

Medical Humanities Report

Spring, 1993

Health Care Methodology and the Disabled

By Rodger L. Jackson, M.A.

As Hillary Rodham Clinton shepherds 24 health care committees toward their May 1 deadline, states like Oregon, Michigan, Minnesota, and New York wonder whether they should continue their own projects. Can local efforts make any difference now?

I think so. They can continue to try to solve the problems their efforts have brought to light, problems about how to decide who gets what care. Oregon has not only proposed, but has tried several methods for making these decisions; and the handicapped community has forced them to recognize serious intrinsic problems in each method. Here are the details.

THE OREGON PROJECT AND JUST CARING

The Oregon Basic Health Services Act of 1989, which has generated so much publicity, both negative and positive, has at least four guiding principles which it shares with the Just Caring project here in Michigan. Both assert: 1) that it is not possible to fund all possible medical therapies which could provide some benefit (however small) to someone, 2) that some treatments are more beneficial than others 3) that, because of 1 and 2, some form of rank ordering will have to take place and 4) it is essential to make a concentrated effort to seek public input on exactly what this rank ordering should look like.

Is such a program discriminatory towards handicappers? The decision to place treatment

for anencephalics and extremely premature infants (less than 500 grams and less than 23 weeks) at the very bottom of the list alarmed a number of groups, including the handicapper community. In fact, it was because Oregon's plan was viewed as violating the Americans with Disabilities Act of 1990 that its request for a waiver of certain requirements of the federal-state Medicare program was turned down by then Secretary of Health and Human Services Louis Sullivan. The overriding concern of the handicapper community is that plans such as Oregon's will simply be budget tools for rolling back hard fought advances in the benefits for the disabled. Severe tensions may be part of the very nature of any program which seeks, as does the Just Caring project, to rank order health care services.

BIAS IN ASSESSING MEDICAL EFFECTIVENESS

The Oregon Health Services Commission developed a list of 709 condition-treatment pairs, that is, combinations of a health condition or diagnosis (e.g., diabetic retinopathy) paired with a treatment likely to be used in providing care to the individual with the condition (e.g. laser surgery). The OHSC held 47 county wide meetings throughout the state which generated a set of 13 community values (e.g., equity, length of life, prevention, personal responsibility, etc.) providing the commissioners with an initial means of ranking the pairs. The commissioners then further ranked the pairs according to the degree of effectiveness of the treatment in

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Methods (cont.)

realizing improvement in the quality of life of the person with the condition. In order to establish the degree of net benefit accrued from the treatment the commission conducted a telephone survey of some 1000 Oregon residents. Those surveyed were provided descriptions of the limitations and symptoms of a medical condition and then asked to rate the degree to which that condition would lower the overall quality of life. The OHSC used descriptions drawn from the Quality of Well Being Scale constructed by Robert Kaplan and John Anderson

Several critics, including the Bush administration, charged that the use of the Kaplan descriptions and the phone survey were biased, or at least had the potential for bias, against the disabled. A number of studies demonstrate that there is discrepancy between such objective features as level of independence in self care or mobility limitation and the perceived quality of life of the person with the condition. The report of the quality of life by the person with the condition is often much higher than had been predicted on the basis of the purely "objective" criteria. Furthermore, there were no handicappers included in the phone survey. The OHSC responded to the criticisms by dropping the phone survey, as well as the Kaplan descriptions of the conditions and announcing that they will spend the next year seeking to construct a non-biased means of assessing medical effectiveness.

This last goal of the OHSC, if it can be achieved, would be an enormous accomplishment for it touches upon a tension within both the Oregon and Michigan projects. **Is it possible to have community involvement when constructing a non-biased means of assessing medical effectiveness?** Whether something is medically effective is generally thought to be a question of whether or not the drug, surgery, therapy, whatever, was successful in improving the quality of life of the person with the condition. It is inevitable that any large scale community input in the evaluation of the relative merits of treatments will entail citizens measuring the

benefits for a condition with which they have no personal experience. Though this was obviously a critical factor in the Bush administration's refusal of the Medicaid waivers, it needs to be pointed out that there is a weak and a strong version of this argument.

The strong version says that no one can really know what it is like to be in a particular medical condition, what the quality of life is like in that situation, and so therefore there are no grounds by which one could judge one treatment as having greater benefit than another and certainly none which is available to the general public. If this is the case then, if we are going to rank procedures at all, there is little point to having public input in the ranking process. The weaker version says that through extensive conversation and education open-minded people can achieve a substantial awareness, albeit not complete, of what it's like to be in a particular medical condition and therefore, be able to compare and contrast the degree of effectiveness of a treatment of the condition. This would probably rule out such things as the phone survey, but not necessarily the community gatherings, provided the meetings were suitably detailed and thoughtful when it came to considerations of this sort.

CONDITION-TREATMENT PAIRS VS. COMORBIDITY

Advocates for the disabled frequently point out that society pays so much attention to what a disabled person can't do that they miss out on all the things that the person can do. They see a person with multiple disabilities (e.g. a paraplegic with respiratory disease, blindness) and assume that there is nothing that could be

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done for that person, given their overall condition, to bring them up to a tolerable quality of life. Given that such a mindset is fairly common some handicapper advocates are fearful of proposals which would set priorities primarily on the basis of a person's condition, instead of a condition-treatment pair. Such a procedure would play into the pessimism discussed in the previous section and a number of severely disabled individuals might not receive any treatment at all since they could never be brought up to the "base line." Oregon has thus far avoided this problem by focusing on a single condition and its likely treatment, ignoring whether the person has other medical conditions as well.

The obvious disadvantage with this is that any realistic assessment of how effective a medical therapy would be would necessitate taking all other underlying medical conditions into account. However, the more numerous a set of ailments a patient has the more difficult it becomes for non-clinicians to grasp the benefits from a specific treatment on the overall condition of the patient and so it seems doubtful that the state could seek very detailed input from the community in ranking one treatment over an-

other. One remedy for this would be to simply drop the treatment aspect of the condition-treatment pairs and focus primarily on the person's condition. But this raises the problem discussed at the beginning of this section; and hence, it hardly seems a satisfactory solution. Therefore, if one did want to take comorbidity into account it would seem the best thing to do is severely limit whatever input the community would have in the ranking process. However, now the emphasis on community involvement has been ignored and crucial decisions about everyone's health care will be made by a relatively small group of people.

CONCLUSION

Since the Just Caring project shares these crucial premises of the Oregon project it will need to decide how to deal with these two tensions. At present the Just Caring project is only in its pilot phase and so there is plenty of time to incorporate any changes which might respond to the problems encountered in Oregon. The accompanying article by Leonard Fleck is intended to do just this.

Just Caring: Priority Setting Through Democratic Decisionmaking

By Leonard Fleck, Ph.D.

In a world with only limited resources for meeting health needs can priorities be fairly and rationally established through a process of informed democratic decisionmaking? The "Just Caring" project would offer an affirmative answer to this question. Let me begin my defense of this claim with some comments on Oregon's efforts at priority setting.

A frequent criticism of Oregon's efforts is that the list of 709 condition-treatment pairs is too crude an approach to assessing the appropriateness of various medical treatments, that

medicine requires skillful clinical judgments at the bedside that are responsive to the subtle clinical circumstances of individual patients. Given this, what sane person would want their medical care democratically determined? Further, both fairness and efficiency are threatened by this approach because in some cases a treatment ranked high on the priority list would yield very small benefits relative to costs for this patient, while in another case treatments entirely off the priority list might yield substantial benefits for this patient. Again, if this is what

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Decisionmaking (cont.)

democratic decisionmaking yields, then this seems to speak strongly against such approaches to priority setting in health care.

The other criticism of the Oregon approach, nicely sketched by Rodger Jackson, is that incorporating quality-of-life considerations into the priority setting process is a threat to those with various disabilities, especially if we allow a largely ignorant, able-bodied democratic majority to impose its prejudices on groups of individuals with various disabilities.

Let me begin my response by noting that no process of democratic priority setting can correctly rank 709 condition-treatment pairs. That kind of detailed ranking may be politically necessary in the context of the current Medicaid program where a relevant moral consideration is protecting administrative fairness, but it ought not be part of a larger process of national health reform. For fair and effective health reform we need to identify what we collectively judge to be non-costworthy health care, the sort of health care that provides only marginal benefits that we reject because, in the context of a limited budget, there are other more beneficial health services that we would prefer for ourselves. These are the kinds of judgments that can and ought to be made openly in deliberative democratic forums.

Imagine, for example, that 250,000 of us belong to a managed care plan (a very likely scenario under a Clinton health reform proposal). The issue before us is whether the plan ought to pay for an anti-cancer therapy that offers a 25% chance of six extra months of reasonable quality life (then death) for \$100,000. My suspicion is that most of us think well enough of ourselves that we believe we are worth that expenditure of someone else's money---because that is how we see the situation. Of course, it is really our own money that is at stake. If we ask ourselves instead whether we would spend our children's entire college fund, plus take out a \$50,000 second mortgage on the house, thereby risking the impoverishment of a surviving spouse, in order to have that 25% chance of six extra months of life, then I

suspect the vast majority of us would give a very different answer to this question. No doubt there would be some who would still want the opportunity to spend that \$100,000. In this case there is no compelling moral reason why they should be denied that option. But it will be their money that they have to spend. They would have no just claim to the resources of the community for that therapy. They would be treated neither unjustly nor uncaringly by a community that had denied itself in the past and for the future that therapy.

There are literally hundreds of examples like this that can be the focus of fair and informed democratic deliberation, and that can yield the sort of rationing (cost-effectiveness) protocols that will have to be central to any reformed health system of the future. A critical point to note is that rationing protocols like this are not discriminatory in a morally objectionable sense from the perspective of the disabled. That is, there will be the whole range of medical illnesses to which the disabled will be exposed, just like everyone else. To deny a blind or paraplegic individual the cancer therapy discussed above is to do nothing unjust, so long as it is the case that all who are similarly situated are also denied that non-costworthy therapeutic option.

A more difficult sort of case will bring in directly quality-of-life issues. How vigorously should we sustain the life of an 84-year old individual who has suffered a massive stroke that will leave him permanently and severely mentally incapacitated, specifically, to the point of not knowing who he is or who those are who are around him? Can we trust democratic decisionmaking processes not to devalue the lives of impaired individuals like this? Is it true that we lack the relevant knowledge to make informed judgments about the degree to which a life of such quality is worth sustaining?

I will readily concede that we cannot know perfectly whether a life with that degree of impairment is worth sustaining for our future

selves. Some sighted individuals, for example, will say that they would prefer to be dead rather than blind, and then discover after suffering blindness that they are able to adapt, and that life continues to be worth living. What should we conclude from this? Probably we should conclude no more than we already know empirically, namely, that with proper support systems and social services the vast majority of individuals with disabling conditions can have lives that they find worthwhile. What we need to emphasize, however, is that all we need to do for resource allocation purposes is make crude comparative judgments of quality-of-life diminishing medical circumstances. This is not beyond the capacity of reason or the capacity for fair and informed democratic decisionmaking. Does anyone seriously believe that we have no rational capacity to decide between two future possible states of ourselves--- a blind state or a grossly demented state that is a product of a

stroke--- when we must judge which state has a prior claim to limited health resources? To make such judgments is not discriminatory in a morally objectionable sense to the interests of the disabled since the disabled of which we speak are future possible states of ourselves.

What we lack in our current health care system is the sustained capacity for engaging in such informed democratic decisionmaking processes as well as the institutional mechanisms that will assure us that rationing decisions we make are made for our future selves, not the selves of others who are poor and vulnerable. The "Just Caring" project speaks to the first of these needs, and it is hoped that the Clinton Administration reform package to be revealed in May speaks to this other need for organizational reform, specifically, the development of "closed" health plans and hard budgets for those plans.

Further Commentary on "When Bioethicists Shouldn't Testify in Court"

The Winter issue of the MHR featured articles by Howard Brody and Leonard Weber concerning a court case in which they were both expert witnesses for the defense. I subsequently received these letters from Daniel Bronstein and Arnold Werner and in the interest of furthering debate on such an important topic I have decided to reprint them here. -- R. Jackson, ed.

From Daniel A. Bronstein, S.J.D.

As a lawyer who also teaches in the medical schools at MSU I feel compelled to make some comments on the pieces by Drs. Brody and Weber in the Winter 1993 issue. It is my belief that they have both made a fundamental mistake in their discussions.

There is no rule which states that ethical issues cannot arise in litigation which involves money. I believe that had the case they discussed involved a suit by Ms. A against Dr. X instead of a suit by Mr. A, both commentators would have happily testified against Dr. X. Clearly, such a suit would have been just as much for money as the case they were actually

involved in.

Similarly, one can easily picture a case arising in which the family of a hospitalized patient sues the facility and the attending physicians for failure to follow an advance directive of termination of life support. Such a suit would seek a great deal of money -- reimbursement of the excess treatment costs incurred and pain and suffering for the time during which such treatment was rendered. It is obvious that such a case would clearly and directly involve ethical issues such as patient, physician and hospital autonomy, and would set important ethical standards for the future, even though it was a case seeking money.

I believe that both Drs. Brody and Weber made the fundamental mistake of agreeing to testify in a manner which made them feel "used". Since they felt "used" they blame the fact that this was a suit involving money,

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Letters (cont.)

whereas it was really that they did not like what Dr. X had done, even though they agreed, intellectually, that it was not unethical. They thus violated the fundamental rule that I advocate in my class in *The Role of the Expert Witness* (which Dr. Brody took many years ago) and my book, *Law for the Expert Witness* (Lewis/CRC 1993) -- never testify in a case in which you feel personally uncomfortable.

The fact is that most people cannot advocate abstract intellectual positions when they feel that the result in that particular instance is personally distasteful. There is nothing wrong with this; it is part of human nature. Blaming it on the fact that a lawsuit involved money, however, is incorrect.

From Arnold Werner, M.D.

Howard, your piece in the Medical Humanities Report on bioethicist's testimony raised interesting points also faced by other specialists who testify. As a psychiatrist who has evaluated people involved in the legal system, testified in court and given depositions, I can appreciate what you faced.

Regarding the behavior of the parties involved, I wonder what kind of statement the Academy of Family Practice has about the ethics

of personal involvements with patients. In my experience, intimate involvements with patients are not uncommon. In spite of all the attention that the behavior of psychiatrists has received, these involvements are probably at least as frequent in other areas of medicine. The American Psychiatric Association has a very clear statement prohibiting sexual involvement with patients. The general consensus these days is that involvement with former patients is also unethical because of the continued meaning of the relationship even after treatment has ended. In the latter case, some people argue that there may be exceptions. Regarding the case you described, the behavior of the physician is clearly unethical by the above standards.

I do object to the way you and your colleague characterized the people involved. What are decent and legitimate experts in ethics doing calling people sleazeballs? These people may have acted foolishly, may have been unethical, may have been troubled, may have been unaware and certainly were human. Can a person do something unethical and not be a sleazeball? What is the definition of a sleazeball and does using this sound bite word in this setting do anything to further the intellectual process?

Literature in Review

***First, Do No Harm*, by Lisa Belkin. Simon and Schuster, New York:1993.**

By Tom Tomlinson, Ph.D.

In this book, Lisa Belkin chronicles the life of a hospital ethics committee over half a year by following the stories of a handful of patients whose treatment and lives are to be affected by the committee's deliberations.

There's Armando, whose cervical spine was smashed by the bullet that remains lodged at the base of his skull, leaving him permanently quadriplegic (a "head in a bed" as some of the residents describe it). But he insists on resuscita-

tion and maximal therapy, much to the staff's surprise; and to their consternation, for now the question becomes who will pay for it. There are the premature newborns Landon Sparks and Taylor Poarch, whose parents must struggle not only with their own desperate ambivalence, but with ethical and medical disagreements among the physicians and nurses caring for their children. And there is Patrick, whose story runs most prominently throughout the book, culminating in his death in the climactic chapter. Born

with Hirschsprung's disease (a bowel disorder resulting in chronic obstruction), at 15 he has had virtually all of his bowel removed. Dependent now on a central line for nutrition, he is prey to chronic bacterial and fungal infections, and to the toxic side-effects of the medications used in the foreseeably doomed effort to keep those infections in check and the central line open.

The 23-member committee is at Hermann Hospital in Houston, Texas, a teaching hospital within the University of Texas Medical School. The "whole" committee (the quorum is 6) meets as needed to provide consultation on cases brought to it. Chaired by a nurse-administrator, the committee's consultations result in a terse one-paragraph opinion formally signed by all those present, which is then made part of the patient's record.

The special value of this book lies in its attempt to tell the fully human stories which so often lie unspoken behind the abstracted skeletons of the "cases" that get discussed in the scholarly medical ethics literature. In this, Belkin is at least partially successful. Her personal and extensive knowledge of the individuals and circumstances involved reveals how the actual course of decisions about ethical problems is in fact driven as much by personality conflicts, professional disagreements and bureaucratic snafus as it is by clear-eyed appeals to moral principle.

In other ways, however, the attempt falters. One would hope, for example, that such a book would reveal to the reader the depth of emotions involved in these terrible situations for patients, families and caregivers, perhaps illuminating how those intense feelings might sometimes be sources of insight rather than disorientation. But despite the frequent mention of a host of strong feelings in those involved, the narrative remains emotionally detached from its subjects.

In part this may be an effect of the book's chronological structure, which strings the patients' stories along the time-line of the ethics committee, for whom these patients' lives swim

in and out of view as crises in their care rise and fall. Thus, Armando's and Patrick's stories are each told over a half-dozen widely-scattered chapters, making it difficult to hold any full or detailed picture of them in mind. (Of course, this unsatisfying level of understanding may precisely replicate that confronted by ethics committees, who are chronically worried about whether they have the "whole story" about cases they are consulted on. It's just not a very rich source of insight for readers.)

In addition, one is always aware that the author is a reporter (for The New York Times) and not a novelist. When it comes to the emotional dimensions of these decisions, Belkin's instinct is to describe them, wrongly thinking that she will have conveyed them at the same time. This results in numerous places in overwrought language and strained metaphors ("[trying to help some parents see the bigger questions about treatment]...he tried to coax them away from the trees and into the forest.")

One final reservation about the book is its potential for misleading readers about substantive questions in the ethics and law of treatment limitations. Physicians, nurses, ethics committee members and others make assertions about medical ethics and law throughout the book, which are simply reported and never commented on regardless of how controversial or questionable they are. In discussions of Patrick's care, "DNR" is used as a euphemism for "Supportive Care Only," which in turn is used as a euphemism for "Everything except surgery to replace the central line." Repeatedly the Texas Natural Death Act is invoked to suggest that in Texas one must be terminally ill before life-sustaining treatment can be withdrawn. And most jarring for someone who began his medical ethics career in 1981: "Medical ethics became chic in the early 1980s, brought front and center by the case of Nancy Cruzan..." If you give this book to a friend, be sure to affix a warning label.

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