Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

RACIAL AND GEOGRAPHIC DISPARITY IN THE DISTRIBUTION OF ORGANS FOR TRANSPLANTATION

JUNE GIBBS BROWN
Inspector General

JUNE 1998
OEI-01-98-00360

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

JUN 10 1998

The Honorable Thomas M. Barrett
House of Representatives
Washington, DC 20515-4905

Dear Mr. Barrett:

I am in receipt of your letter of May 4, 1998, asking our office to conduct an update of our 1991 report entitled, "The Distribution of Organs for Transplantation: Expectations and Practices." (We include your letter in Appendix A of this report.) You indicate that much has changed since the issuance of the report and that an update could help in the consideration of current policy recommendations concerning organ allocation. You also request that, as part of the inquiry, we examine if the recently proposed final rule of the Department of Health and Human Services (HHS) is likely to correct current deficiencies in the organ allocation system.

In response to your request, we have prepared the following report. In it, we have reviewed the data available from the Organ Procurement and Transplantation Network (OPTN) in two of the major areas that we addressed in our 1991 report and that you have expressed interest in: racial and geographic disparities in waiting times for cadaver kidneys and livers. Our findings indicate that both racial and geographic disparities in waiting times still exist and, in some cases, seem to be growing.

The available OPTN data suggest that median waiting times for both liver and kidney transplants have continued to increase across race. However, while waiting times for liver transplants have been nearly equal for whites and blacks, black recipients still wait longer than white recipients for kidney transplants. In fact, the difference in waiting times has grown.

Geographic differences in waiting times exist across regions, both in general and in regards to race. For both kidney and liver registrants of all races, median waiting times vary substantially from OPTN region to region. The difference in waiting times between white and black kidney registrants also varies widely across OPTN regions.

This review leads us to reemphasize the importance of the central thrust of our 1991 report--that the national organ allocation system should focus on equity among patients, not among transplant centers; and on common medical criteria, not the circumstances of a patient's residence or transplant center affiliation. We continue to believe that the April 2, 1998 HHS rule on organ allocation moves in that direction.

In the following report, we close by indicating that the national discussion of organ allocation has led us to recognize even more fully the underlying importance of having organ donation and procurement systems function as effectively as possible. We note some follow up work we will be doing in that regard, focused on State laws requiring hospitals to refer all deaths to Organ Procurement Organizations.

I appreciate your interest in our work and will keep you informed of our continued efforts in the field of organ transplantation. If you have any questions or comments, please call me or have your staff call Helen Albert, Director, External Affairs, at (202) 619-0275.

Sincerely,

June Gibbs Brown
Inspector General

Enclosure

Introduction

In 1991, we issued a report entitled "The Distribution of Organs for Transplantation: Expectations and Practices" (OEI-01-89-00550). In that report, we documented the expectations that Congress and professional leaders had of organ allocation systems and then contrasted those expectations with actual practices. As a result, we found a particularly disturbing mismatch between expectations and practices concerning the equity of organ allocation systems. Congress and professional leaders, we showed, clearly expected the development of an equitable system, with each person on a transplant waiting list having an equal opportunity to receive a transplant, subject to established medical criteria. The reality, we found, was quite different, particularly with respect to race and geography. Our findings led us to call for an organ allocation system that focuses on (1) equity among patients, not among transplant centers and (2) common medical criteria, not the circumstances of a patient's residence or transplant center affiliation.

We reiterated these recommendations during our testimony at the April 8, 1998 hearing of the Subcommittee on Human Resources of the Committee on Government Reform and Oversight. Further, we indicated that the HHS rule published on April 2, 1998 in the Federal Register moved in a direction responsive to the thrust of our findings and recommendations by calling for: performance goals for standardized criteria for listing patients on transplant waiting lists, standardized criteria for the medical status of those on waiting lists, and organ allocation policies that give priority to those whose needs are most urgent. With currently three times as many individuals awaiting a transplant as there were in 1991, we stated that it was even more imperative that congressional expectations of the organ allocation system closely match the actual practices.

Subsequent to that testimony, Congressman Tom Barrett, a member of the Subcommittee on Human Resources, asked that we update the findings of our 1991 report. This brief report is a response to that request, focusing on two of the major areas we addressed in it: racial and geographic disparities in waiting times for transplantation. It is based on a review of data available from the Organ Procurement and Transplantation Network (OPTN).

Racial Disparities

In addressing this issue in our 1991 report, at a time when liver transplants were just moving beyond the experimental stage, we focused on black-white discrepancies in waiting time for a first kidney transplant. We found that between October 1, 1987 and March 31, 1989, the median waiting times for blacks was almost twice as long as for whites: 13.9 months compared with 7.9 months.

The available OPTN data suggest that in the ensuing years there has been no improvement in this discrepancy and perhaps even some slippage. The data on kidney transplants are not exactly comparable to our earlier data, as they reflect waiting time to a transplant (not necessarily a first transplant) and a somewhat different methodology. Further, the OPTN data allowing black-white comparisons are available only through 1994.[1] They reveal that waiting times have continued to

escalate for both blacks and whites, but somewhat more so for blacks than whites. From 1988 to 1994, the median waiting time for whites for a kidney transplant increased from 11.3 months to 20.1 months (78 percent).[2] (See table 1 below.) During that same period, the median waiting time for blacks increased from 20.1 months to 39.7 (98 percent).

Table 1
Median Waiting Time (in Months) to Kidney Transplant By Race

Year	Black Recipients	White Recipients	Difference
1988	20.1	11.3	8.8
1989	21.4	12.7	8.7
1990	24.9	13.3	11.6
1991	26.7	14.1	13.7
1992	29.8	16.0	13.8
1993	34.9	18.7	16.2
1994	39.7	20.1	19.6

Source: Organ Procurement and Transplantation Network (OPTN), *1997 OPTN/SR AR 1988-1996. UNOS; DOT/HRSA/DHHS.*

In regard to waiting times for liver transplants, which we did not examine in our 1991 report, the picture is quite different. (See table 2 below.) Here, too, we find that there has been a significant increase in waiting times, but that the waiting time for whites and blacks has been more nearly equal than in the case of kidney transplants. During the period of 1988 to 1996, the median waiting time for the two races remained close for each year until 1996 when the median waiting time for whites was considerably greater than that for blacks: 12.4 months compared with 9.2 months. Whether this is a 1 year aberration or the beginning of a trend remains unclear to us at this point.

Table 2 Median Waiting Time (in Months) to Liver Transplant By Race			
Year	**Black Recipients**	**White Recipients**	**Difference**
1988	1.1	1.0	0.1
1989	1.2	1.2	0.0
1990	1.7	1.4	0.3
1991	2.1	2.2	-0.1
1992	3.9	3.4	0.5
1993	4.5	4.7	-0.2
1994	5.6	5.3	0.3
1995	8.0	8.4	-0.4
1996	9.2	12.4	-3.2

Source: Organ Procurement and Transplantation Network (OPTN). *1997 OPTN/SR AR 1988-1996. UNOS; DOT/HRSA/DHHS.*

Geographic Disparities

In our 1991 report we also examined variations among transplant centers in waiting time for a first kidney transplant. We found that from October 1987 through March 1989, the median patient waiting time for a first kidney transplant ranged from a low of less than 1 month at one center to a high of 71 months at another. In the background presented with its April 2, 1998 rule on organ allocation, HHS presented considerable data indicating that geographic disparities are still significant among transplant centers, local Organ Procurement Organization service areas, and OPTN regions.

In our review of the most recent OPTN data available on median waiting times for OPTN regions, we were struck by the significant differences that continue to exist, both in general and with particular respect to white-black differentials. Table 3 below presents the picture for kidney registrants in the 1993-1995 period. For each race, we find substantial differences in median waiting time across the 11 regions. Whereas the median waiting time for whites in Region 6 was 9 months, it was more than 3 times that in Region 1 (33 months). The similar range for blacks was from a low of 16.3 months in Region 4 to a high of 43.8 in Region 6. Further, for each

region, we find that blacks wait longer than whites.[3] The difference is most profound in Region 11, where the median waiting time for blacks is 37.2 months compared with 13.6 for whites. It is smallest in Region 4, where the differential is 16.3 verses 9.1.

Table 3
Median Waiting Time (in Months) for Primary Kidney Registrants from 1993-1995 by OPTN Region

OPTN Region	Black Recipients	White Recipients	Difference
1	42.5	33.0	9.5
2	36.8	23.4	13.4
3	23.6	9.5	14.1
4	16.3	9.1	7.2
5	41.3	27.0	14.3
6	43.8	9.0	34.8
7	40.5	20.1	20.4
8	20.7	12.9	7.8
9	NA	32.0	NA
10	40.2	17.5	22.7
11	37.3	13.6	23.7

Source: Organ Procurement and Transplantation Network (OPTN). *1997 Report of the OPTN.*
NA- Data not available.

Table 4 below provides the comparable waiting time information for liver registrants in the 1994-1996 period. Here, consistent with table 2 above, we find that for most regions the median waiting times for whites and blacks are quite similar. For each race, however, we see that there is considerable inter-regional variation. In Region 3, the median waiting time for blacks was only 3 months compared with a high of 16.4 months in Region 5. For whites, the range was from 3.5 months to as much as 28.3. (It should be noted, here, that the number of black registrants in some regions was quite small--for instance, only 16 in Region 6 and 91 in Region 8.)

Table 4
Median Waiting Time (in Months) for Primary Liver Registrants from 1994-1996 by OPTN Region

OPTN Region	Black Recipients	White Recipients	Difference
1	NA	28.3	NA
2	14.5	14.6	-0.1
3	3.0	3.5	-0.5
4	6.0	6.9	-0.9
5	16.4	15.9	0.5
6	10.9	9.0	1.9
7	14.7	8.2	6.5
8	7.4	7.6	-0.2
9	8.1	12.2	-4.1
10	13.3	12.0	1.3
11	4.3	5.0	-0.7

Source: Organ Procurement and Transplantation Network (OPTN). *1997 Report of the OPTN.*
NA- Data not available.

Concluding Points

Our brief review of these data lead us to reaffirm the importance of the central message we presented in our 1991 report--that the national organ allocation system should focus on equity among patients, not among transplant centers and on common medical criteria, not the circumstances of a patient's residence or transplant center affiliation. We continue to believe that the April 2, 1998 HHS rule moves in that direction.

The national discussion on organ allocation also leads us to recognize even more fully the importance of having organ donation and procurement systems that function as effectively as possible. More productive systems will expand the total pool of organs available for transplantation and in so doing could help ease some of the controversy about who might gain and lose under different allocation schemes.

Thus, we will be giving priority attention to examining the early implementation efforts of the required referral laws that some States have passed in recent years. These laws call for hospitals to refer all deaths to their local Organ Procurement Organizations (OPOs) so that trained OPO staff can consider their suitability as donors. Our intent is to examine promising approaches that states have used in carrying out these laws as well as some of the barriers they have encountered, in order to assist other state efforts to move in this direction.

Endnotes

1. The OPTN states that due to long waiting times to kidney transplant, median waiting times could not be computed after 1994. (1997 OPTN/SR AR 1988-1996. UNOS; DOT/HRSA/DHHS)

2. For Tables 1-4, we converted median waiting times from days (as provided by OPTN) into months. The OPTN defines median waiting time as " the estimated number of days until at least 50% of new registrants have been transplanted and are off the waiting list" (1997 OPTN/SR AR 1988-1996. UNOS; DOT/HRSA/DHHS, 12).

3. The disparity in waiting times for blacks and whites also varies widely across OPTN regions, from 7.2 months difference in Region 4 to 34.8 months difference in Region 6.

THOMAS M. BARRETT
5TH DISTRICT, WISCONSIN

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Congress of the United States
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May 4, 1998

June Gibbs Brown
Inspector General
Department of Health and Human Services
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330 Independence Avenue, SW
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Dear Inspector Gibbs:

The purpose of this letter is to request that your office update a 1991 report entitled "The Distribution of Organs for Transplantation: Expectations and Practices." At the time this report was issued by the Office of Inspector General, 20,000 people were waiting for organ transplants. The impetus for the report stemmed from concerns about fairness in the organ allocation process. Despite the 1984 enactment of the National Organ Transplant Act, serious problems remained in the organ donation and allocation system.

Because of reported deficiencies in the system, your office issued a report to (1) clarify expectations governing organ distribution practices in the United States; (2) determine the extent to which actual practices were in accord with expectations and, (3) offer recommendations that facilitated accord between expectations and practices. The most striking finding was that patient access to donated organs remained unequal and that minority populations were likely to remain on the waiting lists for longer periods and were less likely to attain organs once on the list.

Today, about 60,000 people are waiting for organ transplants, the need for organs continues to outweigh the donation rates and concerns remain about racial and economic equity in allocation decisions. As you know, the Department of Health and Human Services recently put forth a proposed final rule governing a national organ allocation system. Much of the rationale underlying the new proposed rule is based on data gathered and conclusions reached in your 1991 report.

After seven years, the data which formed the premise of the conclusions reached in your report may no longer be valid. To assure that the current policy recommendations are likely to resolve the current problem, recent and reliable data are necessary. Therefore, I am requesting that you update your 1991 report in light of the current information available governing the organ allocation system. Additionally, I would like you to examine whether the policies set forth in the

proposed final rule promulgated by HRSA are likely to correct the current deficiencies in the system. I am particularly interested in the continued existence of economic and racial inequities in the organ distribution system and the likely affect the new rules will have on any such inequities. I look forward to your response to this request no later than May 15, 1998. If you have any questions, please contact Tama Mattocks at 225-3571 or Cherri Branson at 225-5051.

Sincerely,

Tom Barrett

Tom Barrett
Member of Congress

TB:tm