

# 'Tis Better to Receive than to Give: The Relative Failure of the African American Community to Provide Organs for Transplantation

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## Abstract

There is a serious, continuous and increasing shortfall of organs, especially kidneys, for the purpose of transplantation. This shortfall is especially remarkable in African American populations. Because the incidence of hypertension (HTN) and associated end-stage renal diseases (ESRD) is 17 times greater in African Americans, this minority group, which comprises only 12% of the U.S. population, represents 34% of the dialysis population and 30% of the national kidney waiting list. Furthermore, while black individuals comprise 22–24% of kidney recipients, they comprise only 8–11% of donors. Because of the histocompatibility differences between the races and because tissue matching is part of the United Network for Organ Sharing (UNOS) allocation formula, African Americans wait twice as long for kidneys as Caucasians. Also, because they get more poorly matched organs, their kidney transplant graft survival is 10–20% lower than that for other racial groups. The African American community is unaware of the special needs in members of their own race. Steps must be taken to increase minority awareness of the need for well-matched transplant organs and their involvement in the donation process. **Key Words:** Organ donation, kidney transplantation, organ transplantation, organ donation by minorities, organ shortage.

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THE TRANSPLANTATION PROCESS is probably the most carefully administered medical program in our country. Virtually every aspect of procurement, allocation, and subsequent results of transplantation are monitored on an hourly basis and recorded in a national data bank.

Because of the remarkable advances in the field of transplantation, the majority of organ failure patients can now be offered a reasonable chance of a normal life. Accordingly, with more sick individuals opting for this therapy, the shortfall in donor organs is increasing. Thus, with the supply not keeping up with the demand, more patients are dying for lack of life-saving transplants.

The following two case histories help illustrate one puzzling reason for this shortfall.

**Case 1.** A 19-year-old respirator-dependent female, living at home after an auto accident two

years before, suffers a respiratory arrest when a tracheostomy plugs and an alarm system malfunctions. She is declared brain dead and her family wills a single kidney only to a 60-year-old diabetic, hypertensive father who has been on dialysis for 8 months. No other organs are offered, but her liver is also donated when the procurement coordinator informs the family that the medical examiner will take it anyway. All the other potentially transplantable organs are wasted.

**Case 2.** A 35-year-old with heroin-induced nephropathy has been on dialysis for 5 years when his 55-year-old mother, a school secretary, suffers a fatal stroke. His family, which includes a sister who is a dialysis nurse, offers the mother's kidney only to him. No other organs are offered. When the family is informed that the patient is too infected at that time to undergo transplant surgery, they withdraw their offer of donation and this organ is also wasted.

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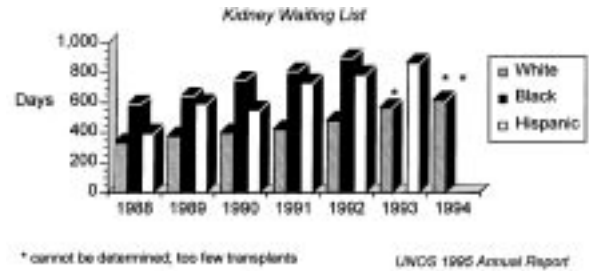
One salient fact has been omitted from both of these histories. Both families were middle-class African American families. The African

American community has been providing donor organs at a significantly lower rate than that of the white population (1, 2). This imbalance has been detrimental not only to the recipient population at large, but especially to African American patients waiting for transplants.

Why this disparity? Dr. Clive Calendar, a transplant surgeon and also an African American, has been seeking the reason(s) for this unwillingness to consider organ donation since the 1970s. He has spearheaded and participated in many minority research programs. In 1980, the results of one of these research efforts showed that the incidence of hypertension and associated renal disease was 17 times greater among African Americans than among Caucasians. Even though African Americans make up 12% of the national population, 34% of the dialysis patients in the U.S. are African American. Furthermore, of those waiting for kidney transplants in the U.S., 30% are also African American. Unfortunately, the kidney transplant graft survival for African Americans is 10–20% lower than for any other racial group. In addition, African Americans wait twice as long for kidneys as Caucasians, and their organ donation rate is less than 8% (3).

According to data from the United Network for Organ Sharing (UNOS), African Americans comprise 30–35% of the patients on the national waiting list (Fig. 1) (1). Yet they clearly wait longer than any other racial group (Fig. 2). One might wonder whether discrimination is a factor in this difference—but the UNOS allocation system for kidneys is strictly patient driven, without respect to race and—with the exception of children under the age of 17—without respect to age as well.

The United Network for Organ Sharing assigns points to each candidate waiting for a kidney, using specific standardized criteria (Table). These points include the duration the prospective

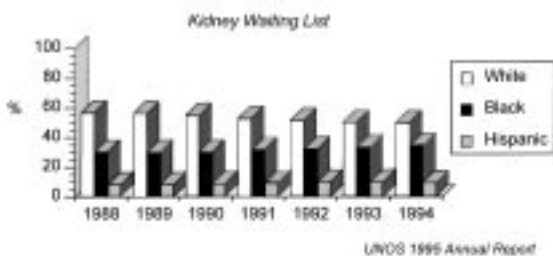


**Fig. 2.** Median waiting times to transplant. Kidney waiting list. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).

recipient has been on the transplant list, and the degree of tissue typing (Human Leukocyte Antigens—HLA) match with the donor. For those patients who are immunologically very sensitized (as indicated by elevated Panel Reactive Antibodies—PRA), additional points are assigned, since it is very difficult to obtain a compatible organ for them. The point scores of each prospective recipient are then totaled and ranked by computer with every cadaver organ. The prospective recipient’s placement on the UNOS printout depends on that total score. The poor antigen matching for African Americans is also reflected by the shortfall of black donors, and has been cited as one of the causes for their 10–20% lower kidney graft survival rate.

The bar graph in Fig. 3 shows the percentage of patients transplanted for the years 1988–1994. When compared to the percentage of kidney donors by race as seen in Figs. 4 and 5, clearly the disparity between Caucasian, and African American and Hispanic recipients is shown. African Americans have historically donated significantly fewer cadaver kidneys than they have received. They have received and benefited from Caucasian organ donation (1).

Since 1988, there has been a slight increase in the percent of total minority donations: from 16.4 to 22.8% for cadaveric donors and for living

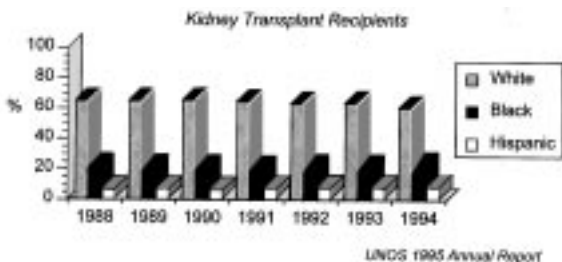


**Fig. 1.** Percentage of patients by race. Kidney waiting list. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).

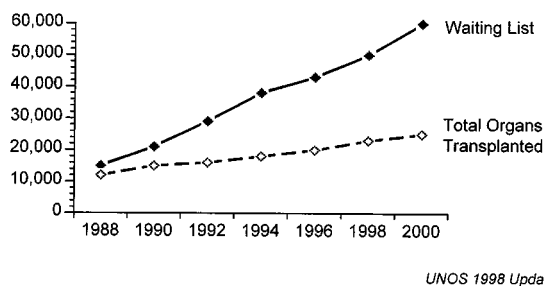
**TABLE**  
*The UNOS Point System for Local Kidney Distribution.*

| Points          | Category       |
|-----------------|----------------|
| 2–7             | HLA matching   |
| complex formula | Time waiting   |
| 4               | PRA ≥ 80%      |
| 4               | Age < 11 years |
| 3               | Age 11–18      |

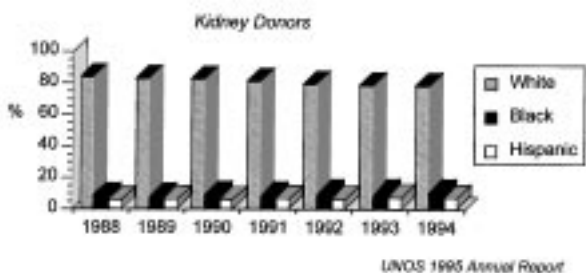
From the United Network for Organ Sharing (UNOS) Policy 3.5. March 24, 1999 (4).



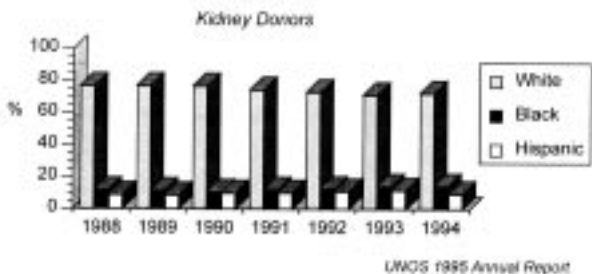
**Fig. 3.** Percentage of patients transplanted by race. Kidney transplant recipients. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).



**Fig. 6.** UNOS - wait list size and total organs transplanted. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).



**Fig. 4.** Cadaveric donors by race. Kidney donors. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).



**Fig. 5.** Living donors by race. Kidney donors. From the United Network for Organ Sharing (UNOS) 1995 Annual Report on U.S. Scientific Registry for Organ Transplantation & Procurement, Richmond, VA (1).

donors an increase from 24 to 27.5% (1). This fact, however, is overshadowed by the ever-increasing demand for organs (Fig. 6). Why then, in light of the special need for organs by African Americans, has there not been a similarly greater donation rate? Why do African Americans say no to donation?

Dr. Clive Calendar identified the obstacles to donation in the minority community as lack of awareness, fear of premature death, religious beliefs or concerns with issues of resurrection,

and the belief that body parts would be needed in the other world. Another factor cited is the lack of trust that medical professionals would do everything possible to save their loved ones if the family was to consider organ donation. The history of the Tuskegee experiment serves to reinforce this mistrust. Some have even expressed the view that medical professionals work on a commission basis and would benefit from their loved one's death. Some African Americans consider the signing of a donor card as akin to a "death wish." Also, some African Americans bear hostility toward whites for the years of oppression and feel that they are owed something for it—yet here they are being asked to give away something of great personal importance (2).

What are the possible solutions to this problem? It has been recommended that minorities be included and involved in the planning and implementation of the donor process within their communities. This participation would allow them to be part of the solution to the donor shortage and would help empower their community. Another suggestion has been to utilize key persons from minority groups, such as transplant recipients, transplant donors, transplant candidates and donor families, as effective messengers to help overcome distrust of medical professionals. Also, the public and private sector should expand funding to pay for the cost of preparing and marketing materials such as videos and brochures, which would enhance donor education. And finally, steps need to be taken to foster positive media representation of the organ and tissue donation process (2).

In conclusion, African American patients receive a disproportionately larger number of transplant organs—especially kidneys—from the cadaver donor pool, but African Americans donate organs at a significantly lower rate. The withholding of organs by this community is detrimental to the African American dialysis popula-

tion, which must wait much longer for organs than Caucasians and generally receive more poorly matched kidneys because of histocompatibility differences between the races.

The reluctance to donate may be due to mistrust of the medical establishment as well as to lack of awareness, to religious beliefs, to fear that signing a donor card could lead to withdrawal of needed medical treatment, and to resentment of past or present racism.

Without a doubt, if more African American families were involved in the donation process, all patients would benefit greatly. Concerted efforts must be made to educate and involve this segment of the population in the donation process.

#### References

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