

## **ORGAN DONATION IN THE HISPANIC POPULATION: DONDÉ ESTAN ELLOS?**

Antonio A. René, PhD, MPH, Emma Viera, MPH, Dennis Daniels, DrPH, and Yolanda Santos, DrPH

New Orleans, Louisiana; Galveston, Texas; and Houston, Texas

According to the United Network for Organ Sharing (UNOS), 20 882 persons waited for organs to become available in June 1990. Three patients from the waiting list die each day as a consequence of a shortage of organs. The deficit of transportable organs has become the major limitation in clinical transplantation. Due to dramatically improving results in organ transplantation, the number of patients seeking transplants has far surpassed the more gradually increasing number of donors. As a result, one of the major problems facing most transplant centers is the need to obtain enough organs for their rapidly expanding patient populations. Refusal by next of kin is a major barrier to cadaver organ retrieval. Previous reports have shown that, compared with whites, awareness of transplantation and organ donation is lower in nonwhite populations.

Hispanic Americans are the second largest minority group in the United States, comprising approximately 10% of the total population. They are one of the most rapidly growing populations in the United States. Mexican Americans make up the largest part of this population in the United States—13.49 million (60%) according to the 1990 US Census. Puerto Ricans are the second largest Hispanic group (12%), and Cuban Americans make up the third largest Hispanic group (5%). Among Hispanic groups in the United States, Cuban Americans are at almost the same level of education and financial status as whites. On the other hand, Puerto Ricans and Mexican Americans have

significantly lower levels of education and income than the white population.<sup>1</sup>

Although hypertension has been found to be the major cause of end-stage renal disease (ESRD) in the African-American population, this is not the case with Hispanics. This population is known to have an excess of obesity and noninsulin-dependent diabetes mellitus, but similar or lower rates of hypertension when compared with non-Hispanic whites.<sup>2-4</sup> Diabetes mellitus appears to be the most important cause leading to dialysis in this population. Mexican Americans are a minority group who have economic disadvantages similar to, but cultural and genetic backgrounds different from African Americans. They have fewer visits per person per year to a physician, a higher percentage of persons who have had no visits to a physician in the last year, and lower rates of hospitalization than do African Americans or non-Hispanic whites.<sup>5</sup>

Dialysis is the most common treatment modality for ESRD. Although transplantation is the desired treatment modality for some dialysis patients, it is currently attainable only after long periods due to waiting lists for kidney transplantation, which continue to grow as a result of insufficient supply of organ donors and the great demand for transplantable organs. At present, no data are available on rates of ESRD in Hispanics in the United States. The United States Renal Data System (USRDS) does not report on Hispanics. Consequently, there is little national information available related to cadaver transplants in Hispanic populations. The incidence of ESRD among Hispanics worldwide varies from 30 new cases per million annually in Costa Rica to 250 in the Dominican Republic. The average incidence in Puerto Rico is 170 per million and has been found to vary by region from 120 to 240.<sup>6</sup>

---

Requests for reprints should be addressed to Dr Antonio A. René, Dept of Epidemiology and Biostatistics, Tulane University School of Public Health and Tropical Medicine, New Orleans, LA 70112.

The greater the pool of transplantable organs, the greater the impact on kidney transplant waiting lists. Adding more Hispanic donors to the pool of available organs would benefit all ESRD transplants, regardless of ethnicity. In recent years, the gap between organ supply and the need for organs for desperately ill transplantation candidates has widened significantly. Investigations aimed at a better understanding of the issues affecting Hispanic donors have the potential to make a great impact. The significance of addressing organ shortages is not unique to the United States. Other countries have also concluded that much of the shortfall could be met if more eligible brainstem-dead patients were referred as potential organ donors.

## **FACTORS IN ORGAN PROCUREMENT**

### **Medical Staff**

Organ donor awareness is not only for the nonmedical public; it also should be a concern for the medical community and other professionals who may play a role in the organ procurement process. A 1986-1987 survey of transplant professionals<sup>7</sup> polled physicians, nurses, hospital administrators, and staff in at least 176 US transplant centers. The attitudes toward organ donation and transplantation were overwhelmingly positive. In contrast, their levels of knowledge about organ donation, maintenance, brain death, and transplant statistics were surprisingly low.

The problem of lack of organ donations is a multifactorial one. Important factors related to knowledge and sensitivity of the personnel in critical care units, operating rooms, and emergency rooms should be addressed. The death of a relative is a tragic event in any family, and it must be perceived as such. Interruption of the grief process with a request for donation or the interruption of powerful manifestations in the process will result in an insurmountable break in communication that will prevent donations from taking place. An understanding of cultural factors and the actual participation of the physician in the grief process may help the family during the ordeal and, at the same time, may open communications enough to effect donation. Prottas and Batten studied health professionals and hospital administrators and found general approval for organ procurement but hesitation when dealing with the donor families.<sup>8</sup>

Researchers have investigated factors correlating a Hispanic person's willingness to consider organ donation.<sup>9-11</sup> Dominguez et al<sup>9</sup> (Puerto Rico Transplant Program) identified the following explanations for the lack of organ donation by Puerto Ricans in Puerto Rico:

- lack of adequate communication between Puerto Ricans and the medical community,
- overburdened neurosurgical and resident staff, and
- lack of knowledge and poor attitudes of neurological and general surgical residents caused by rapid turnover and discontinuity of information.

Other studies in non-Hispanic settings also may give some indication of the success of the organ procurement process. Stroeckle<sup>12</sup> found that the level of knowledge and experience with organ donors and recipients affected the attitudes of critical care nurses toward organ donation. Bidigare and Oermann<sup>13</sup> reported differences between the area in which nurses worked and the extent to which they would participate in the care of a patient for organ donation. Significant associations were found between nurses who had previously cared for donors and the following variables: comfort in obtaining consent, participation in patient care, and knowledge of organ procurement procedures. The results of the study revealed a need for additional awareness and education for nurses.

Physicians and nurses are key professionals in the area of organ procurement because they are often the first to recognize patients as potential donors. The role of these individuals is to identify potential donors, approach families about donation, and care for organ donors. A physician who is viewed as caring by the family of a potential donor may be the deciding factor in whether they donate.

### **The Public**

A number of factors may affect refusal rates in Hispanics. The language barrier and the significance of extended family members may play important roles. It is common for Hispanic family members living in the United States to agree to donate a loved one's organs pending an agreement with extended family members in their native land. Family refusal is often due to hostility, fear of mutilation and suffering, and denial that the patient is actually dead, as well as to two other factors apparently only seen in Hispanics—the power of the extended family and collective hysteria.<sup>10</sup> Even with the presence of next of kin in the hospital, the family will prefer to wait for an uncle, brother, godfather, or other members of the extended family considered by them to be more educated or successful.

The poor donation pattern of the African-American population in the United States has been studied extensively.<sup>14-16</sup> Donation patterns among Hispanics in the United States, however, have received little attention. Perez et al<sup>17</sup> studied the donation pattern in three

large cities in the United States. They found that African Americans and Hispanics had a similar family refusal rate, which was significantly higher than that of the white population in each city. The refusal rate in New York was significantly higher than in Los Angeles or Miami. Although not significant, the fact that Miami Hispanics had a lower family refusal rate than Hispanics in New York and Los Angeles invokes additional cultural factors, ie, Miami Hispanics are mostly of Cuban origin.

Dominguez et al,<sup>9</sup> in a study of Puerto Ricans sampled from a shopping center and a transplant hospital, reported a high level of knowledge about organ donation and transplantation compared with other reports in the literature. Age and occupation correctly predicted level of knowledge. Sex, residence, place of work, religion, income, and having a friend or relative on dialysis did not influence knowledge about donation or transplantation. These findings were suggestive of a positive impact of educational programs on public awareness in Puerto Rico.

The “Dominguez Paradox” is a curiosity that has an effect on the Hispanic donation rates. Respondents were more likely to agree to donate their own organs after death than that of a deceased relative for transplantation to another person. This might suggest a curious paradox on how the respondent views his or her own responsibilities toward the deceased relative versus that of his or her own body. This paradox seemed to hold true in another recent survey in a Hispanic population.<sup>18</sup> Although 54% indicated that they would donate an organ if they knew the process, only 25% stated that they would donate the organs of their child.

Information about attitudes toward organ donation among Hispanics is virtually nonexistent, and much of what is known about this subject is based on anecdotal information or conjecture. Monetary compensation, for example, is a controversial issue that has been hotly debated. In a recent survey that included questions directed at compensation for organ donation in a Puerto Rican population,<sup>18</sup> results showed that only 6% were interested in being paid for an organ while alive. A slightly higher percentage (14%) indicated that if their family was paid, they would be willing to donate after death, and less than 25% of the population indicated that they would agree to donate organs if their funeral expenses were paid. Based on these low positive responses, it appeared that compensation in the form of money or paid funeral expenses would not influence certain segments of the Hispanic population to donate. In addition, although it has been reported that religion

was a barrier to organ donation, religion has not been found to be a factor in the Hispanic population.<sup>14-16,19</sup> In fact, in this predominantly Catholic population, religious beliefs appeared to benefit donation.

## FUTURE RESEARCH

It will take work such as that of Dominguez,<sup>9</sup> Santiago-Delpin,<sup>10</sup> Perez,<sup>17</sup> and others to adequately address the issue of the paucity of Hispanic donors and to support it with appropriate data and analysis. Although there has been some work with respect to the Puerto Rican population, information related to the Mexican-American population is virtually nonexistent. Expansion of the scope of research to include qualitative methods examining the influence of the cultural values of respect, familism, and spirituality on the decision-making process is needed.

Daniels et al<sup>20</sup> have suggested additional research areas that were important in the African-American populations and can be applied to any minority population. These areas are relevant and have been modified here for use in the Hispanic population:

- *Identification and understanding of barriers to organ donation with particular emphasis placed on the Mexican-American and Latin-American populations.* Within 1 year of donor decision, those families who were unwilling to donate a loved one's organ should be surveyed, and their concerns should be compared with those of families who chose to donate.
- *Measurement of knowledge, attitudes, and beliefs in Hispanic populations regarding organ donation.* Panel discussions should be held at community centers, churches, and clinics regarding ESRD, organ donation, and transplantation.
- *Examine knowledge, attitudes, and beliefs of professionals most likely to be involved in the organ donation decision.* Health professionals at local/regional trauma centers who work in the response area of the organ procurement center should be surveyed. Inservice training should be scheduled to discuss issues/concerns discovered as a result of the survey. Information about Hispanic cultural factors related to the procurement process, methods of communication, the results of organ transplantation, the need for organs, the process of organ donation, and certification of brain death should be addressed.
- *Propose and implement interventions aimed at increasing public awareness of the organ donation process being sensitive to cultural and/or ethnic concerns.* Brochures and posters should be distributed to physicians' offices, clinics, and hospitals, and radio

and television advertisements recorded in Spanish that discuss ESRD should be aired.

## SUMMARY

Few studies have investigated organ donation among Hispanics, although in major US cities, Hispanics, like African Americans, make up a large percentage of the general population. In fact, the 1990 census<sup>1</sup> reports that of all Hispanics in the country, 90% live in urban areas.

The tendency for Hispanics to use hospital emergency rooms rather than visit a physician's office may result in an inadequate exchange of information between minority patients and health-care providers. Hospitals that serve minority populations have been reported to have the lowest organ procurement rates. These hospitals are often funded by local, county, or state funds and are usually dedicated to a patient mix that is largely indigent. The heavy work load of health-care providers who often have limited resources does not lend itself to an adequate exchange of information between patients and health-care providers. The existence of this type of environment impacts on patient communication, increases the fear of complication, and may diminish the discussion of potential organ procurement.

There are multiple individual and structural reasons for the high family refusal rates among Hispanics. Procurement specialists may see a proportionally small number of Hispanic families, mainly due to a lack of referrals from hospital staff concerning possible Hispanic donors. White procurement workers may not be familiar with the Hispanic family makeup and cultural attitudes. Organ procurement workers may not pursue the issue of donation with Hispanic families as much as they do with white families. Whatever the reason, if we are to increase organ donation in the Hispanic community, these complex issues will need to be addressed.

## Literature Cited

1. US Bureau of the Census. *Estimates of the Population of the United States by Age, Sex, and Race: 1990*. Washington, DC: US Government Printing Office; 1990.
2. Roseman JM. Diabetes in black Americans. In: Harris MI, Hamman RF, eds. *Diabetes in America*. Bethesda, Md: US Dept of Health and Human Services; 1985:1-24. NIH publication 85-1468.
3. Gardner LI, Stern MP, Gaskill SP, et al. Prevalence of diabetes in Mexican Americans: relationship to percent of gene pool derived from native American sources. *Diabetes*. 1984;3:86-92.
4. Stern MP, Rosenthal M, Haffner SM, et al. Sex difference in the effects of sociocultural status on diabetes and cardiovascular risk factors in Mexican Americans: the San Antonio Heart Study. *Am J Epidemiol*. 1984;120:834-851.
5. Trevino FM, Moss AJ. Health indicators for Hispanic, black and white Americans. *Vital Health Stat [10]*. 1984;148.
6. Burgos-Carlderón R. Magnitud del problema de la Enfermedad Renal Permenante de Puerto Rico; 1991.
7. Ettner BJ, Youngstein K, Ames JE. Dialysis. *Transplant*. 1988;17:72-78.
8. Prottas J, Batten HL. Health professionals and hospital administrators in organ procurement: attitudes, reservations, and their resolutions. *Am J Public Health*. 1988;78:642-645.
9. Dominguez JM, González ZA, Morales Otero LA, et al. Knowledge and attitude about organ donation in a Hispanic population. *Transplant Proc*. 1991;23:1804-1806.
10. Santiago-Delpin EA, González ZA, Morales Otero LA, et al. Transplantation in Hispanics: the Puerto Rico experience. *Transplant Proc*. 1989;21:3958-3960.
11. Fernandez M, Zayas ZA, Gonzalez LA, Morales Otero LA, Santiago-Delpin EA. Factors in a meager organ donation pattern of a Hispanic population. *Transplant Proc*. 1991;23:1799-1801.
12. Stoeckle ML. Attitudes of critical care nurses toward organ donation. *Dimensions of Crit Care Nurs*. 1990;9:354-361.
13. Bidigare SA, Oermann MH. Attitudes and knowledge of nurses regarding organ procurement. *Organ Transplantation*. 1991;20:20-24.
14. Callender CO. Organ donation in blacks: a community approach. *Transplant Proc*. 1987;19:1551-1554.
15. Callender CO. Organ donation in the black population: where do we go from here? *Transplant Proc*. 1987;19:36-40.
16. Callender CO, Bayton JA, Yeager C, Clark JE. Attitudes among blacks toward donating kidneys for transplantation: a pilot project. *J Natl Med Assoc*. 1982;74:807-809.
17. Perez LM, Schulman B, Davis F, Olson L, Tellis VA, Matas AJ. Organ donation in three major American cities with large Latino and black populations. *Transplantation*. 1988;46:553-557.
18. René AA, Viera E, Daniels DE. Organ donation awareness: knowledge, attitudes and beliefs in a Puerto Rican population. *Transplant Proc*. In press.
19. Davidson MN, Devney P. Attitudinal barriers to organ donation among African Americans. *Transplant Proc*. 1991;23:2531-2532.
20. Daniels DE, René AA, Fish JC, et al. The African-American donor: unwilling or unaware? *Dialysis and Transplantation*. 1992;21:591-597.