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## DO PATIENTS WANT TO TALK TO THEIR PHYSICIANS ABOUT ORGAN DONATION? ATTITUDES AND KNOWLEDGE ABOUT ORGAN DONATION: A STUDY OF ORANGE COUNTY, CALIFORNIA RESIDENTS

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**ABSTRACT:** This study surveyed Orange County, California residents to determine their attitudes and knowledge about organ donation and in particular to determine what factors influence the decision to donate one's organs upon death. Respondents were recruited from the Orange County Superior Court jury pool (N = 378). Each completed a 44 item questionnaire. Findings from the analysis of Questionnaire Data reveal that nearly three-quarters of respondents had considered donating their organs, yet less than one-third had made arrangements to donate. Having an accurate knowledge about organ donation and being willing to accept a donated organ were particularly robust factors associated with the likelihood to donate. Having spoken with a physician was also a positive factor, yet just 5% of the sample had done so, and two-thirds of respondents did not want to discuss organ donation with their physician. The study's findings suggest that enhanced recruitment may be achieved by focusing on education (especially increased emphasis on the family's role) and by targeting both parents and their children. Finally, although physicians are encouraged to discuss organ donation with patients, more information is needed to explain why patients may not want to talk about this topic with their doctors.

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### INTRODUCTION

During 1994, 19,034 transplantation operations were performed in the United States.<sup>1</sup> By January 1995, the number of people waiting for an organ transplant rose to 37,609, an increase of over 12% from the previous year.<sup>2</sup> During this same period, however, the number of donors increased by only 5%.<sup>3</sup> Nearly nine people die each day while waiting for an organ to be donated.<sup>4</sup> These trends are exacerbated by longer lifespans, improve-

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ments in technology and antirejection medications, an aging population, and a lack of willing donors, all of which fuel a shortage of organs.

An understanding of the attitudes, beliefs and opinions of potential organ donors must be achieved before well targeted, cost effective educational strategies to enhance organ donation can be designed and implemented. The literature points to various ways to enhance organ donation. Many of these are directed at recruitment by physicians. For example, Travitzky argues that physicians must begin to consider how to offer the choice of organ donation,<sup>5</sup> and Moore advocates that primary care providers furnish an opportunity during routine health care visits for patients to authorize an advanced medical directive for organ donation.<sup>6</sup> Other investigators have sought to understand the level of knowledge in the population regarding organ donation in an effort to better define the issues and attitudes underlying the organ donor shortage.<sup>7,8</sup> The latter approach was adopted in this study as well.

While most Americans (85%) support the general concept of organ donation, only 28% have actually taken the steps necessary for their organs to be donated upon their death.<sup>7</sup> Much of this can be explained by misinformation, including the failure to recognize that surviving family permission is required for one's organs to be donated—even if a driver's license authorization has already been signed. The purpose of our investigation was to further define potential objections to donation and the level of knowledge about the process by examining the attitudes and beliefs of both donors and non-donors.

## METHODS

The study group consisted of 378 volunteers who were recruited from the Orange County, California Superior Court jury pool between August 29 and September 1, 1994 (response rate = 86.4%). On each of four consecutive days, jury pool members (those waiting to be assigned to a case) were asked to complete a 44 item questionnaire regarding organ donation. Every potential respondent by virtue of being a member of the jury pool was a U.S. citizen, an Orange County resident, literate in English, and at least 21 years old. The jury pool is selected from county voter rolls and state motor vehicle records, and is claimed to represent a fair cross-section of the community.<sup>9</sup> Questionnaires were distributed to those who raised their hand, pencils were provided if requested, and the completed questionnaires were collected. Each question was then coded by a standard coding scheme, the codes were entered into a statistical computer pro-

gram, and the data analyzed based on the study's dependent variable which differentiated respondents *who had made or planned to make arrangements to donate* versus those *who had not decided or had no intentions to donate*. Statistical analysis of the resulting data utilized chi-square tests and both bivariate and multivariate logistic regression, which produced odds ratios indicating respondents' inclination to donate their organs (odds ratios greater than one denote a positive inclination, those less than one a negative inclination).<sup>10</sup> The criterion for statistical significance was a "P" value less than or equal to .05. This study was reviewed and approved by the Human Subjects Review Committee.

## RESULTS

### Demographics

Respondents were 48% male and 52% female with a mean age of 44 years. 77% were non-Hispanic white, 11% Asian/Pacific Islander, 7% Hispanic, 2% American Indian/Native Alaskan, 1% non-Hispanic black, and 2% other. Approximately two-thirds were married and the same proportion reported having children. Fifty-four percent had completed college and/or some post graduate study. Forty-two percent were Protestant, 26% Catholic, 3% Jewish, 3% Mormon, 3% Buddhist, 16% no religious affiliation, and 7% other. Sixty-six percent of respondents considered themselves religious persons, with 30% reporting that they attend religious services, watch religious television programs, and/or listen to religious radio programs one or two times each week. Fifteen percent had annual incomes less than \$25,000, 41% between \$25,000 and \$50,000, 20% between \$50,000 and \$75,000, 13% between \$75,000 and \$100,000, and 11% had incomes greater than \$100,000.

### Decisions and Knowledge About Organ Donation

Nearly three out of four respondents had considered donating their organs upon death, yet less than one-third (32%) had actually made arrangements to donate. Eighty-six percent of all respondents reported that the single most important reason to donate was to help someone else and/or to save someone's life. Table 1 summarizes factors significantly associated with an increased likelihood to donate one's organs upon death. As shown in the table, those who thought they knew how to make arrangements to donate were more than four (unadjusted odds ratio) times as likely to donate compared with those who did not know how to make the

**TABLE 1**  
 Frequency Distributions, Odds Ratios of Factors Associated with  
 Likelihood to Donate Organs<sup>1</sup>

<i>Factor</i>	<i>Percentage of Respondents (%)</i> <i>N = 378</i>	<i>Unadjusted Odds Ratios (95% CI)</i> <i>N = 378</i>
<b>Knows How to Make Arrangements to Donate</b>		
Yes	74.5	4.47**** (2.62–7.64)
No	25.5	
<b>Knows Next of Kin Can Donate Family Member's Organs</b>		
Yes	49.3	2.27*** (1.50–3.44)
No	50.7	
<b>Believes Body Appears Normal After Harvest</b>		
Yes	64.8	2.48**** (1.60–3.85)
No	35.2	
<b>Willing to Accept Organ Donation from a Stranger</b>		
Yes	92.5	3.85** (1.52–9.79)
No	7.5	
<b>Knowing Someone Who Had Donated or Plans to Donate<sup>2</sup></b>		
Yes	41.6	2.63**** (1.71–4.03)
No	58.4	
<b>Has Seen or Read About Organ Donation</b>		
Yes	73.5	1.77* (1.11–2.82)
No	26.5	
<b>Knows Estimated Number Waiting for Organs<sup>3</sup></b>		
Yes	63.2	1.58* (1.03–2.41)
No	36.8	
<b>Believes Donating Organs Is Same as Donating Body to Science</b>		
Yes	27.1	0.58* (0.36–0.93)
No	72.9	
<b>Believes Their Religion Allows Organ Donation</b>		
Yes	85.8	2.44** (1.28–4.66)
No	14.2	

- \*  $P < .05$ ; \*\*  $P < .01$ ; \*\*\*  $P < .001$ ; \*\*\*\*  $P < .0001$ .  
 95% CI = 95% Confidence Interval.
- Odds ratios/statistical significance derived from Bivariate logistic regressions.
  - Respondents answering in the affirmative were additionally asked their relationship with the person planning to donate. The strongest impact on organ donation was the intention of their spouse (odds ratio, 2.93\*\*,  $N = 151$ ).
  - Answers of 10,000 or 40,000 were coded as "correct." Other possible responses were: none, 100, 1000, 5000, and "don't know."

arrangements to donate. Of the approximately three-quarters of respondents who knew how to make arrangements to donate, 91% thought that signing the back of their driver's license was the easiest way to do so, while only 1% believed that telling a family member was the easiest way to make the arrangements. Just over one-half of respondents did not know that as next of kin, their permission is required to donate their deceased loved-one's organs upon their death. Those who were aware of this fact were more than twice as likely to donate their own organs as compared with those who were not.

With regard to the body's condition after organ harvest, 30% believed that the body looks different or is mutilated, and 4% believed that the body is automatically cremated after the donated organs are removed. Those who thought the body appeared "normal," as though no organs were removed (64.8%), were nearly two and one-half times as likely to donate their organs. Furthermore, respondents who were willing to accept an organ donation from a stranger were almost four times as likely to donate their organs as compared with those who were not willing. Also, those who knew someone, especially a spouse, who had or planned to donate their organs were more than two and one-half times as likely to donate their own organs upon death. Finally, those who saw a television program or read about the experiences of donors, recipients, and/or their families were 1.77 times as likely to donate, and those who were aware of the number of people waiting for organs were 1.58 times as likely to donate.

Respondents who believed that donating organs is the same as donating one's body to science were just less than half as likely to donate their organs. Greater than one in four respondents believed that donating organs is the same as donating one's body to science. Conversely, approximately eighty-six percent believed that their religion allows organ donation. This belief was associated with an almost two and one-half times greater likelihood of donating organs. Religiosity per se was not significantly associated with donation.

The multivariate logistic regression, in which odds ratios and significance levels are calculated adjusting for the effects of all factors that were found to be statistically significant in the bivariate analysis (Table 1), was then computed. The resulting multivariate model (Table 2) shows that knowledge on how to make arrangements, the role of next of kin, and the body's appearance, along with the respondents' willingness to accept a donated organ were all associated with intent to donate. All other factors listed in Table 1 did not remain significant predictors of organ donation.

In addition to the above beliefs that were significantly associated with the likelihood to donate one's organs upon death, other interesting

**TABLE 2**  
Multiple Logistic Regression of Factors Significantly Associated with Likelihood to Donate Organs<sup>1</sup>

<i>Factor</i>	<i>Adjusted Odds Ratios<sup>2</sup></i> <i>(95% CI) N= 347</i>
Knows how to make arrangements to donate	4.71*** (2.66–8.35)
Knows next of kin can donate member's organs	2.08** (1.30–3.33)
Believes body appears normal after harvest	2.18** (1.32–3.58)
Willing to accept organ donation from a stranger	5.35** (1.85–15.47)

\* P < .05; \*\* P < .01; \*\*\* P < .001; \*\*\*\* P < .0001.

95% CI = 95% Confidence Interval.

1. Initial Multiple Regression (not shown) was performed using all nine bivariate-significant factors shown in Table 1. Reduced-form equation shown here incorporates only those factors that remained significant controlling simultaneously for all seven additional factors.

2. Odds Ratios and Significance Levels are applicable controlling simultaneously for each of the three other factors shown in the table. Respondents with missing data on one or more variables were excluded from the regression.

responses were given. For example, even though 96% of the sample believed that donated organs are used for surgical transplantation into people who need them, nearly half also believed that *organs are used for scientific research*, over one-third believed that *organs are also used for medical student education and anatomy lab training*, and one in six believed that *donated organs are used for the production of new drugs*. Even with these misconceptions, 97% claimed to know how donated organs are used.

### Why Not Donate?

Just over two-thirds of respondents had not made arrangements to donate their organs upon death. Of these, 58% were undecided about whether or not to donate, 25% planned to make the arrangements in the future, and 17% had no intentions of ever donating their organs. Multiple reasons were given for why arrangements to donate had not been made (see Table 3). The top three reasons why respondents were *undecided* about whether or not to donate their organs upon death were: i) *not sure how family feels about organ donation*; ii) *haven't given it much thought*; and iii) *want more information about what happens to donor's body*. The top three reasons why arrangements had not been made for those respondents who *planned* to make the arrangements in the future were: i) *still have unanswered questions and would like more information*; ii) *don't know how to make arrangements*;

TABLE 3

## Reasons Why Arrangements to Donate Have Not Been Made

<i>Undecided N = 147</i>	<i>Plan to Later N = 62</i>	<i>Never will Donate N = 42</i>
57% Not sure how family feels	41% Still have unanswered questions	33% Want to be buried intact
52% Haven't given it much thought	36% Don't know how to make arrangements	27% Don't want body used for science/education
38% Want more information	26% Haven't gotten around to it	21% Afraid life might not be saved to get organs
15% Afraid my body will be used for science	14% Too old for organs to be useful	21% Too old for organs to be useful
13% Not sure religion allows donation	5% Too young to worry about it	16% Not sure how family feels about me donating my organs
11% Too old for my organs to be useful	5% I would make arrangements immediately if I could choose which organs I donate	13% Religion doesn't allow me to donate
11% Too young to worry about it		10% Afraid body will be mutilated
10% Afraid body will be mutilated		5% Too young to worry about it
4% Funeral might be delayed		5% Funeral would be delayed
4% May not be able to have open casket funeral		3% May not be able to have open casket funeral

68% of respondents had not made arrangements to donate their organs upon their death. Of these, 58% were undecided whether or not to donate, 25% planned to in the future, and 17% had no intentions of ever donating their organs upon their death (multiple reasons were allowed).

and iii) *haven't gotten around to it*. The top three reasons why respondents had no intentions of donating their organs were: i) *want to be buried intact*; ii) *don't want body used for scientific/educational purposes*; and iii) *afraid life might not be saved so that my organs could be given to someone else*.

#### Patient-Doctor Relationship

Most surprising was that, if given the opportunity to do so, 66% of the respondents preferred not to discuss organ donation with their physician. Yet having spoken with a physician (5% of respondents,  $p < 0.0001$ ),

and wanting to talk to a physician about organ donation (34% of respondents,  $p < 0.0001$ ) were both associated with the likelihood to donate. Of those who had spoken with their physician about the possibility of donating their organs, 86% started the conversation themselves, 46% were *very* satisfied with the conversation, 38% *somewhat* satisfied, and 16% were either *not very* or *not at all* satisfied with the discussion.

### DISCUSSION

Although a high percentage of this sample, 98%, knew that they could donate their organs, only 74% had actually considered donating their organs, less than one-third had actually made arrangements to donate their organs upon their death, 25% did not know how to make the arrangements, and 51% did not know that next of kin has the ultimate responsibility for authorizing donation. Similar findings were recently published by The Partnership for Organ Donation and The Gallup Organization in a report that summarizes the largest survey ever conducted on public attitudes towards organ donation and transplantation.<sup>7</sup> In this nationwide survey, only 28% of respondents (compared with our 32%) had actually granted permission for organ donation on their driver's license or a signed donor card. Both studies suggest confusion about the role of the family. In our study, 51% (compared to 34% in the Gallup study) did not realize that surviving family permission is required to have one's organs donated and only 1% thought that telling a family member of their desire to donate was the easiest way to make the necessary arrangements.

Not knowing that the surviving family plays a clear and important role in organ donation may have a tremendous impact on the number of organs ultimately donated. For example, the Gallup survey also found that only 47% of Americans would be likely to donate a family member's organs without having discussed the subject prior to his / her death, compared to 93% if such a discussion had occurred. On a more positive note, Gallup also reported that of the 48% of Americans who had not discussed donation with their family members, 89% were willing to do so. Further encouragement comes from our research where we found an increased likelihood to donate one's organs if the donor knew someone who had donated or planned to donate an organ, especially a spouse or a parent. Promotion of family discussions is a strategy repeatedly found in the literature for increasing the supply of donated organs; when these discussions occur, families of those willing to donate will be more likely to grant con-



sent when asked.<sup>7,11,12</sup> These combined findings, especially the increased likelihood to donate if one's spouse or parent has donated or plans to donate, and the importance of family consent, point to an opportunity to increase recruitment of organ donors by taking steps to encourage family discussions and family donations. Alternatively, attention has been directed toward mandated choice where a person's desire to donate is registered prior to death, thus avoiding family involvement.<sup>13,14</sup> Ethical issues, public acceptance, willingness to register, and a myriad of logistical barriers may keep this concept from becoming a practical solution. In the meantime, with the information we already have, prudent policy mandates an educational program that includes increasing awareness about who, under our present system, ultimately authorizes donations and thus the need for family discussions.

Physicians and other health care workers have been identified as potential agents in promoting organ donation. It has been argued that physicians can play an important role in raising awareness, promoting education and ultimately increasing the number of people willing to donate their organs. Other investigators have identified potential barriers to such physician-patient discussions. Siminoff et al found that the attitudes of health care professionals (HCPs) were more important than their actual knowledge about donation. Their results indicate that it is crucial to educate HCPs about the donation process.<sup>15</sup> Cross-cultural issues also create barriers to meaningful discussions about organ donation, as addressed in a recent study by McQuay.<sup>8</sup>

Our study provides evidence to encourage breaking down these and other barriers. We found that having spoken with a physician and wanting to speak with a physician about organ donation were both associated with an increased likelihood to donate. This finding is tempered, though, by the low number of respondents who had actually spoken with or who wanted to speak with their physician. Additionally, it is unclear as to whether or not there were factors that predisposed this group toward a willingness to donate. While approximately one-third of respondents did want to talk to their physician about organ donation, of those surveyed, only 5% have actually had such a discussion, and of these the patient began the conversation most of the time. Clearly, it can be argued that physicians can be more proactive in these discussions.

However, a surprising two-thirds of respondents indicated that they did not want to talk to their physician about organ donation. This finding indicates a barrier to current efforts encouraging physician-patient discussions. More needs to be learned about patient hesitation. Is it due to perceived physician attitudes or awkwardness associated with cross-cultural is-

sues or does it relate more directly to the subject matter? Further, how should physicians broach the subject and how do various approaches influence patient satisfaction with the discussion and their future likelihood to donate? In our study, 84% of those who had spoken with their physician about the possibility of donating their organs were either very satisfied or somewhat satisfied, while 16% were either not very or not at all satisfied with the discussion. Focused efforts by future investigators are needed to provide further insight into patient-physician interaction. It is essential that we understand why so many patients do not want to discuss organ donation with their physician before we decide how to encourage such encounters.

As more information regarding organ donation becomes known, physicians may be in a better position to effectively engage in these conversations with their patients. Several recent studies, including ours, have identified the importance of family discussions. Physicians could provide the impetus for patients to initiate such discussions. The physician's role could also be influential in dispelling myths by providing basic education about the process of donation. Such education should reassure potential donors that donating organs is not the same as donating one's body to science, that organs are not used for scientific research or medical student education/anatomy lab training, and that the body's condition after harvest appears normal. Potential donors should also be made aware of the impact of organ shortages on the number of potential recipients. In our study, each of these educational end-points was significantly associated with an increased likelihood to donate one's organs upon death.

In a more general sense, perhaps through public service marketing campaigns, potential donors could be encouraged to consider their willingness to accept an organ donation if needed. We found a significantly greater likelihood to donate one's organs among those who were willing to accept an organ donation if needed. The recent Gallup study found that 79% of Americans were willing to accept an organ donation. We also found a significantly greater likelihood of donation among those who have seen a television program or read about the experiences of donors, recipients and/or their families, although it is not clear from our data whether confounding variables were present prior to this exposure.

Finally, of those respondents who had not made arrangements to donate their organs, 83% were either undecided or planned to do so in the future. Because this represents a large group of potential donors, efforts to address their hesitancy should focus on the specific reasons for their inaction. Specifically, those potential donors who are *undecided* must be encouraged to discuss the issue with their family, since not knowing

how their family feels was the number one reason given for not having made arrangements to donate. Potential donors who *plan to make* donation arrangements in the future must have their unanswered questions defined so that well-focused, cost-effective educational campaigns can be designed and implemented, thus eliminating their number one reason for having not made arrangements to donate. Surprisingly, of those who planned to make donation arrangements in the future, 36% did not know how to make the arrangements. Efforts must be focused on educating the public about the procedures involved in arranging for organ donation. In addition to teaching people to sign their donor cards, they must also be taught the importance of communicating their organ donation intentions to their families. Finally, in light of the large number of "undecideds" in our sample, all efforts at increasing general public awareness should encourage people to act sooner rather than later.

#### REFERENCES

1. *United Network for Organ Sharing*. Number of U.S. Transplants by Organ and Donor Type, 1995, Sept. 25.
2. *United Network for Organ Sharing*. OPTN Waiting List. 1995, January 1.
3. *United Network for Organ Sharing*. Number of U.S. Organ Donors. 1995, July 31.
4. *United Network for Organ Sharing*. Reported Deaths on the Waiting List by Organ. 1995, February 24.
5. Travitzky VA, Smart F, Hayes DH, Jacobbi LM. Medical choices in the 90s: transplantation and donation. *J La State Med Soc* 1993; 145:207-12.
6. Moore CV. Organ donation authorization: an advance medical directive. *Nurse Pract Forum* 1992; 3:28-9.
7. *The Gallup Organization*. The American public's attitude toward organ donation and transplantation. Survey conducted for the Partnership for Organ Donation 1993.
8. McQuay JE. Cross-cultural customs and beliefs related to health crises, death, and organ donation/transplantation: a guide to assist health care professional understand different responses and provide cross-cultural assistance. *Crit Care Nurs Clin North Am* 1995; 7:581-94.
9. Maharah D. U.S. Jury Pool Change Angers Lawyers in O.C. *Los Angeles Time*. 1995; Aug. 15: page A1.
10. Hosmer DW, Lemeshow S. *Applied Logistic Regression*. New York: Wiley, 1989.
11. DeJong W, Drachman J, Grotmaker SL. Options for increasing organ donation: the potential role of financial incentives, standardized hospital procedures, and public education to promote family discussions. *Milbank Q* 1995; 73:469-73.
12. Siminoff LA, Arnold RM, et. al. Public policy governing organ and tissue procurement in the United States: results from the National Organ and Tissue Procurement Study. *Ann Intern Med* 1995;123:10-17.
13. Klassen AC, Klassen DK. Who are the donors in organ donation? The family's perspective in mandated choice. *Ann Intern Med* 1996; 125:70-3.
14. Spital, A. Mandated choice for organ donation: Time to give it a try. *Ann Intern Med* 1996; 125:66-69.
15. Siminoff LA, Arnold RM, Caplan AL. Health care professional attitudes toward donation: Effect on practice and procurement. *J Trauma* 1995; 39:553-9.