

# ORGAN DONATION SURVEY RESULTS OF A BUFFALO, NEW YORK, AFRICAN- AMERICAN COMMUNITY

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In order to evaluate general patterns of attitudes relating to organ donation based on age and educational levels in a typical northeast urban African American community, a survey was conducted in Buffalo, NY, a city with a high African American presence.

Data for this study was obtained from a seven-question survey. The participants in the survey consisted of 173 African American respondents, 96 females and 77 males.

Organ donation awareness was high, with 88% of the participants being familiar with organ donation. The 25- to 35-year-olds were more familiar than the other age groups. Thirty-six percent of the sample indicated they would not donate organs, 31% would donate, and 33% were unsure. Educational levels were a factor in the decision of whether to donate. Of the sample that would not donate organs, 35% had 12 or fewer years of formal education. Seventy-one percent admitted their family did not discuss organ donation. The 18- to 24-year-olds had the highest rate of lack of family discussion. The 36- to 73-year-olds most often cited religious reasons for not donating. The fear that their organs would be taken before they were dead was the rationale chosen more by the 18 to 24-year-olds. One hundred percent of the 25- to 35-year-olds were afraid they would not receive proper medical attention if they were organ donors.

Thirty-two percent of the sample stated that they did not trust doctors; 24% indicated trust; and 44% indicated little trust. Awareness of being a living donor was lowest for the 25- to 35-year-olds—36% stating that they were not aware of this option.

Seventy percent of the 18- to 24-year-olds believed that organs would go to select people and not to those who really need them. (*J Natl Med Assoc.* 2002;94:979-986.)

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## INTRODUCTION

In order to obtain an impression based on age and educational levels from African Americans toward organ donation, a study was conducted in June 1999-2000 in Buffalo, New York. An attempt was made to ascertain general patterns of attitudes and behaviors as they relate to organ donation in a typical northeast urban African American community. The technique consisted of professional researchers

canvassing a pre-selected area going door-to-door and also interviewing people on the street, speaking with as many African Americans as possible.

Due to the high incidence of kidney disease among African Americans, we attempted to get an impression concerning the subject of organ donation from a sample of African Americans. We also wanted to determine if age and educational levels or other variables might affect the decision to participate in the organ donor process.

In New York State, for the calendar year 2000, there were 6563 newly diagnosed chronic end-stage renal disease (ESRD) patients. Of these, African Americans accounted for 2069 and whites 3702. The primary diagnoses for African Americans that were attributed to ESRD were diabetes and hypertension. Also in New York State, for this same year, there were 7980 patients in need of an organ, with kidneys being most sought after.<sup>1</sup>

As of December 31, 2000, there were 8251 African Americans and 10,083 whites on active renal disease dialysis in New York State. Dialysis deaths (patients that died while undergoing dialysis) for the year 2000 were 1421 for African Americans and 2724 for whites. The number of dialysis deaths in New York State for that same year was 1439 for all other ethnic groups. This is of great concern, given that only 195 African Americans in New York State received a renal transplant, compared to 457 whites in that same year.<sup>1</sup>

The contribution of kidneys by African Americans in New York State for the year 2000 were from living relatives (n = 60), non-relatives (n = 9), and cadavers (n = 125), for a total of 194 recovered kidneys. The contribution by whites were from living relatives (n = 154), non-relatives (n = 43), and cadavers (n = 260), for a total of 457 recovered kidneys in 2000.<sup>1</sup> This represents a great disparity of available organs between the two groups. Fortunately, African Americans receive non-African American organs, which is helping to address this disparity.

According to the 2000 United States Census, the Buffalo, NY, area has a total population of 292,648 individuals. The African American population in Buffalo consists of 108,951 individuals, 37% of the total population. Whites consist of 159,300 individuals, 54%, and the remainder consists of a variety of other ethnic groups.<sup>2</sup>

According to the National Transplant Waiting List (United Network of Organ Sharing) for the year 2000, there were a total of 47,831 patients on the active transplant waiting list in need of kidneys. Of that number, 17,239 were African Americans and 26,650 were whites. African Americans comprised 36% and whites 56% of patients waiting for kidneys in 2000. Recovered kidneys consisted of African Americans contributing 1,331 and whites contributing 8,209 kidneys of the total number. In that same year, there were 13,338 total kidney transplants performed. African Americans received 2,996, or 23% of transplanted kidneys and whites received 8,007, or 60% of that total number.<sup>3</sup>

## MATERIALS AND METHODS

Data for this study was obtained from an eight-question voluntary survey. The technique used consisted of canvassing a pre-selected African American community in Buffalo, NY, located on the east side of the city, and speaking with as many African Americans as possible. Respondents were given the survey and asked to read the questions and check the appropriate boxes for each question. Out of the 200 African Americans approached, only 27 refused to participate in the survey.

The survey consisted of questions about the following topics: awareness of organ donation, family discussions, trust of doctors, and whether the participant would consider organ donation (Table 4). Personal information consisted of age, sex, ethnicity, religion

and level of education. This survey had 173 respondents, slightly more than half (57%) of which were females. The majority of the sample, 91%, identified their ethnicity as African American. The remainder of the sample identified themselves as African American, but indicated they consisted of other ethnic backgrounds, as well. The age distribution of the sample ranged between 18 and 73 years, with a mean of 32.96 years, a median of 29.53 years, and a standard deviation of 12.14 years (Table 2).

### Statistical Methods

A *t*-test was used to evaluate the difference of continuous variables between different groups. Cross tabulations were utilized to calculate the percentage distribution for each question in gender, ethnicity and religion groups. The Mann Whitney test was used to test the difference of the percentage distributions in gender, education, ethnicity and religious groups.

### RESULTS

Organ donor awareness was high among the total population, with 88% of the sample having some knowledge of organ donation. Of this sample, the 25- to 35-year-olds were more aware of organ donation in general than the other age groups. The lack of trust for doctors and the medical system was found to be greater among the 18- to 24-year-olds.

The discussion of organ donation with family members was found to be greater among the 25- to 35-year-olds. This same age group indicated the lowest level of awareness for participating as a living donor with 41% of the responses clustered within this group (Table 1).

Religious affiliations in the sample were represented, with Baptist being the largest religious group. Forty-percent of participants indicated Baptist as their religious affiliation. The

**Table 1. Indicates Responses by Age Groups**

	Age	No.	%
Are aware of Organ Donation	18-24	47	29
	25-35	65	40
	36-73	52	32
Have a lack of trust for doctors	18-24	23	37
	25-35	22	36
	36-73	17	27
Are aware of living donors	18-24	39	32
	25-35	50	41
	36-73	32	26
No family discussion of organ donation	18-24	51	38
	25-35	47	35
	36-73	35	26
Not willing to donate organs	18-24	26	38
	25-35	23	34
	36-73	19	28

remainder of the sample consisted of Pentecostal, 11% (n = 18), and Episcopal, 9% (n = 15). Those who did not specifically identify their religious affiliation were placed in the "other" category.

Educational attainment varied from elementary school to some college, with the vast majority indicating that they were high school graduates (Table 2).

Of the sample, the 36- to 73-year-olds (18%)

**Table 2. Religious/Education/Demographics**

	No.	%
Education		
Non High School Graduates	49	28
High School Graduates	67	39
Some College	57	33
Religious Affiliation		
Baptist	73	40
Pentecostal	18	11
Episcopal	15	9
Other category	67	40
Demographics		
Males	77	44
Females	96	56
Age Distribution		18-73
Mean		32.96
Median		29.53
Standard deviation		12.14

**Table 3. Objections to Donating Organs by Age Groups†**

Reasons	Age	%	Age	%	Age	%
Religious	18-24	0	25-35	46	36-73	55
Personal reasons	18-24	39	25-35	31	36-73	31
Family consideration	18-24	43	25-35	29	36-73	29
Afraid organs taken before death	18-24	50	25-35	38	36-73	13
If donor won't get medical attention	18-24	0	25-35	100	36-73	0
Organs given to selected people	18-24	75	25-35	25	36-73	0

N = 173.

†Respondents were asked to choose more than one response.

indicated religious reasons more often for not donating, compared to other groups.

Personal and family reasons were indicated more often by the 18- to 24-year-olds for not participating as organ donors. The fear that their organs would be taken before they were actually dead was more of a concern for the 18- to 24-year-olds, as well.

The 25- to 35-year-olds expressed more concern about not getting medical attention if they were organ donors than other groups. The group that indicated the greatest concern that organs would go to select individuals instead of to people who really need them was the 18- to 24-year-olds (Table 3).

The willingness to donate an organ was more problematic. Of the total sample, 36% indicated they would not donate organs; 33% indicated they might donate organs; and 31% indicated their willingness to donate organs. Of the 25- to 35-year-olds, 14%, indicated the greater willingness to participate as organ donors (Figure 1).

Of those who indicated they would donate organs, the majority indicated they would do so if it would save a life. Those indicating they would not donate organs, approximately 42%, said it was for personal reasons. Slightly more than one-fifth of the sample were afraid that their organs would be taken before they were declared dead and 18% indicated religious reasons for refusal to donate organs (Table 3).

The subject of organ donation was not a

topic of family discussion among the majority of the respondents. Of the total sample, 71% indicated that organ donation was not discussed within their families. The 18- to 24-year-olds, 38% of the sample, indicated the greatest lack of family discussion. Males indicated a greater lack of family discussion compared to the females. Twenty percent of females in the sample indicated family discussion, compared to 9% of males (Table 1).

The overall trust for doctors and the medical system was found to be low among the sample. A little more than one-third of the total sample (34%) indicated a lack of trust

**Table 4. Survey Questions**

1. Have you heard of an organ donor program?
2. Would you donate an organ to someone?
3. If no, what are your objections?
  - Religious reasons
  - Personal reasons
  - Family considerations
  - Afraid organs will be taken before I am dead
  - Afraid if I am an organ donor won't get necessary medical attention
  - Afraid my organs will not go to those who really need them
4. If yes, why?
  - To help save a life
  - For medical research
  - To give someone a better quality of life
5. Has this subject been discussed in your family?
6. Do you trust doctors and the medical system?
7. Would the ethnicity of the person who receives your organ matter?
8. Do you know or know of anyone who has donated an organ?

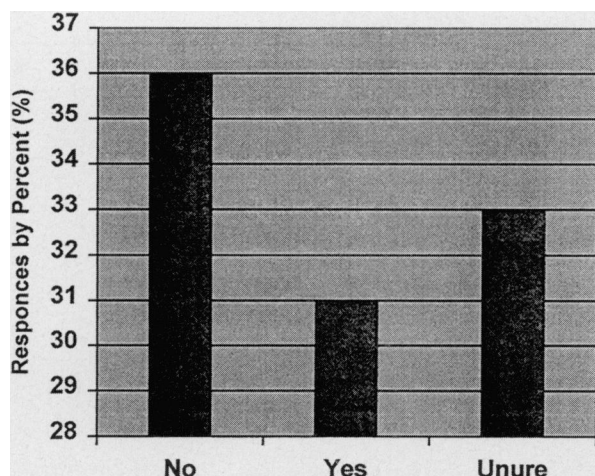


Figure 1. Willingness to donate organs by sample.

for doctors and the medical system, with 44% indicating that they somewhat trusted doctors and the medical system. Only 22% of the sample indicated a trust for doctors and the medical system. The lack of trust for doctors and the medical system was found to be greater among the 25- to 35-year-olds (Table 1).

The ethnicity of the possible recipients of donated organs was of concern to only 15% of the sample, with the 35- to 73-year-olds expressing the greatest concern.

## DISCUSSION

The results of this study have revealed that age and educational levels are important factors influencing participation in organ donor programs. These two factors must be taken into account when educating African Americans concerning organ donation. Results also revealed that the age group that requires the most focused organ donation education is the 18- to 24-year-olds.

Organ donation awareness was greatest among the 25- to 35-year-olds that comprised 40% of the sample. Educational levels were not a factor in terms of relative awareness of

organ donation. However, educational levels were found to be factors that influence the willingness to become an organ donor.

The willingness to donate organs was approximately twice as likely for females, with 65% of females and 35% of males indicating they would donate organs. Respondents that had an education further than high school—approximately 33%—indicated a greater willingness to participate as an organ donor. One-third of the 25- to 35-year-olds, or 14%, indicated a willingness to donate organs; one-third of those older than 35 years old, or 11%, indicated such; and 6% of those less than age 25 were so predisposed. Twenty-eight percent of the sample that indicated they would not donate organs had less than a high school education.

The trust for doctors and the medical system appears to be crucial with respect to the likelihood of donating organs. Of those respondents who said that they did not trust doctors and the medical system, 46% indicated that they would not donate and 34% indicated that they might donate. Of those who only somewhat trusted doctors, a third of the sample indicated they would not donate an organ and 41% indicated that they might donate an organ. There were no gender, age, or educational patterns for trust or distrust of doctors. The lack of participation in organ donor programs by African Americans is revealed by past studies that give factors as religious beliefs, distrust of doctors and the medical system, lack of education or awareness, and access to medical care.<sup>3,4</sup>

Studies have shown that African Americans have far less trust in the medical system with regard to organ donation (Siminoff). This mistrust has led to high refusal rates by African Americans to donate organs. Whites, however, have a much greater trust of the medical system and donate organs two to three times more often than African Americans. Siminoff also found that African Americans had a greater general distrust of the medical system and be-

Table 5. Indicates Responses by Males and Females

Number and percent of each response by males and females	Males		Females	
	#	%	#	%
Are aware of organ donation	73	38	92	48
Has lack of trust for doctors	28	32	33	25
Are aware they can participate as living donor	58	48	63	52
No family discussion of organ donation	71	53	64	47
Not willing to donate organs	33	49	35	52
Willing to donate an organ	21	24	39	38
Unsure about donating organ		33% of the total sample		
Do not know or know of a person who has donated an organ	79	49	84	52

lied that health care professionals would not work as hard to save them if they were found to be organ donors. It also was suggested that African Americans are undereducated concerning organ donation.<sup>5</sup>

Historically, African Americans have been mistreated by the medical system and, therefore, may hesitate in seeking medical advice or treatment.<sup>6</sup> Satisfaction with and trust of physicians was shown to be a factor that influences African American participation in the health care system.<sup>7</sup>

Peters, in his 1996 study, evaluated general attitudes of organ donors and non-donors by using focus groups. General information pertaining to organ donation was found to be equal between both groups. His study revealed that non-donors indicated a high lack of trust for the entire medical system and in the fairness of organ allocation. The focus group consisting of donors believed that the organ allocation system worked equitably. Donors generally trusted the medical system and felt that organs were given according to medical and biological priorities.<sup>8,9</sup>

As for knowing of anyone who had donated an organ, 85% of the sample indicated no knowledge of such a person. In the group of 18- to 24-year-olds, only 22% said they knew or had knowledge of anyone who had donated organs (Table 5).

Organ donation awareness was found to be the lowest among the 18- to 24-year-olds.

Awareness of participating as a living donor (i.e., donating a kidney, section of liver, or bone marrow) was found to be low among the total sample, as well. One-third, 36%, of the sample indicated they were not aware of this option (Table 1).

Participation as organ donors was found to be more problematic for the 18- to 24-year-olds. This group was found to have the greatest objections for not participating as organ donors. The concerns that were indicated most often by the 18- to 24-year-olds for not donating were: personal reasons, family consideration, and the fear that their organs would be taken before they were dead. Worth noting, the fear of not getting adequate medical attention if they were organ donors was indicated by 100% of the 25- to 35-year-olds. The older group, consisting of 36- to 73-year-olds, indicated religious reasons more often for not donating (Table 3).

A 1999 study, conducted by Minniefield, Yang and Muti, compared general attitudes between 249 African Americans and 492 whites.<sup>10</sup> The majority of respondents for all groups indicated some college or college graduate as their highest level of education. Out of a total of 249 African American respondents, 187 indicated some college, 17 were college graduates, followed by 42 as having some high school or being high school graduates.

A total of 412 whites indicated some college or were college graduates, followed by

44 indicating some high school or being high school graduates, and 36 indicating graduate school or professional education. While African Americans were mainly characterized as having some high school or being high school graduates, whites were most often classified in the highest category of education—some college.<sup>10</sup>

Ninety percent of whites were found to be more willing to donate organs, compared to 63% of African Americans. One hundred percent of whites were aware of organ donation, compared to 93% of African Americans. Fifty-five percent of whites, compared to 35% of African Americans, had family discussion of organ donation, and 78% of whites trusted doctors and the medical system, compared to 54% of African Americans. Age and educational levels were found to be factors that influenced organ donor participation by African Americans and whites.<sup>10</sup>

## CONCLUSION

Due to cultural factors and differences such as language and every day practices, African Americans require non-traditional approaches when dealing with the subject of organ donation and other health issues. This is reflected by the low donor participation rate.<sup>9,11</sup>

African Americans remain separated from the benefits of organ donation in the United States. However, African Americans are beginning to become more involved by creating and establishing educational programs that encourage organ donation. In fact, organ donation education programs must include more age-specific components to target those age groups that are in need of more education.

Another avenue that might prove beneficial would be for churches within the African American communities to establish family discussion groups. This would include trained minority educators working with church members and their families.

Some programs that have had success in educating and encouraging African Americans to become organ donors are the District of Columbia Organ Donor Program (DCODP), Dow Chemical Co.'s Take Initiative Program (DOWTIP), and the National Minority Organ Tissue Transplant Education Program (MOTTEP).<sup>12,13</sup>

In response to the needs of Buffalo and the Western New York area, the Minority Organ Donation Education Program (MODEP) was developed by a minority health professional to encourage participation in organ donor programs by African Americans and other minorities. This program also provides education to various age groups by addressing health issues such as hypertension, diabetes, risk factors, and life style changes.

More programs that focus on the educational needs of the African American population based on age and educational attainment, as noted above, are essential to increasing the organ donor rates among this population.

## ACKNOWLEDGMENT

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