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A National Minority Organ/Tissue Transplant Education Program: The First Step in the Evolution of a National Minority Strategy and Minority Transplant Equity in the USA

by Clive O. Callender, Alvina S. Bey,
Patrice V. Miles, and Curtis L. Yeager

In 1978, members of the Southeastern Organ Procurement Foundation approached us concerning the disparity between the large number of African American patients, 50% to 70% of all patients on dialysis (artificial kidney machines), and the small number of African American donors (3%), and asked us why and what could be done about it? From my perspective as an African American transplant surgeon at Howard University, these observations piqued my curiosity and I agreed to investigate them. Our investigation took us into three areas:

1. An evaluation of the data regarding transplantation in patients at the Howard University Hospital Transplant Center (HUTC).
2. A search to find the actual incidence and cause of end-stage renal disease (ESRD) in the District of Columbia (DC) and throughout the nation.
3. Finding an answer to the question "Why are African Americans reluctant to leave organs and tissues behind, after the death of their loved ones?"¹

Materials and Methods

The first step of the investigation was internal and required us to identify the number of African American cadaver kidneys used for transplantation into HUTC patients. We found that 41 of 47 (87%) in 1982² and 48 of 61 (78%) of the organs in 1985³ that were transplanted into HUTC patients were from Caucasians and 20% or less of donated organs were from African Americans. The next step was to look at the incidence of ESRD in the District of



Columbia (DC) and nationally and identify the most common causes.⁴ This investigation unmasked the fact that DC, in 1980, had the highest incidence of ESRD in the nation and that hypertension was the leading cause of ESRD in DC, and the African American population at HUTC accounted for 60% of the cases of ESRD.⁵ With these questions answered and the nature of the problems unmasked, attention was then directed to the third issue. Why were African Americans reluctant organ and tissue donors? We then discussed these data with Dr. James Bayton, the nationally renowned psychologist at Howard University. Together, we identified a pilot project to answer questions relating to the paucity of African American donors. With the psychology team designated and appropriate questions selected, 2-hour interview sessions were scheduled. This pilot project was then funded with \$500 used to interview 40 African American DC residents.⁶ This project began in 1980 and was completed in 1981. The two major accomplishments of this pilot project were:

1. We identified the five most common reasons for unwillingness to donate by the black population of DC, they were:
 - (a) A lack of renal disease and transplantation awareness.
 - (b) Religious myths, misperceptions, and superstitions.
 - (c) A lack of trust in health care providers and the health administrative process.
 - (d) A fear that signing organ donor cards might change the emphasis from life-saving priority to organ donor priority.

- (e) A fear that the racism, which African Americans experience on a daily basis in life, would remain after death and all black donated organs would go to white people.
2. We observed that, prior to the interview session, 10% of those interviewed had signed organ donor cards; but after the 2-hour interview sessions, 100% of those interviewed were willing to sign organ donor cards. This suggested to us that the modus operandi used in the interview sessions—face-to-face dialogue—was the key to changing the attitudes and behavior of African Americans toward organ donation. With this in mind, we identified a strategy emphasizing a face-to-face dialogue, grass roots effort with a minority targeted message (directed to the five obstacles identified by this survey) delivered by ethnically and culturally similar and sensitive community messengers who were health care providers, transplant recipients, patients waiting for organs, and donors and/or their family members. We later found that spouses and significant others from these groups were also very effective messengers.⁷

The District of Columbia Organ Donor Program (DCODP) was born in August of 1982 under the auspices of the HUTC and the Capital Area's National Kidney Foundation. Between 1982 and 1986, the impact of this project was evident with organ donor designations increasing from 25 per month in 1982 to greater than 600 per month by 1986 and the number of organ donations from African Americans doubling as determined by reviewing Southeastern Organ Procurement Foundation regional data.⁸ These data were presented at the American Council on Transplantation's annual meeting in Chicago, in the Spring of 1986. There, representatives from the Dow Chemical Company became interested in the shortage of African American donors and initiated the Dow Black Donor Education Programs which followed under the umbrella of the Dow Take Initiative Program (DOW-TIP). These programs were active from 1986 to 1992,⁹ and included the following black donor-targeted education programs:

1. A 30-city National Black Donor Education Outreach Program (1986 to 1992).
2. Dow/NAACP, a National Black Community Grass Roots Black Donor Awareness Program in six pilot cities: New York, St. Louis, Detroit, Memphis, Baltimore, and Houston. With each NAACP chapter receiving detailed programs, handbooks, brochures, Bill Cosby PSA's, and ongoing counsel (1989 to 1991).
3. The Dow Transplant a Miracle Donor Education Brochure—100,000 distributed since its creation in 1987.
4. "A Second Chance" Donor Education Video—produced in 1990 and viewed by thousands—350 copies distributed initially.
5. A Dow/Clive Callender Fellowship Program, which was developed in 1989 and granted to seven medical students to work with transplant surgeons

in an effort to increase the number of African Americans and other minority transplant surgeons.

6. A College Donor Awareness Program (1991 to 1992) which was taken to four historically black colleges, i.e., Howard University, North Carolina A&T University, Prairie View A&M University, and Southern University (Baton Rouge and New Orleans campuses). With Dow's support, student organizations worked with local organ procurement organizations and spearheaded week-long donor awareness campaigns. More than 40,000 students and faculty at the participating universities, their families, and surrounding communities learned about the importance of organ/tissue donation and transplantation through these campus activities.

Results

As a consequence of the prior efforts of the DCODP and the DOW-TIP, the following results were achieved:

1. The DCODP was formally commended in 1990 by the National Kidney and Urologic Disease Advisory Board of the National Institutes of Health "for the enormous success their work had achieved."¹⁰
2. The DOW-TIP Black Donor Education Program was cited and selected in 1991 by the authors of *Public Education in Organ and Tissue Donations, Reviews and Recommendations: A Planning Tool for the Transplant Community*, as the successful organ donor program to analyze and fully evaluate as a role model for organ donor programs.¹¹
3. The DCODP and DOW-TIP programs were partially responsible for the following remarkable accomplishments:
 - (a) The organ donor consent rate in the District of Columbia increased from 10% in 1978 to 51% in 1993.¹²
 - (b) The number of DC residents signing organ donor cards increased from 25/month in 1982 to 750/month in 1988.
 - (c) The number of African Americans aware of the highly successful nature of transplantation increased from 10% in 1985 to 31% in 1990 (1985 and 1990 Dow Gallup Surveys).¹³
 - (d) The number of African Americans signing organ donor cards increased from 7% in 1985 to 24% in 1990 (1985 and 1990 Dow Gallup Surveys).
 - (e) The number of African American organ donors per million increased from 8 in 1982 to 20 in 1992.
 - (f) The number of African American donors increased from 3% in 1982 to 11.6% in 1993.¹⁴
 - (g) Organ donation in blacks—a critical frontier highlighting (a)-(f), was published in *The New England Journal of Medicine* (August 1991), the premiere medical journal in the United States.¹⁵
 - (h) By 1993 the transplanted kidneys received from African American donors at the HUTC had increased from 6 of 47 (20%) in 1982 to 26 of 60 donors (41%) in 1993.

(i) As a consequence of their role in the successes of (a) through (g)—the HUTC received a \$1,257,458.00 research contract from the Office of Research on Minority Health Research at the National Institutes of Health from June 1993 to June 1995 to establish the Minority Organ Tissue Transplant Education Program (MOTTEP). This contract allowed us to establish and extend community-based transplant education programs to minority populations in 11 cities with the highest minority populations: Washington, DC; Cleveland, Ohio; Los Angeles, California; Birmingham, Alabama; Houston, Texas; Brooklyn, New York; Honolulu, Hawaii; the Pima Indian Reservation in Arizona; Chicago, Illinois; Nashville, Tennessee; and Atlanta, Georgia. The goal of this contract is the development of a model organ tissue transplantation program to increase minority organ tissue donations. This program has developed a pre- and post-test and survey tool which will allow for the objective evaluation of community presentations as well as their optimization; it will also search for a correlation between the signing of organ donor cards, family discussions, and an increase in minority donation rates. A successful MOTTEP Program with an increase in donations of only 5 per year in the African American and Hispanic (Latino) populations alone can save \$50 to \$100 million from kidney donations and upwards of one billion dollars if other life-saving organ transplants are considered.¹⁶

Discussion

The lesson learned from these grass roots community educating and empowering efforts is that we have underestimated the power of an educated community as an effective change agent. Before we began this effort it was widely believed that minorities (blacks and Hispanics) just would not donate. Our initial efforts give much credence to the belief that this just isn't so. The difference I believe is the empowered community. To this end, I believe the answer to the problem of minority overrepresentation on dialysis and transplant waiting lists is to overcome the lack of minority participation at all levels.¹⁷ Education, research, and resource allocation are critical, but as long as these continue to be characterized by minimal minority participation and decision making power, these efforts are doomed to fail. The new thrust must be to allow minority community input and responsibility at all levels. MOTTEP is an important first step, but the steps that follow must allow utilization of a newly formed group, the American Society of Minority Health and Transplant Related Professionals, to participate at all levels of resource allocations for minorities—they must be permitted to serve as the brain trust for all minority endeavors in America. This then would launch, in a major way, serious efforts to narrow

the gap between minorities and others. This would be a giant step forward and mark the beginning of the implementation of a national minority transplant strategy, thus making the still elusive minority transplant equity a reachable dream in America.

Notes

¹C.O. Callender, J.A. Bayton, C.L. Yeager, et al., "Attitudes Among Blacks Toward Donating Kidneys for Transplantations: A Pilot Project," *Journal of National Medical Association*, 74:807 (1982).

²Ibid.

³C.O. Callender, "The Results of Transplantation in Blacks: Just the Tip of the Iceberg," *Transplantation Proceedings*, 21:3407 (1989).

⁴Callender, Bayton, Yeager, et al., "Attitudes Among Blacks Toward Donating Kidneys for Transplantations."

⁵I. Cruz, C.O. Callender, I. Cummings, et al., "Malignant Hypertension Revisited: The Role of Bilateral Nephrectomy," *Journal of National Medical Association*, 72:453 (1980).

⁶Callender, "The Results of Transplantation in Blacks." Also see C.O. Callender, L.E. Hall, C.L. Yeager, et al., "SPECIAL REPORT Organ Donation and Blacks—A Critical Frontier," *The New England Journal of Medicine*, 325:442 (1991).

⁷See a series of publications for further understanding of this issue: Callender, Bayton, Yeager, et al., "Attitudes Among Blacks Toward Donating Kidneys for Transplantations" and Callender, "The Results of Transplantation in Blacks" and Callender, Hall, Yeager, et al., "SPECIAL REPORT Organ Donation and Blacks" and L.E. Hall, C.O. Callender, C.L. Yeager, "Organ Donation and Blacks: The Next Frontier," *Transplantation Proceedings*, 23:2500 (1991).

⁸For additional information about the Southeastern Organ Procurement Foundation's data, see Callender, "The Results of Transplantation in Blacks" and Callender, Hall, Yeager et al., "SPECIAL REPORT Organ Donation and Blacks" and Hall, Callender, Yeager, et al., "Organ Donation and Blacks."

⁹Callender, "The Results of Transplantation in Blacks." Also see Callender, Hall, Yeager, et al., "SPECIAL REPORT Organ Donation and Blacks" and Hall, Callender, Yeager, et al., "Organ Donation and Blacks."

¹⁰The National Kidney and Urologic Disease Advisory Board 1990 Long Range Plan: U.S. Department of Health and Human Services, Public Health Services, and National Institutes of Health. (NIH Publication Number 90-583, March 1990), 151.

¹¹E.T. Oberley, P.A. Sacksteder, R.B. Curtin, et al., *Public Education in Organ and Tissue Donation: A Planning Tool for the Transplant Community*. (The Medical Media Publication, Inc.:Madison, WI, 1991), 15.

¹²Callender, Hall, Yeager, et al., "SPECIAL REPORT Organ Donation and Blacks." Also refer to Hall, Callender, Yeager, et al., "Organ Donation and Blacks."

¹³Gallup Organization: Prepared for the Dow Chemical Company (Take Initiative Programs) (GOP25033, April 1990), 1.

¹⁴Hall, Callender, Yeager, et al., "Organ Donation and Blacks." Also see United Network for Organ Sharing (UNOS): Presidential Letter (Douglas Norman), January 1994.

¹⁵Callender, Hall, Yeager, et al., "SPECIAL REPORT Organ Donation and Blacks."

¹⁶C.O. Callender, Surgeon General's Workshop on Increasing Organ Donation: Background Papers, U.S. Department of Health and Human Services Public Health Service, Washington, DC. July 8-10, 1991.

¹⁷R.J. Blendon, L.H. Aiken, H.E. Freeman, "Access to Medical Care for Black and White Americans," *Journal of American Medical Association*, 261:278 (1989). For additional publications to refer to, see R.L. Braithwaite, W. Lythcott, "Community Empowerment as a Strategy for Health Promotion for Black and Other Minority Populations." *Journal of American Medical Association*, 261:282 (1989) and C.M. Olson, "Health Educators Turn to Black Community's Leaders, Organizations, Other Strengths," *Journal of American Medical Association*, 261:194 (1989).

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