denying life-extension technology to some 80-year-olds who are in a state of "decline," but allowing them for 80-year-olds who are not yet in "decline," could be argued to amount to invidious discrimination against persons with disabilities. So either the crude or the sophisticated version of Callahan's scheme is equally ruled out on ethical grounds.

Here a critic might object to my dismissal of the "crude" form of Callahan's position (which is, after all, closer to what Callahan actually wrote in his book, *Setting Limits*). At least, cutting off life extension treatment at age 75 or 80 or whatever is a clear, rule-based approach. Allowing others to decide when one has reached a stage of "decline" and when therapies should be forgone seems much murkier, and opens the door for a number of abuses, which the social habit of routine discrimination against persons with disabilities can only exacerbate.

My reply to this critic would be that admittedly, what I am construing as the more sophisticated version of the Callahan position would call for murkier decision making. But is this an abuse, or is it simply an acknowledgement of the fuzziness of the real-life issues and variables on which good decisions ought to be based? Callahan admitted that there was no way one could implement his proposal overnight; rather he envisioned a period of perhaps one generation during which social values and preferences gradually changed. We therefore would have a long period of time to promulgate both Callahan's idea that at some point in the aging process one should stop seeking to extend life and turn instead to the quality of life; and the widespread view that a person does not become less worthy simply because he or she is living life with one or more disabilities.

Callahan warned us of bad consequences if we did not accept some version of his model. First, we would eventually break the bank, as there would be no end to increases in health care costs as we added new technology on top of new technology in the vain pursuit of immortality. Second, and even more serious, we would always and inevitably fail in our quest to make human life both longer and happier through the use of new medical technology. The failure results mainly because our refusal to face our own mortality is at root a spiritual problem, and spiritual problems do not have technological solutions, no matter how much money we pour into research and development. Immortality would still elude us, but we would be even more frustrated as well as financially poorer, even more lacking in the social-spiritual resources that could help us to deal with mortality.

Is the disabilities perspective, then, simply a disguised way of denying human mortality, and of calling for the social direction that Callahan warned us was both futile and unsatisfying? Asch stated that both bioethics and the disabilities community need to do a lot more homework around the issue of rationing. One bit of homework that needs to be done, it would seem, is to see whether disabilities advocates can or will distinguish between the impairment that is part of aging and mortality, and the impairment that is relatively stable and that need not prevent a person from living a full, satisfying, and productive life. If they are willing to draw no moral distinction, they must then explain how they can avoid the dangers that Callahan warns against.



InkLinks is a regular column in which readers reflect on issues related to the previous lead article. In the last issue of MHR, Paul Thompson argued that “bioethics” properly involves much more than “medical ethics.” (“Agriculture and Food Issues in the Bioethics Spectrum,” Spring 2004). The essay elicited a number of responses – in every case, enthusiastic agreement and expansion of his points.

A Science Professor: MSU Published *Global Bioethics*, Then Forgot It

Ted Lopushinsky
Integrative Studies and General Science, MSU

It was with great pleasure that I read the opening sentence of Professor Thompson’s article. His mention of Van Rensselaer Potter coining the term “bioethics” in 1970 is my focus here.

I applaud the recognition given to Potter. He is too little recognized for the significance of his philosophy regarding *acceptable* human survival via a system of medical and environmental priorities. Dr. Thompson correctly indicated how “bioethics” had been appropriated by the medical profession to the exclusion of the ecology-environmental community. It is to this feature that I would like to call attention in Potter’s 1988 book, *Global Bioethics: Building on the Leopold Legacy*, published by our MSU press.

In *Global Bioethics*, Potter is clear in his concern about what has happened to his idea: “With the focus on medical options, the fact that bioethics had been proposed to combine human values with ecological facts was forgotten...the ethics of how far to exercise technological options in the exploitation of the environment” was ignored (pp. 1-2).

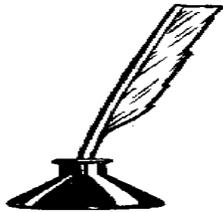
Potter was brought here to MSU for a seminar on bioethics in 1995 by his ex-student and friend Dr. James Trosko, MSU Professor of Pediatrics and Human Development. It was a pleasure for me to talk with the man whose ideas were so significant to the general education science classes I taught. His ideas were instrumental in leading students to the realization that there is an ethical and moral aspect to a scientific understanding of nature. V.R. Potter died at age 90 in 2003.

Other comments in the 2004 Spring MHR indicate that “bioethics” as envisioned by Potter is acknowledged by the MSU agricultural community. But much remains yet to be done regarding the teaching of his “bioethics” to the largest group at MSU: the non-science student. The availability and reasonable cost of his paperback *Global Bioethics* could greatly expand student awareness of the importance of their decisions regarding *acceptable* human survival - a feature especially important in today’s political climate where science is being manipulated for political agendas. Again, Potter addresses this concern well:

“Global bioethics is proposed as a secular program of evolving a morality that calls for decisions in health care and in the preservation of the natural environment. It is a morality of responsibility...the natural laws governing the biosphere - indeed, the universe- are not

going to change according to the wishes of individuals, governments, or religious preferences”(pp. 152-153).

If a major role for a university is to expose its students, faculty, and staff to challenging ideas, then *Global Bioethics* by Potter should be utilized to a greater extent than is presently the case at MSU. The Spring 2004 *Medical Humanities Report* is to be congratulated as an early step in this matter.



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A Dietitian: Where Would the Olive Oil Come From?

Mary Noel
Family Practice, MSU

Professor Thompson pointed out that agricultural issues are public health issues as well, through their impact on nutrition on the one hand and on rural society on the other. Four months later the problems are becoming still more intense, as the Department of Agriculture reviews its food guidance and food pyramid. It is increasingly difficult for any of us to decide what to eat, as we weigh considerations of health, pleasure, and convenience (the latter usually being the decisive factor). Some researchers now argue that everyone should consume a Mediterranean Diet (*JAMA*, September 22/29, 2004). But where are Americans going to find the olive oil, which is a mainstay of this diet? It would take 20-25 years to produce the olive groves needed, and doing so would make major changes in American agriculture. Until then, Americans could deplete the olive oil production of the entire world. We would probably also gain weight, consuming more calories without increasing our physical activity (the usual pattern when Americans take up a new diet style).

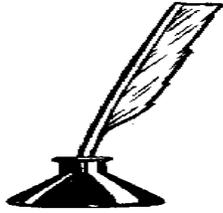
Fruits and vegetables are another example of good nutritional advice with unforeseen effects. The consumption of local produce could promote sustainable agriculture. Instead, though, the public rarely finds local produce in its groceries. Many people have no idea what is locally grown, or even what is in season. (Do bananas grow in Michigan? Are oranges harvested in August?)

Nutritional science seems to be following the model of medicine rather than agriculture and home economics of its roots. Recent nutrition conferences have titles like “Food as Medication” (take a little broccoli for your cancer, or yogurt for your probiotics). The billion-dollar “nutriceutical” industry illustrates how little confidence some feel in our food supply. Land grant universities have developed “Functional Foods” concentrations within nutrition and food science departments, to deal with food’s medicinal properties.

Where does this leave agriculture? Michael Jacobson, executive director for the Center for Science in the Public Interest, believes that “Congress should move the whole process [of developing dietary guidelines] to the National Academies of Science. It would ... help depoliticize” the activity. But he also believes that food interests are so powerful that the move would be blocked. Furthermore, as the so-called ‘War on Obesity’ heats up, our rural communities seem inordinately vulnerable—the people are usually heavier than their urban

counterparts, and the economy is reliant on the farming of products which are targets for reduction, like dairy, meat products, and local produce.

What is a dietitian to do with so many conflicting sciences, cultures, and recommendations? Maybe what the public is doing—ignore it all!



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A Physician: Public Health Ethics is Another Leg for the Milking Stool

Ross Upshur
University of Toronto

Professor Thompson is to be commended for his summary as he has opened up an important dimension of ethics that has been long-neglected. The point of his article is to raise questions about food issues and place them within the agenda of mainstream bioethics. I would urge the bioethics community to heed Professor Thompson’s challenge, and point out that this is an opportunity for the integration of ethical reflection from a variety of domains. Many of the issues in nutrition have both clinical and public health implications, and the integration of bioethics and public health ethics is certainly needed to address them. I could not agree more when he says the time may be ripe for a more extended conversation between agricultural and medical ethics, and I would argue that additional legs to his milking stool would be public health ethics and environmental ethics. If, as some have argued, the individualistic focus of contemporary bioethics is a barrier to understanding more complex questions of public health, then this integration is essential. I look forward to the ongoing discourse.



NIH Training Grant Funds Bioethics Partnership with University of Malawi

The Center for Ethics and Humanities in the Life Sciences (CEHLS) has been awarded a grant of more than \$725,000 by the Fogarty International Center of NIH to fund a program that will help develop African scholarship and teaching on human subjects research. CEHLS is collaborating with the Bioethics Research Unit at the University of Malawi College of Medicine to select and train five persons from the Malawi region over the next four years. The program targets individuals with advanced degrees in a discipline relevant to some aspect of research ethics scholarship, who are already well established in their career and who wish to expand their active research and teaching interests into the area of research ethics. Trainees will spend a semester at MSU taking advanced courses pertinent to their discipline and planned research project. The rest of their 15-month training period will be spent in Malawi, taking additional courses, developing their research projects, and planning a course on research ethics to be taught at their home institution. Research projects will be planned and implemented under the guidance of two mentors, one from MSU and one from Malawi, who will collaborate electronically. Trainees will be awarded a certificate of completion when they have succeeded in publishing their research in a peer-reviewed journal and have taught their planned course.

Our hope is that at the end of this project, we will have helped create a vibrant and stable community of research ethics scholars in the Malawi region.



News & Announcements

TOM TOMLINSON

- Presented “Caring for Risky Patients: Duty or Virtue?” as part of the American Society of Bioethics and Humanities annual meeting, Philadelphia, PA (Oct. 29, 2004).

LEN FLECK

- Gave the keynote address at the annual meeting of the Michigan Pharmacist Association, “Ethical Issues at the End of Life: Whose Conscience Should Count?” Lansing, MI (Nov. 2004).
- Published an article entitled “Sharing Genetic Information: What is a Minimally Decent Sibling to Do?” in the Philosophy and Medicine Newsletter of the American Philosophical Association (Spring, 2004), pp. 35-39.

JUDY ANDRE

- Chaired and participated in a panel on “Police Relations: Issues of Confidentiality” at the ASBH conference, Philadelphia, PA (Oct. 28, 2004).
- Spoke to the annual conference of Executive Officers Council on Conflicts of Interest, Holland, MI (Oct. 20, 2004).

HOWARD BRODY

- With co-authors Zahra Meghani and Kimberley Greenwald (both graduate students in the MSU Department of Philosophy), spoke on “Michael Ryan and Anglo-American Medical Ethics” for the ASBH History of Medical Ethics affinity group, Philadelphia, PA (Oct. 29, 2004).
- Spoke on “Clinical Care versus Clinical Research and the Therapeutic Misconception” for the course, “Ethical and Regulatory Aspects of Clinical Research,” Department of Clinical Bioethics, NIH, Bethesda, MD (Oct. 27, 2004).