

# Organ Donation Decision: Comparison of Donor and Nondonor Families

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**Family members continue to play a prominent role in donation decisions at time of death. This study examined the relative influence of donor and next-of-kin factors, requestor characteristics, communication processes and satisfaction with the health care team on the donation decision. Data were gathered via structured telephone interview with 285 next-of-kin of donor-eligible deceased individuals who had been approached by coordinators from one organ procurement organization (OPO) in the southeastern USA from July 2001 to February 2004. Univariate and multivariate analyses showed that several variables were associated with the donation decision. Subsequent logistic regression analyses revealed that donation was more likely when the deceased was younger, white (OR = 3.20, CI = 1.3, 5.7) and had made his/her donation intentions known (OR = 4.35, CI = 2.6, 7.3), and when the next-of-kin had more favorable organ donation beliefs (OR = 8.72, CI = 5.2, 14.7), was approached about donation by an OPO coordinator (OR = 3.74, CI = 2.2, 6.4), viewed the requestor as sensitive to their needs (OR = 2.70, CI = 1.6, 4.5) and perceived the timing of the request as optimal (OR = 6.63, CI = 3.6, 12.1) (total regression model, chi square = 133.2,  $p < 0.001$ , 92.7% of cases correctly predicted). Findings highlight the need for continued public education efforts to maximize positive beliefs about organ donation, to share and document donation decisions and to improve communication processes among the OPO personnel, hospital staff and prospective donor families.**

**Key words:** Consent, donation attitudes, organ donation

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## Introduction

The medical, quality of life, psychological and economic benefits of solid organ transplantation are well documented (1–5). Extending these benefits to more individuals in need is limited by the scarcity of donated organs. The number of patients wait-listed for transplantation far exceeds the number of donated organs, which portends even higher rates of morbidity and mortality unless this gap can be successfully closed.

There are encouraging data suggesting that deceased donation rates are increasing. The Organ Donation Breakthrough Collaborative, initiated by former US Secretary of Health and Human Services, Tommy G. Thompson in 2003, has facilitated the replication and implementation of best practices across participating organ procurement organizations (OPOs) and donor hospitals. The Breakthrough Collaborative, along with the dramatic growth in the number of donations after cardiac death and expanded criteria donors (6), has contributed to a 10.7% increase in deceased donors recovered from 2003 to 2004, the largest percentage increase in nearly 15 years (McBride G, Organ Donation Breakthrough Collaborative, personal communication, May 7, 2005).

In recent years, many states have passed 'first-person consent' or 'donor designation' legislation, which makes paramount the deceased's donation intentions and reaffirms the donor authorization precedent established under the Uniform Anatomical Gift Act of 1968. OPOs have the legal authority to proceed with organ recovery without family consent when the deceased has documented such authorization or intention. Nevertheless, next-of-kin remain actively involved in making the decision to donate or not, especially when the deceased's donation intentions are not known. Therefore, it is necessary to understand the factors that influence next-of-kin donation decisions, as well as their perceptions about the process. Only half of all donor-eligible deaths lead to the donation of organs, whether or not family members have been asked explicitly for consent.

The primary aim of this study was to further examine factors that may be relevant in next-of-kin decisions by comparing those who agreed to donation with those who did not along several relevant dimensions, including deceased and next-of-kin characteristics, requestor characteristics,

communication processes and satisfaction with the health care team. Several recent studies suggest that next-of-kin donation decisions are multi-determined, with various patient and family characteristics (ethnicity, age, cause of death), prior knowledge of the deceased's donation intentions, OPO request patterns (amount of contact with OPO personnel, person making the formal donation request), understanding of brain death, number of other family members present at the time of request and degree of satisfaction with medical care received all identified as influential factors in the donation decision (7–11). The current study uses an extensive interview process to simultaneously examine multiple domains known to potentially affect donation decision making. Moreover, this study will add contemporary findings to the literature that can be used in the further development and implementation of organ donation initiatives.

## Methods

### Recruitment procedures

Next-of-kin who were approached by coordinators from one OPO in the southeastern United States from July 2001 through February 2004 were recruited for this study using a passive recruitment strategy. Following the donation decision, an OPO coordinator unaffiliated with the study gave the next-of-kin or legal surrogate a laminated 8.5" × 6" study information card, along with other informational handouts that are routinely distributed to families approached about organ donation. This card contained information about the study's purpose, the inclusion criteria and likely time commitment, how to indicate interest in the study and monetary reimbursement (\$75.00). This passive recruitment strategy was chosen because it did not interfere with the donation request and decision-making process and because it was determined to be the most sensitive and ethically justifiable approach by an advisory panel of donor families, organ procurement coordinators, transplant physicians, hospital administrators and institutional review board members.

Next-of-kin called a toll-free number to express their interest in participating in the study. The majority (76%) of study inquiries were made within 1 month of the family member's death. We sought to distinguish this study from others by attempting to interview next-of-kin as soon as possible after the donation decision. We believed that interview data collected in close proximity to the event in question would be most reliable and less influenced by memory and decision justification processes over time. Nevertheless, we did not exclude any next-of-kin from study participation if they called more than 1 month after the donation decision. At the time of their initial call, each prospective participant spoke directly with a research assistant who provided more information about the study, answered questions, requested study participation, and for those desiring to participate, scheduled an interview time.

### Data collection procedures

Semi-structured clinical interviews were conducted via telephone with next-of-kin participants. When more than one next-of-kin was involved in the donation decision, we asked to interview the one who was most active in the decision-making process. Mean interview duration was 42.3 min, with a range of 31–77. Interviewers were six research assistants who received several hours of training and behavioral rehearsal, as well as highly specialized education and training about the organ donation request process,

grief and bereavement, crisis management and the protection of human research participants.

The interview was designed to gather information about the deceased's demographic characteristics and death circumstances, the donation request and decision-making process of the next-of-kin, the contextual circumstances surrounding the deceased's hospitalization and the donation request, the next-of-kin's understanding of brain death, beliefs and attitudes about organ donation, and sociodemographic information about the next-of-kin. Interview items were developed based on prior research (7–9), theoretical considerations (12), recommendations of our advisory panel and our own pilot work. Two psychologists and one health educator reviewed the items and categorized them according to these a priori conceptual domains. When there were disagreements about assigning items to domains, the three professionals discussed their opinions and a consensus decision regarding assignment was reached. At the end of each interview, participants were provided with a referral to a mental health professional, if they so desired. The University of Florida Institutional Review Board approved all study procedures.

### Statistical analysis

Interview responses were recorded on the data collection tool developed for this study and coded based on the response options for each of the questions. Two research assistants that were not involved in the interviews served as reliability checks and re-entered the data from the original data collection tool. All data were entered and analyzed using the Statistical Package for the Social Sciences (SPSS, Version 11, Chicago, IL) database.

Univariate relationships between the questionnaire items and the next-of-kin donation decision (donation or refusal) were examined using *t*-tests for continuous variables, the Fisher's exact test for variables with 2 categories or a 2-tailed chi square test for variables with 3 or more categories. Individual interview questions were grouped into 5 conceptual domains: deceased's characteristics, next-of-kin characteristics, requestor characteristics, communication processes and overall satisfaction with the deceased's health care (Table 1). Logistic regression analyses were then conducted to examine the predictive relationship between modifiable variables that were statistically significant in the univariate analyses and the next-of-kin donation decision, while controlling for stable (i.e. nonmodifiable) demographic characteristics.

## Results

### Sample characteristics

Four hundred fifty-six (219 donors, 237 nondonors) next-of-kin received a study information card. This represented 67% of the 680 next-of-kin the OPO approached about donation during the study period. Not all eligible next-of-kin received a study information card because of various logistic and practical reasons. Of the 456 who received study information, 312 (68%) made inquiries regarding study participation and 285 (147 donors, 138 nondonors) completed telephone interviews. The 27 individuals (20 donors, 7 nondonors) who initiated contact but did not complete participation in the study cited time constraints, provided no explanation for study refusal or did not keep a scheduled telephone interview appointment. Overall, the organ donation consent rate among study nonparticipants ( $n = 171$ ) was 61.4%. Next-of-kin participants had a mean age of 49.3 years ( $\pm 13.2$ ; range: 18–85 years), and were predominantly

**Table 1:** Specification of the five conceptual domains included in statistical analyses

Domain	Item content
Deceased's characteristics	Sociodemographic variables (sex, age, race, marital status, education, employment status)
	Donation intentions (donation intention known or unknown, signed donor card, license donor designation, previous discussion regarding intention with next-of-kin participant, previous discussion regarding intention with someone else)
	Death circumstances (cause of death, hospital days)
Next-of-kin characteristics	Sociodemographic variables (sex, age, race, marital status, education, employment status, relationship to deceased)
	Donation intentions (signed donor card, license donor designation, shared donation intention with others)
	Attitudes toward organ transplantation (general transplant attitudes, would accept transplant if medically indicated)
	Attitudes toward organ donation (general organ donation attitudes)
	Beliefs about organ donation (knowledge beliefs, religious beliefs, altruistic beliefs, attributional beliefs, beliefs about the medical profession)
Requestor characteristics	Knowledge of brain death
	First mention of donation (OPO coordinator, physician, social worker, clergy, next-of-kin or family member, other)
	Donation requestor (OPO coordinator, physician, social worker, clergy, next-of-kin or family member, other)
	Familiarity with donation requestor
	Perceived sensitivity Perceived compassion
Communication processes	Timing of initial donation discussion
	Given enough time to make donation decision
	Given enough information to make informed decision
	Involvement of others in donation decision (family members, friends, clergy, medical staff)
	Brain death explanation given Adequacy of brain death explanation Timing of brain death explanation (before donation discussion, same time as donation discussion, after donation discussion)
Overall satisfaction with health care team	Level of satisfaction (perceived adequacy of care, communication with family about medical issues other than donation and brain death, respect for deceased and family members)

female (80%), white (78%; 16% black, 4% Hispanic, 2% other), married (55%), college educated (77%) and employed (59%). Their relationship to the deceased was as follows: spouse (36%), parent (26%), adult child (21%),

sibling (10%) and other (7%). Deceased patients had a mean age of 46.1 years ( $\pm 16.3$ ; range: 18–76 years), and were predominantly male (56%), white (78%; 15% black, 4% Hispanic, 3% other), not married (56%), less than college educated (65%) and employed at time of death (59%). These donor characteristics are representative of the OPO population during the study period (mean age = 42.0; 59% male; 80% white). Mean length of time between death and next-of-kin study participation was 13.7 d ( $\pm 9.1$ ; range, 1–68), and there were no differences in elapsed time between donor and nondonor participants ( $p > 0.05$ ).

### **Donation decision and characteristics of the deceased and next-of-kin**

Several characteristics of the deceased were significantly associated with donation decision (Table 2). Patients who were younger, white, not married and employed had next-of-kin who were more likely to consent to donation. Consistent with previous research (7,8,10,13), the deceased's donation intentions were significantly associated with the donation decision. Patients who had a donor designation on their driver's license or some other documentation and who had previously spoken to family members or others about organ donation were more likely to become donors. Patient sex, educational level, cause of death and hospital length of stay were not significantly associated with next-of-kin donation decisions.

As noted in Table 3, next-of-kin who were white (57.5%) and employed (58.6%) were significantly more likely than non-whites (31.2%) and those not working (41.4%) to consent to donation. Relationship to the deceased was also significant, with parents (65.8%) and adult children (52.5%) more likely to donate than spouses (43.3%) and siblings (42.9%). An expressed intention to be an organ donor was strongly associated with the decision to donate, whether that intention was in the form of a driver's license designation, a signed donor card or a discussion with others. Next-of-kin with more favorable attitudes toward organ transplantation and donation were more likely to consent to donation ( $p < 0.001$  and  $p < 0.0001$ , respectively). Those who consented to donation had significantly more favorable beliefs about organ donation at the time of their loved one's death than those who did not donate ( $p < 0.0001$ ). Finally, 70.5% of next-of-kin that had complete knowledge of brain death agreed to donation, compared to only 29.2% of those with incomplete or inaccurate knowledge of brain death ( $p < 0.0001$ ). Next-of-kin sex, age, marital status and educational level were not significantly associated with donation decision.

### **Requestor characteristics and donation decision**

Rates of donation differed significantly based on who first mentioned organ donation and who made the formal donation request. Donation was more likely when an OPO coordinator (72.2%) or a family member (74.0%) first mentioned it, rather than when it was first raised by a

**Table 2:** Characteristics of the deceased: significant univariate associations with donation decision

		Donation decision		Statistical analysis
		Yes (n = 147)	No (n = 138)	
Sociodemographic variables				
Age, mean (SD)		42.3 (17.2)	59.9 (14.9)	$t(283) = 9.21, p < 0.0001$
Race, no. (%)	White	127 (57.5)	94 (42.5)	$p < 0.0001^*$
	Non-white	20 (31.2)	44 (68.8)	
Marital status, no. (%)	Married	52 (40.9)	75 (59.1)	$p = 0.001^*$
	Not married	95 (60.1)	63 (39.9)	
Employed, no. (%)	Yes <sup>†</sup>	97 (57.4)	72 (42.6)	$p = 0.02^*$
	No	50 (43.1)	66 (56.9)	
Donation intentions				
Previous donation discussion with next-of-kin, no. (%)	Yes	90 (62.9)	53 (37.1)	$p < 0.0001^*$
	No	57 (40.1)	85 (59.9)	
Previous donation discussion with others, no. (%)	Yes	46 (66.7)	23 (33.3)	Chi square (2) = 9.12, $p = 0.01$
	No	58 (44.3)	73 (55.7)	
	Don't know	43 (50.6)	42 (49.4)	
Donation intentions known by next-of-kin, no. (%)	Wanted to be donor	110 (83.9)	21 (16.1)	Chi square (2) = 103.4, $p < 0.0001$
	Did not want to be donor	5 (14.7)	29 (85.3)	
	Donation wishes unknown	32 (26.7)	88 (73.3)	
Donor designation on license, no. (%)	Yes	60 (84.5)	11 (15.5)	$p < 0.0001^*$
	No	82 (41.4)	116 (58.6)	
Signed donor card or other documentation, no. (%)	Yes	27 (69.2)	12 (30.8)	$p = 0.01^*$
	No	83 (46.1)	97 (53.9)	

\*Only p-value is reported because Fisher's exact test does not yield formal test statistic or critical value.

<sup>†</sup>Full-time students were considered employed.

**Table 3:** Next-of-kin characteristics: significant univariate associations with donation decision

		Donation decision		Statistical analysis
		Yes (n = 147)	No (n = 138)	
Sociodemographic variables				
Race, no. (%)	White	127 (57.5)	94 (42.5)	$p < 0.0003$
	Non-white	20 (31.2)	44 (68.8)	
Employed, no. (%)	Yes <sup>†</sup>	99 (58.6)	70 (41.4)	$p = 0.005^*$
	No	48 (41.4)	68 (58.6)	
Relationship to deceased, no. (%)	Spouse	45 (43.3)	59 (56.7)	Chi square (4) = 9.63, $p = 0.05$
	Parent	48 (65.8)	25 (34.2)	
	Child	31 (52.5)	28 (47.5)	
	Sibling	12 (42.9)	16 (57.1)	
	Other	11 (52.4)	10 (47.6)	
Donation intentions				
Donor designation on license or registered donor, no. (%)	Yes	106 (71.1)	43 (28.9)	$p < 0.0001^*$
	No	38 (29.0)	93 (71.0)	
Previous donation discussion with others, no. (%)	Yes	116 (65.5)	61 (34.5)	$p < 0.0001^*$
	No	29 (29.3)	70 (70.7)	
Attitudes toward transplantation				
Would accept transplant if medically necessary	Yes	134 (56.8)	102 (43.2)	$p < 0.0001^*$
	No	12 (25.0)	36 (75.0)	
General attitudes <sup>‡</sup>		11.1 (1.6)	10.3 (2.0)	$t(283) = 3.30, p < 0.001$
Attitudes toward organ donation <sup>#</sup>		16.9 (2.7)	13.5 (4.1)	$t(283) = 8.40, p < 0.0001$
Beliefs about organ donation <sup>¶</sup>		71.2 (7.1)	58.0 (10.9)	$t(283) = 12.20, p < 0.0001$
Adequate knowledge of brain death	Yes	98 (70.5)	41 (29.5)	$p < 0.0001^*$
	No	21 (29.2)	51 (70.8)	

\*Only p-value is reported because Fisher's exact test does not yield formal test statistic or critical value.

<sup>†</sup>Full-time students were considered employed.

<sup>‡</sup>Measured using 4-point Likert scale. Range = 4–16, with higher scores reflecting more positive attitudes toward transplantation.

<sup>#</sup>Measured using 4-point Likert scale. Range = 6–24, with higher scores reflecting more positive attitudes toward organ donation.

<sup>¶</sup>Measured using 4-point Likert scale. Range = 22–88, with higher scores reflecting more positive beliefs about organ donation.

**Table 4:** Significant univariate associations between requestor characteristics and donation decision

		Donation decision		Statistical analysis
		Yes (n = 147)	No (n = 138)	
Person who first mentioned donation	OPO personnel	39 (27.2)	15 (27.8)	Chi square (2) = 43.03, p < 0.0001
	Non-OPO professional <sup>†</sup>	54 (34.2)	104 (65.8)	
	Family member	54 (74.0)	19 (26.0)	
Person who asked for donation consent	OPO personnel	82 (75.9)	26 (24.1)	p < 0.0001*
	Non-OPO professional <sup>†</sup>	65 (36.7)	112 (63.3)	
Family's familiarity with person asking for consent	Never met before consent request	94 (66.7)	47 (33.3)	Chi square(2) = 37.72, p < 0.0001
	Met briefly before consent request	19 (23.7)	61 (76.3)	
	Met several times before consent request	34 (53.1)	30 (46.9)	
Perceived sensitivity <sup>‡</sup>		3.5 (0.6)	2.8 (0.9)	t(283) = 7.78, p < 0.0001
Perceived compassion	Very compassionate	120 (67.4)	58 (32.6)	Chi square(2) = 49.14, p < 0.0001
	Somewhat compassionate	20 (29.9)	47 (70.1)	
	Not at all compassionate	7 (17.5)	33 (82.5)	

\*Only p-value is reported because Fisher's exact test does not yield formal test statistic or critical value.

<sup>†</sup>Includes physician, nurse, social worker and hospital clergy/chaplain.

<sup>‡</sup>Measured using 4-point Likert scale. Range = 1–4, with higher score indicating that the requestor was perceived to be sensitive to the family's needs.

physician, unit nurse, social worker or hospital clergy/chaplain (34.2%). Similarly, next-of-kin were more likely to donate when the person who asked for consent was an OPO coordinator (75.9% vs. 36.7% for non-OPO professionals). The interpersonal skills of the requestor also appear to be related to donation decisions. Next-of-kin who consented to donation perceived the requestor as significantly more sensitive ( $3.5 \pm 0.6$  vs.  $2.8 \pm 0.9$ ) and compassionate. When the requestor was seen as very compassionate, donation occurred at a much higher rate (67.4%) than when the requestor was perceived to be somewhat compassionate (29.9%) or not at all compassionate (17.5%) (Table 4).

### Communication processes, satisfaction with health care and donation decision

For next-of-kin who thought that the timing of the donation discussion was appropriate, 68.4% donated (vs. 31.6% who did not), whereas only 17.9% consented to donation if they considered the timing to be poor (Table 5). Providing

the family with an adequate explanation and definition of brain death appears to be more important than the timing of the explanation. Rates of donation were higher when a brain death explanation was provided (p < 0.0001), although the timing of this explanation was not significantly associated with the donation decision (p = 0.33). Donation occurred at similar rates regardless of whether the brain death explanation occurred before donation was discussed (56.0%), after donation was discussed (53.7%) or at the same time as the donation discussion (50.0%).

In 67.7% of the cases, the next-of-kin involved family members or others in the decision-making process. While donation rates did not differ significantly based on whether others were involved in the decision making (53.4%) or not (47.8%), the nature of these discussions appeared to be important. When family members disagreed with each other, donation was significantly less likely (34.4%) than when there was full agreement about the decision (62.1%).

**Table 5:** Communication processes and satisfaction with health care: significant univariate associations with donation decision

		Donation decision		Statistical analysis
		Yes (n = 147)	No (n = 138)	
Communication processes				
Perceived timing of donation discussion	Timing was right	130 (68.4)	60 (31.6)	Chi square(2) = 65.03, p < 0.0001
	Should have occurred earlier	8 (15.4)	44 (84.6)	
	Should have occurred later	9 (20.9)	34 (79.1)	
Brain death explanation given	Yes	67 (74.4)	23 (25.6)	p < 0.0001*
	No	52 (43.0)	69 (57.0)	
Given enough time to discuss donation	Yes	128 (59.8)	86 (40.2)	p < 0.0001*
	No	19 (26.8)	52 (73.2)	
Disagreement among family members about donation	Yes	21 (34.4)	40 (65.6)	p < 0.0003*
	No	82 (62.1)	50 (37.9)	
Overall satisfaction with health-care team <sup>†</sup>		44.5 (6.0)	39.3 (7.0)	t(283) = 6.81, p < 0.0001

\*Only p-value is reported because Fisher's exact test does not yield formal test statistic or critical value.

<sup>†</sup>Measured using 4-point Likert scale. Range = 14–56, with higher score indicating more satisfaction with the health care team.

Finally, we found that the amount of time taken by the family to discuss donation and to make a decision may be less relevant than their perception that they were given enough time for this process to play out. Although there was considerable variability in the time taken to make a decision, the amount of time for discussion was not significantly associated with donation. However, 59.8% of families that felt they had ample time for discussion consented to donation, while only 26.8% of those who felt they had insufficient time for discussion donated organs.

#### Overall satisfaction with health care team

We assessed the degree to which next-of-kin were satisfied with the care received by their loved one before and after death, the medical staff's communication with the family about the loved one's medical status and prognosis, and the degree of respect shown by the medical team toward their loved one and family members. Overall satisfaction ratings were significantly higher for next-of-kin who consented to donation ( $44.5 \pm 6.0$  vs.  $39.3 \pm 7.0$ ) (Table 5).

#### Multivariate predictors of donation decision

Logistic regression analysis was used to examine the relative contribution of modifiable variables in predicting the donation decision, while controlling for stable demographic characteristics. Only those variables that were previously shown to be statistically associated with donation (described above) were included in the analysis. Demographic characteristics were entered first, followed by those variables that lend themselves to some modification via donation education, changes in donation attitudes and beliefs, the donation approach and request, and OPO coordinator training.

The goodness of fit statistics for both steps and for the total model, as well as the parameter estimates and odds ratios for those variables that remained significant in the final model, are presented in Table 6. The total model is sta-

tistically significant and predicted the next-of-kin donation decision in 92.7% of the cases. Younger donor age, white race, knowing the donation intentions of the deceased, organ donation beliefs that are positive, OPO personnel asking for donation consent, high levels of requestor sensitivity and perceptions that the timing of donation discussion was right were all significant predictors of consent for donation.

## Discussion

Our findings confirm and expand what has been reported in similar studies with donor and nondonor families around the world (7–22). Univariate analyses found several important associations between the donation decision and various characteristics of the deceased, next-of-kin, and requestor, communication processes and overall satisfaction with the health care received at the time of the donation request. Most importantly, however, multivariate analyses found that knowing the deceased's donation intentions and organ donation beliefs at the time of the donation approach are the most important decision-making factors for next-of-kin. Furthermore, approaches made by OPO personnel in a sensitive manner and at a time perceived as optimal by next-of-kin appear to be the most important request-specific variables influencing donation decision-making by next-of-kin. Collectively, findings from this study and others yield several important implications regarding efforts to increase rates of organ donation.

The importance of communicating donation intentions to family members, especially those who are likely to be approached about organ donation (i.e. next-of-kin or legal surrogate) in the event of death, is underscored by our findings. The expressed wishes to the deceased are usually carried out when family members are aware of these donation intentions. Interestingly, however, we found that next-of-kin did not always make the decision based on

**Table 6:** Logistic regression model summary

Model step/variables	Step		Total model		Individual variables		
	$\Delta$ chi-square	-2 Loglikelihood <sup>†</sup>	Chi-square	% correct prediction	B	Wald	OR (95% CI)
Demographics <sup>‡</sup>	17.6***	190.7	17.6***	68.2			
Donor age					-0.05	11.1***	0.95 (0.8–0.9)
Donor race					1.20	5.1**	3.20 (1.3–5.7)
Modifiable factors <sup>‡</sup>	95.6***	95.1	133.2***	92.7			
Deceased's donation intentions known by next-of-kin					1.47	9.12***	4.35 (2.6–7.3)
Next-of-kin donation beliefs					2.17	23.25***	8.72 (5.2–14.7)
Person who asked for consent					1.32	13.44***	3.74 (2.2–6.4)
Perceived sensitivity of requestor					0.99	4.84*	2.70 (1.6–4.5)
Perceived timing of donation request					1.89	12.88***	6.63 (3.6–12.1)

<sup>†</sup>-2 Log Likelihood for the constant-only model was 208.21.

<sup>‡</sup>Hosmer-Lemeshow goodness-of-fit test: 8.5,  $p = 0.38$  for step 1; 5.2,  $p = 0.74$  for step 2.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

the known donation intentions of the deceased. In 16.1% of cases in which it was known that the deceased preferred donation, the next-of-kin did not consent to donation. In 14.7% of the cases, next-of-kin consented to donation when it was known that the deceased did not want to be a donor. Next-of-kin were less likely to donate when the deceased's donation intentions were unknown (26.7% vs. 73.3%). Indeed, when donation intentions are not known, the decision is more likely to be influenced by other variables and consent will not be obtained in the majority of these instances.

Since the donation request usually occurs within the context of intense grief and despair, knowledge of the deceased's intentions helps to reduce ambiguity and conflict among family members and to lessen the saliency or interference of other variables in the decision-making process (10,23). Martinez et al. (10) found that donation was less likely when there is more family conflict. Similarly, we found that consent is less likely when family members are not in complete agreement about donation. These data support public education and community campaigns promoting the necessity of sharing donation intentions with others. Of particular note, however, is the finding that next-of-kin refused donation in 16.1% of the cases in which it was known that the deceased wanted to be an organ donor. Florida enacted donor designation legislation 2 years into the data collection phase of this study, although the OPO practice of requesting next-of-kin consent continued throughout the study period. To the degree that donor designation legislation leads to pragmatic change in the donation request process, we can anticipate a significant reduction in donation refusals when the deceased has documented his/her donation intention.

Donor age also showed a significant and predictive relationship to the donation decision. Although the number of donors over the age of 50 has increased significantly in the last decade (6), older adults generally are less willing to be organ donors (11). Consistent with other studies (7,24), we found that family members of older adults are less likely to donate when asked. It is possible that older adults, and those making decisions on their behalf, believe that advanced age precludes donating organs or that it renders organs less desirable for transplantation (12). While older donor organs are associated with poorer outcomes than younger donor organs (1–3), they may nevertheless yield a better survival advantage when compared to remaining on the waiting list or to maintenance treatments such as dialysis (25). Donation initiatives should be expanded to include educating middle-aged and older adults about the increased use of expanded criteria donors with an aging wait-list population. Appropriate venues for such initiatives could include primary care physician offices, workplace initiatives and civic organizations.

Our finding that donor race was strongly associated with the donation decision mirrors that of other researchers

(24,26). A retrospective study completed by the Association of Organ Procurement Organizations, for instance, found that whites consented to organ donation 61% of the time it was requested, compared to consent rates of 30–40% for non-whites (24). Notwithstanding the efforts of the Minority Organ Tissue Transplant Education Program (27) and OPO initiatives (e.g. ethnic-matching families and requestors) (28), minorities remain disproportionately impacted by the organ shortage yet donate at a significantly lower rate. There is a need for heightened sensitivity and training of OPO and critical care professionals about racial and ethnic differences in the experience of death and grief reactions (29).

While several next-of-kin characteristics were found to be associated with donation decision in the univariate analyses, only their beliefs about organ donation emerged as a significant predictor in the multivariate analysis. As hypothesized by others (12), next-of-kin with attributional, religious, knowledge and cultural beliefs more favorable toward organ donation are more likely to consent to donation. In this study, we sought to examine the specific beliefs that study participants held at the time of the donation request (e.g. 'I believed that organ donation would delay (deceased's name's) funeral.' 'I believed that donating (deceased's name's) organs would allow something positive to come out of his/her death.' 'I believed that the medical team would treat (deceased's name's) body with dignity and respect.'). This belief system may play a particularly important role in the decision when the deceased's donation intentions are unknown. Many study participants who refused donation reported concerns to us about the motivations of health providers, the potential for donation to lead to suffering and mutilation, and possible religious ramifications. It is unlikely that these concerns were expressed openly to the health care team or to the OPO professional. As Siminoff et al. (7) noted, perhaps OPO requestors should be trained to probe sensitively for these concerns, especially among those family members who are ambivalent or initially opposed to donation, and to address them directly. In general, however, organ donation belief structures are multimodal and complex in nature. It is necessary to repeatedly expose the public to sufficient and accurate information that allows for the continuous re-evaluation of organ donation beliefs in the context of past, current and future life circumstances. Also, considering the affective core of belief structures, community- and media-based programs that use transplant candidates, transplant recipients and donor families to emphasize the human tragedy and triumph of organ donation and transplantation are likely to be more effective than similar programs delivered by health professionals.

An adequate understanding of brain death has been thought to be essential for obtaining donation consent (7,9,10,14,15). As in the Siminoff et al. study (7), we found that many next-of-kin are confused about when death occurs, even after being informed about brain death. For

instance, 15.2% thought that brain death was possible only if the heart also stopped beating, 19.9% believed that it was possible to recover from a brain death diagnosis and 24.2% conceptualized brain death as comparable to being in a coma and with the possibility of some restoration of function. Although next-of-kin with these beliefs about brain death were significantly less likely to consent to donation, this finding was not retained in the multivariate analyses. This may suggest that understanding of brain death may not be as significant in the decision-making model as other variables.

Some communication processes have been found to be associated with donation decisions by next-of-kin (7–10,15–17). Our multivariate analyses suggest that donation is more likely when an OPO professional asks for consent, the family perceives the requestor as sensitive to the family's needs, and the timing of donation discussion is favorably perceived by family members. Involving OPO coordinators early in the process is consistent with the Centers for Medicare and Medicaid Services requirement that the family be approached by an OPO representative or designated requestor, it likely maximizes the opportunity for donation consent (7), and it removes health providers from the donation discussion when they may lack sufficient knowledge about the procurement process to answer family members' questions (30). Indeed, research has shown that in-hospital OPO coordinators can successfully educate the health care team about organ donation and procurement, facilitate effective interactions between health providers and the family, establish a relationship with the family, optimize the timing of donation discussion, coordinate the consent process and make the official request, and provide effective donor management services throughout the process (10,28,31,32). It seems likely that an in-hospital OPO coordinator program would also lead to greater satisfaction among families being approached about organ donation.

Findings from this exploratory study should be evaluated within the context of several important methodological limitations. While our sample was reasonably large and comprised next-of-kin who consented to and refused donation, there is an inherent selection bias given our recruitment strategy and the overall participation rate. Those who chose to participate in the study may have been more favorable toward organ donation, had a higher need to discuss their experience (positive or negative), highly motivated to participate in research, and/or more emotionally ready to talk about the recent death of a loved one. Another limitation is that the data presented here are based entirely on the experiences of families in one donor service area (region 3) and within one OPO, which necessarily limits generalizability. This limitation, however, is attenuated by similar findings that have been reported in other regions of the country (7–9). Also, while our protocol attempted to reduce memory biases, we did rely entirely on next-of-kin self-report in acquiring these data. Finally, we should note

that our OPO did not join the Breakthrough Collaborative until 7 months after data collection for this study was completed, which obviates the need to evaluate the potential impact of this effort on the study findings.

In summary, our study provides additional data that should be considered by OPOs, hospital administrators and policy makers when designing strategies to enhance organ donation rates. There is an emerging convergence regarding those variables that distinguish consenting families from those that refuse donation, although there is a need for translating these findings into effective intervention strategies that can be used in diverse hospital settings and across donor service areas. The Breakthrough Collaborative represents a significant step in this direction. Indeed, our findings support the Breakthrough Collaborative's designation of the in-hospital OPO coordinator program as a 'best practice' in meeting its goal of a 75 percent conversion rate (i.e. the ratio of actual donors to eligible donors  $\times$  100). Our data further indicate that efforts should focus primarily on those variables that are modifiable, including ensuring that individuals share their donation intentions, addressing negative beliefs about organ donation, limiting organ donation discussions and the request to OPO coordinators, and enhancing the sensitivity and timing of the request process to the degree possible.

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