

Panel Discussion

Daniel Moros:

Professor Baker would like to make a few more remarks to follow up on comments made about his paper.

Robert Baker:

Conferences are dull when no one disagrees, but I didn't quite expect to encounter so much disagreement, so let me go back to where I started. I started on my computer by doing some standard computer searches on minorities in medicine. I hit pay dirt starting in 1980 with an extraordinary amount of material coming out of Washington from two data sources providing statistics on minority comparisons. The first thing that struck me about these data was that between 1900 and 1990, there was a convergence between minority populations and everybody else with respect to health care status. The big picture shows that the difference is becoming smaller and smaller. But if one looks at the details of the way in which the reports were constructed, they all focus, bit by bit, on differences in so-called minority/majority comparisons. This seems fair, given that in 1980 the goal to eliminate disparities was announced. However, around 1987, data on Cubans came out of the minority category, and then data on certain kinds of Mexicans. In fact, when a minority group's statistics really look good, they are promoted into the majority group, making the disparity look worse than it did before. I looked at the rhetoric and realized that the statisticians are, in effect, trying to implement an affirmative action kind of model. They want to get all the resources toward the least advantaged group.

At the same time, I was looking at who had been discriminated against in the long history of Western health care. While there is no category based on socioeconomic status, poverty is certainly coincident to those groups marked by the special language used to describe them. Marking groups by means of special language has become more and more prominent in the government's data. After I reread *Bad Blood*, the definitive study of the Tuskegee study, the fact that the *Journal of the American Medical Association* used the headline "Negro Males" stood out all the more. It was also telling that they were using a civil rights model in working through the health care data. This is indicative of a particular kind of danger. While this approach offers a short-

term advantage (i.e., you get more money with which to benefit a disadvantaged group and, therefore, they are better off), in the long term there are disadvantages. People are marked in exactly the way racists mark them. We want to be very careful about that. I wondered whether we really wanted to superimpose an affirmative action model on public health surveillance. One of today's speakers has argued that we do. But in my view, a convincing case has yet to be made. We've got \$400 million; let's put it to good use.

Leslie Pickering Francis:

Are we really looking at the issue of distribution? Or are we looking at socioeconomic status? Or do we have enough evidence to be suspicious that there is ongoing discrimination in treatment? I allied myself with those who suggested that there are actual differences in the health care encounters people have that still need correction. Some of those differences actually go both ways, because race-based reluctance to participate in medicine exists, as, for example, with Dr. Burrows's discussion about kidney donation. One of the reasons I didn't use the renal transplant data is because if you only glance at the data, it looks as if blacks get fewer transplants. However, a careful review of the data reveals a reasonable explanation. Blacks have poorer tissue matches as a result of donation patterns. So, my suggestion is to look to education. Notice, however, that this too takes race-based action.

Lewis Burrows:

What Maritza Rozon-Solomon and I tried to present was a slightly different perspective. In our field, 99.9% of the time a computer selects the person who will get a given organ. The distribution system is based on a point system which is considered to be fair. Our presentation differs slightly from others by showing how distrust of the system in general affects not only the individual but all members of the same race. African Americans are being denied transplants because members of the African American community, who are well matched for histocompatibility with the African American patients currently on dialysis, are not offering their organs. Thus, they are affecting all people by their refusal to donate. In terms of the allocation system, we've tried to derive a very fair, unbiased method. A current

concern in the transplant community is how to enable more kidneys harvested from Caucasians to be used in transplantation to African American patients. This would enable more African Americans to have transplants sooner than is currently possible. However, kidneys harvested from Caucasians don't do as well in African Americans as would kidneys harvested from other African Americans. Changing the formula would result in a form of reverse discrimination. It would mean that more kidneys harvested from Caucasians would go to African American patients, where they would not do as well as they would if used for transplant to Caucasians. Rather than do this, the push should be to educate the African American community at large to donate organs. If this were to happen, both African Americans and Caucasians would benefit.

Moros:

Dr. Burrows, perhaps the issue you raise spans this entire discussion. Some of our speakers have talked about public policy, others, personal experience in health care. You have described your personal experience with distrust. It has a public policy challenge embedded within it. I wonder if any of the other speakers would like to address the connection between personal experiences of conflict and distrust, and some of the public policy issues?

Chen-Li Sung:

I think Professor Francis raises a very good point, which is, distrust can be taken to another level. It is not simply distrust during an encounter, but distrust of the physician's conduct at the level of treatment, and judgments about which treatment or procedures should be done. So, a question for Dr. Burrows is, do you think physicians and transplant surgeons are the ones who should decide which numbers and scores should be fed into the computer? Or, as Professor Francis describes it, can a case be made that surgeons are making race-based decisions that then affect the protocol?

Burrows:

It can't be done. It's virtually impossible to do that at this point. Let Ms. Solomon describe how we feed the data into the national data base computer on any single patient who comes into our clinic wishing to have a kidney transplant.

Maritza Rozon-Solomon:

The data that's put in is scientific data, not anything that can be manipulated. It's DNA testing

tissue typing. We put in the patient's red blood cell blood type, and the computer calculates on a daily basis how long the patient has been waiting. The clock starts ticking from the time the patient is activated on the computer. That's all that is fed into the computer. Also, once a month we input the current sensitization of the patient, i.e., how many cytotoxic cells the patient has in circulation.

Lynne Richardson:

What about the decision that gets made to put someone on the list?

Rozon-Solomon:

So far, that has not been discussed today. The criteria being used to accept candidates into the system have much more leeway in terms of who gets accepted and who does not. Transplant centers are now accepting more high risk patients, e.g., diabetics, hypertensives, and cardiac cases. These patients have a much higher risk of not making it past the first year post-transplant and dying with a functioning kidney. Since dialysis can maintain such patients and keep them alive, kidney transplantation is more a quality-of-life issue than one of life and death. However, giving such patients a kidney, a scarce resource, is taking it away from someone who would doubtless have a much better outcome.

Francis:

It might be interesting to try to see whether there is reverse discrimination in the decision that you get a score of such-and-such for such-and-such an antigen match. We might consider the possibility of reverse discrimination in altering transplant criteria to accept higher risk patients. I'm not suggesting that the actual data you feed into the computers isn't scientific, but the interesting question concerns how you then evaluate that data with respect to scoring.

Rozon-Solomon:

At the moment, the specificity test on which basis they give points for tissue typing is based on an identical match, e.g., an A for an A and a B for a B. What the United Network of Organ Sharing (UNOS) is proposing instead is, an A1 will be able to match 10 different other specificities, which are not being matched right now, thereby increasing the number of people who will match a given kidney.

Audience:

I wonder whether we've reached a point in this country where our fondness for transplanta-

tion and our preoccupation with high tech medicine is somewhat misplaced. If we're talking about saving lives, one could argue that our focus on saving the lives of people who can't afford the fees is one concern that should be put in the larger context. We should be doing more in terms of prevention and providing health insurance, so we can keep people from having uncontrolled hypertension, for example. If we're going to talk about what's of benefit to minority populations, having health insurance for everybody is a major issue. It would benefit a greater number of people. One wonders how we can improve trust in the doctor-patient relationship when we live in a society that doesn't even guarantee access.

Burrows:

You're not going to get an argument from me. I've devoted most of my professional life to transplantation. It is a very expensive modality for a relatively small percentage of our population. When the federal government decided to select out one disease entity—end-stage renal disease—and provide total care for that group of patients under the Medicare system of the Social Security Administration, that was unique. It's never been done before. What they first projected as costing \$12 million a year is now costing \$3 billion a year. If you want the best for your buck, obviously you wipe out transplantation; it's not really providing that much for that many people. It's a sexy field, it's fun, it's exciting, but if you have a limited amount of money you want to distribute, I would distribute it along the lines that you mentioned: education, preventive health care and the like.

Rosamond Rhodes:

Dr. Schonholz, we have heard a lot about the need for sensitivity to cultural difference, and your program is sensitive to the Jehovah's Witness religious conviction of refusing blood transfusions. I imagine that costs a lot of money. Can you tell us something about the comparison of costs for a normal delivery and the problematic delivery of a Jehovah's Witness? Who is responsible for the extra costs?

David Schonholz:

The Jehovah's Witness community has attempted to solve their problem on a financial basis. Approximately eight years ago, they realized that they were bringing their health care dollars to all the major institutions. But what has happened is fascinating. They've taken the bull by the horns and decided to send Jehovah's Witness patients only to hospitals that are attentive

to their concerns about blood and to recommend only those physicians who honor their precepts.

Rhodes:

I'm interested in how much more it costs for bloodless treatment and who pays for it. If my religious conviction is to have kosher beef, I pay for it. If somebody else's religious belief only permits bloodless surgery and it costs three times more, is that person paying for it or are we all paying for it?

Schonholz:

At the present time, a large portion of the Jehovah's Witness population is covered by Medicaid. So, ultimately it is the government which supports it. However, in the last five years, the Jehovah's Witness religion has put in a self-insurance program for their own support. Their reimbursement is not as great as with other plans, and patients on their plan may have to seek out hospitals and physicians that will accept their reimbursement.

Rhodes:

And do bloodless procedures cost more?

Schonholz:

In actual costs, it is more. The use of a cell saver, for example, would be an added expense, so the dollar cost is more.

Audience:

We've skirted around this issue, but in what sense does ability to pay enter into this whole discussion, and has that been part of this whole issue with discrimination? Also, how has managed care impacted on minorities in the health care system?

Rozon-Solomon:

For any kind of transplant program, financial screening is geared toward whether or not the patients will be able to afford the lifelong immunosuppressive medication. There is no use giving patients transplants when they are not going to be able to maintain it. Patients who have Medicare or Medicaid are eligible from a financial standpoint. Reimbursement to the hospital and to physicians and for other costs may not be as great as it would be, for example, with Oxford or Aetna, but the patients will be accepted and transplanted. Our focus is on assuring that patients can afford the medications. Three years after a transplant, Medicare no longer covers the immunosuppressive medications. How is the patient going to pay for them? The medication

can cost anywhere from \$600–\$1000 per month. If the patient can't afford that, we are doing an injustice by giving him or her a transplant.

Ian Holzman:

For kidney transplants, the ability to get money to pay for immunosuppression medication long term is an issue, but it isn't true for liver or other organ transplants. Medicare will only pay for the immunosuppressive medicine necessary to sustain a kidney transplant for a limited amount of time.

Burrows:

If you want a transplant, the best thing you can have is Medicaid. It provides lifetime support for your transplant. The worst situation is a middle-class person who has limited health care insurance.

Schonholz:

And if you want to have a cell saver and no transfusion, the best thing to have is Medicaid and an institution that will make adjustments to its budget to support the management of this type of patient.

Cheryl Smith:

I was going to make a comment about HIV disease. New York State happens to be very generous when it comes to HIV disease. If a patient comes into whatever system, New York State has an AIDS drug-assistance program that allows us to provide medications and some other limited services for the patients, as well as medical services. It's more limited than Medicaid, but for a short period of time and if the patient does not qualify for Medicaid, the patient is able to take advantage of the program.

Richardson:

I'd like to give a more general response to the question of how ability to pay affects access

to care. In fact, this could be the subject for another conference. I don't think there's any question that the ability to pay is central to everyone's ability to get access to care in this country, be they white, black, brown, etc.—it doesn't matter. Clearly, though, racial minorities are more likely to be in the category of people who are unable to pay, so those financial barriers affect them disproportionately.

On a daily basis, I now see individuals who are in need of health care for which they have no ability to pay. Once they get below the level of a true emergency, I'm unable to obtain treatment for them through the Emergency Department. For example, I see patients with high blood pressure who cannot afford the medications needed to control their blood pressure. When they come back with a stroke or heart attack, however, we do pay to take care of them. This is part of the whole issue about what kinds of health care we ought to pay for. This is especially true, given that much of our available resources is concentrated on inpatients and end-of-life care, and so little is provided for prevention and health promotion programs. These are not only morally questionable decisions and practices, but they are bad medicine, and reveal an unenlightened social policy.

It's true that if you are not well off, the best insurance you can have is Medicaid. The worst position is slightly above the level of poor enough to qualify for Medicaid. This is the situation of part-time workers or those who have a full-time job in a small business that offers no health care benefits. In such cases, there is no access beyond emergency care. I've seen young people with disabling injuries who can't get semi-elective orthopedic procedures because they have no insurance and cannot afford to pay for the procedures themselves. Given my personal experience with such public policies, I don't understand why we tolerate the system.