

Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation

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ORGAN TRANSPLANTATION IS one of medicine's success stories. Improvements in transplant immunology and surgical techniques have transformed transplantation from an experimental treatment to the therapy of choice for patients with organ failure. Not surprisingly, its success has dramatically increased demand. The number of patients waiting for solid organs has increased 70% during the past decade.¹⁻³

Patients who have been declared dead using neurologic criteria (irreversible loss of all brain function but maintained on ventilators) are the single largest source of transplantable organs. Unfortunately, of these 12 000 to 15 000 potential donors,⁴ fewer than 6000 become organ donors each year.⁵

The major factor limiting the number of organ donors is the low percentage of families who consent to donation. A 1995 study of families of donor-eligible patients found that 86.5% were asked to donate but only 47.3% gave consent.⁶ Other studies have confirmed these findings.^{7,8}

Why are consent rates so low? Public opinion surveys show a great deal of support for donation. More than 75% of respondents in a recent Gallup poll stated they would donate their organs if asked.⁹ While epidemiologic data suggest that minorities, families from lower socioeconomic strata, and individuals with less

Context Transplantation has become the therapy of choice for patients with organ failure. However, the low rate of consent by families of donor-eligible patients is a major limiting factor in the success of organ transplantation.

Objective To explore factors associated with the decision to donate among families of potential solid organ donors.

Design and Setting Data collection via chart reviews, telephone interviews with health care practitioners (HCPs) or organ procurement organization (OPO) staff, and face-to-face interviews with family for all donor-eligible deaths at 9 trauma hospitals in southwestern Pennsylvania and northeastern Ohio from 1994 to 1999.

Participants Family members, HCPs, and OPO staff involved in the donation decision for 420 donor-eligible patients.

Main Outcome Measure Factors associated with family decision to donate or not donate organs for transplantation.

Results A total of 238 of the 420 cases led to organ donation; 182 did not. Univariate analysis revealed numerous factors associated with the donation decision. Multivariable analysis of associated variables revealed that family and patient sociodemographics (ethnicity, patient's age and cause of death) and prior knowledge of the patients' wishes were significantly associated with willingness to donate (adjusted odds ratio [OR], 7.68; 95% confidence interval [CI], 6.55-9.01). Families who discussed more topics and had more conversations about organ donation were more likely to donate (adjusted OR, 5.22; 95% CI, 4.32-6.30), as were families with more contact with OPO staff (adjusted OR, 3.08; 95% CI, 2.63-3.60) and those who experienced an optimal request pattern (adjusted OR, 2.96; 95% CI, 2.58-3.40). Socioemotional and communication variables acted as intervening variables.

Conclusions Public education is needed to modify attitudes about organ donation prior to a donation opportunity. Specific steps can be taken by HCPs and OPO staff to maximize the opportunity to persuade families to donate their relatives' organs.

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formal education are less likely to donate, these data do not explain why these patterns exist. Results of several studies of individuals who were asked to donate a family member's organs suggested that the timing and privacy of the request, the involvement of an organ procurement staff person, and improved understanding of the meaning of brain death are key explanatory factors.¹⁰⁻¹²

The goals of this study were to assess the determinants of families' willingness to donate solid organs, to describe the process and content of the conversations surrounding the donation re-

quest, and to evaluate the correlation between these factors and the consent rate.

METHODS

Study Sites

Nine trauma hospitals (including 2 pediatric hospitals) in southwestern Penn-

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sylvania and northeastern Ohio participated. Data were collected from January 1994 through December 1999. The study was approved by the institutional review board of each institution and informed consent was obtained from all study respondents.

Case Accrual Procedures

Medical records were reviewed and analyzed for 11 555 deceased patients using the previously validated chart review form (CRF).⁶ The structure of the CRF and content of the health care practitioner (HCP) and organ procurement organization (OPO) interviews have been described.^{6,13,14} The CRF, developed in conjunction with local OPOs, determines a patient's eligibility to donate any organ based on age, past medical history, current comorbid conditions, and neurologic status. The HCPs who cared for donor-eligible patients were identified from the chart. If any HCP or OPO discussed donation with the family, that family was included in the study. All HCPs or OPOs who spoke with the family about donation were interviewed.

Data Collection Procedures

The HCP and OPO interviews^{6,13} were designed to obtain data about the HCPs' procurement-related behavior (eg, whether health care professionals discussed donation with the family, and the circumstances surrounding those requests) and their attitudes and knowledge about the donation process. Interviews were conducted no later than 4 weeks after the patient's death.

All family members and significant others who were at least 18 years of age and were identified by an HCP or OPO staff person or the chart as being involved in the decision about donation were invited to participate in a face-to-face interview. Letters were sent to families 2 to 3 months after the patient's death. The letters were followed by telephone calls from a trained research assistant, extending an invitation to participate. Home interviews were arranged with those who agreed.

The family interview consisted of 3 parts. The first was an open-ended de-

scription of the events immediately surrounding and following the patient's death. If other family members were identified as being involved in the donation decision, they were subsequently included in the study. The second part was a series of structured and semistructured questions about the donation request. The third part was a series of structured questions to measure attitudes and knowledge about organ donation. Sociodemographic information was obtained from all participants.

Measurement

The interview questions were based on past research and theoretical considerations.^{6,14-19} Those variables that were found to be associated with the donation decision are listed in the BOX.

Statistical Analysis

All interviews were audiotaped and transcribed. A coding scheme was developed based on our past work.⁶ Categories of responses were derived from the data. Structured coding was used to tabulate responses to the semistructured questions. A rulebook was developed to guide the coders. Independent coders double coded the interviews to ensure reliability. Interview data were entered into a FoxPro database (Version 3.0, Microsoft Corporation, Redmond, Wash) and analyzed using univariate and multivariable techniques (SAS Version 8.1, SAS Institute, Cary, NC).

The univariate relationship of independent variables with the family's final decision to donate was evaluated using a 2-tailed χ^2 test for variables with 3 or more categories or the Fisher exact test for variables with 2 categories. The Wilcoxon rank sum test was used for interval or ordinal scale variables.

To describe the relationship of the family's final decision to donate with family and patient characteristics and request process characteristics, independent variables were grouped (Box) based on preidentified conceptual domains (eg, who raised the issue of donation). First, variables identified as significantly associated with donation within each of the domains using bivariate analysis tech-

niques were retained. Second, a separate logistic regression analysis was performed on each of these groups of variables using donation as the outcome. This process created 6 variables representing the estimated probability of donation for each conceptual domain. Third, using the median probability value as a cut point, each of these variables was transformed into a dichotomous variable. Only 6 of the 7 variables had a direct relationship with donation. A log-linear regression using the 6 dichotomous variables and the donation outcome variable analyzed the interrelationships between the 6 categories of variables and donation.

RESULTS

Study Sample

Of the 11 555 records reviewed, 741 (6.4%) of the cases were potential solid organ donors. Requests for donation were made by either an HCP or the OPO for 596 (80.4%) donor-eligible families with a resultant 47.5% consent rate. Analyses reported here are based on a final sample of 420 cases (238 donors and 182 nondonors) for which we have complete HCP, OPO, and family interview data. We were able to obtain participation from 92.5% of patients' HCPs and OPOs. Seventy-four percent of family decisionmakers—84.7% of donor families and 63.6% of nondonor families—consented to be interviewed. There were no differences between participants and nonparticipants by age, sex, or ethnicity. Approximately 2 HCP/OPO interviews and 1.25 family interviews were obtained for each patient. Patients were predominantly male (60.1%) and white (85.6%); their mean age was 40.5 years (range, newborn to 83.9 years). Family decision makers (n=481) were predominantly female (66.4%), white (84.6%), married (66.4%), and averaged 44.7 years of age (range, 18-86 years).

Families' Initial Donation Decisions and Final Decisions

Decisions regarding donation were made quickly, with 55% of families stating they made their decision during the initial request. At initial request, 57.6%

of families were favorable toward donation, 25.5% were unfavorable, and 16.9% were undecided. This initial response predicted the final donation decisions of 69.5% of families. Of those initially favorable, 80.6% eventually consented to donation compared with only 9.4% of families initially unfavorable toward donation and 46.5% of those initially undecided (TABLE 1).

Associations of Factors Predating the Donation Decision

Family and patient characteristics and their attitudes and beliefs about organ donation were significantly associated with the decision to donate organs. Families of white patients (61.4% vs 38.6%, $P < .001$), younger patients ($P = .001$), and male patients (62.2% vs 37.8%, $P = .007$) were more likely to consent to organ donation. However, consent was also associated with deaths due to trauma compared with non-trauma-related deaths (65.1% vs 34.9%, $P = .002$). No associations were found between consent rates and families' educational attainment or income.

Families who reported positive beliefs about organ donation were significantly more likely to donate, as were families who had prior knowledge of the patients' wishes regarding donation. Knowing the patient had a donor card (89.3% knew patient had a card vs 44.4% knew patient did not have card, $P < .001$), having had an explicit discussion about donation with the patient (65.9% vs 34.1%, $P = .002$), and a belief the patient would have wanted to donate, even exclusive of an explicit discussion (86.4% vs 13.6%, $P < .001$), were strongly associated with consent to organ donation.

Finally, no association was found between the decision to donate and the hospital environmental variables or HCPs' sociodemographic characteristics (including age, sex, ethnicity, religious affiliation, and professional role). While HCPs' attitudes toward organ donation did not correlate with consent rates, their comfort with answering families' questions about donation was significantly associated with organ donation ($P < .001$) (Table 1).

Box. Variables Constituting Factors Used in the Multivariable Analyses

Factor 1. Prerequisite variables

Family/patient sociodemographic and medical

- Patient's age
- Family's ethnicity
- Insurance
- Cause of death
- Termination of life supports

Family attitudes and beliefs about organ donation

- Family attitude scale
 - Family member willing to be a donor
 - Religion encourages organ donation
 - HCP's comfort level answering family's questions about organ donation
- Family's prior knowledge about patient's wishes regarding donation
 - Had enough information about patient's wishes
 - Knew patient had donor card
 - Thought patient wanted to donate
 - Explicitly discussed donation with patient

Factor 2. Family understanding of brain death and treatment

- Rating of family's overall understanding of brain death
- Family understanding of when moment of death occurs

Factor 3. Socioemotional and communication process variables

- Family felt harassed or pressured to make decision
- Family perceived at least 1 health care practitioner not caring or concerned
- Family surprised to be asked about donation
- Health care practitioners reported family's initial reaction to donation request to be same as family's self-report (congruence)

Factor 4. Who raised issue of donation and spoke to family

- First health care practitioner/organ procurement organization to raise issue is the same family identifies as most important to them in process
- Family raises issue of donation themselves
- Optimal request pattern

Factor 5. Organ procurement organization request-related variables

- Family reported decision influenced by organ procurement organization
- Amount of time spent with organ procurement organization

Factor 6. Topics discussed with family

- Health care practitioner told family he/she required to ask
- Health care practitioner told family donation helps others
- Costs of donation
- Impact of donation on funeral
- Different body parts could be donated and that family had a choice
- Family concerns about disfigurement
- Family assured donation would not cost anything
- Answered family questions about donation
- Total number of topics discussed with family
- Number of issues of concern to family
- Number of discussions about organ donation

Factor 7. Timing of donation request

- Organ donation mentioned during brain death testing
- Organ donation mentioned before, after, or concurrent with declaration of death

Donation Decisions and Decision Process Variable

Although overall satisfaction with hospital care was not correlated with the do-

nation decision, socioemotional and communication issues were important. Families who believed that 1 or more HCPs involved in their relatives'

care were not caring or concerned were somewhat less likely to donate (56.6% vs 43.4%, $P = .04$). Factors directly associated with the donation request were important. For example, families who were surprised to be asked about organ donation were less likely to donate than families who were not (66.0% vs 34.0%, $P < .001$). Families who felt harassed or pressured to make a decision were also less likely to donate (65.9% vs 34.1%, $P = .002$). Health care practitioners' correct assessment of a family's initial reaction to the issue of donation was strongly associated with the donation decision. Less than half the HCPs (46.9%) correctly ascertained families' initial response to the request to donate organs.

Families who were congruent with HCPs concerning the initial reaction to the donation request were more likely to consent to donate (71.6% vs 28.4%, $P < .001$) (TABLE 2). When we controlled for initial reaction to the donation request, these findings remained for families who stated they were initially prodonation ($P < .001$) or undecided ($P < .001$).

The best time and person to approach families about donation has not been clear.^{7,20} In our study, families who raised the issue themselves were more likely to donate (85.7% vs 14.3%, $P < .001$). Rates of consent were not different when a physician (53.6%), nurse (56.3%), social worker (66.7%), or OPO staff member (64.1%) made the initial request ($P = .30$).

However, when a hospital-based HCP (but not a physician) broached the possibility of organ donation, followed by a meeting with an OPO staff person, the donation rate exceeded that of any other discussion pattern ($P < .001$). Families reported that conversations with OPO staff were crucial to the donation decision. Talking to an OPO staff person before being asked to make a donation decision ($P < .001$), and spending more time with an OPO staff person ($P < .001$) were both factors strongly associated with donation (Table 2). This was true even after controlling for families' initial reactions to donation.

Unlike other retrospective studies that relied on chart review or that had few nondonor respondents in their samples,²⁰⁻²² we found no association between when the donation request was first made and consent rates. This included the timing of the request in relation to testing for brain death or the pronouncement of death (Table 2).

We hypothesized that a salient feature of consent would be a family's understanding that the patient was indeed dead. For example, 18.1% of families reported confusion as to when the moment of death occurred; 20.9% believed that the patient was dead only when the heart ceased to beat. Despite this confusion, 56.6% of family respondents who stated they were unsure as to when the moment of death occurred consented to donate organs, as did 39.8% of families who thought the patient was dead only when the heart stopped. No differences were found between family consent rates and the belief the patient was still alive after the declaration of brain death ($P = .20$).

Certain topics discussed with families, and the number of discussions, were associated with organ donation decisions. Topics correlated with consent to organ donation were the costs of donation, the impact of donation on funeral arrangements, disfigurement of the body, and assurances that the family had a choice about which organs to donate ($P < .001$). When HCPs told families they were required to ask about donation, families were less likely to donate (56.0%

Table 1. Bivariate Analysis of Prerequisite Factors With Organ Donation Decisions*

	Donation		P Value†
	No	Yes	
Patient age, mean (SD), y	43.8 (22.3)	37.0 (19.5)	.001
Median (IQR), y	48.0 (26.0-61.9)	36.2 (21.9-52.0)	
Family's race white, No. (%)	137 (38.6)	218 (61.4)	<.001
Patient's sex male, No. (%)	94 (37.8)	155 (62.2)	.007
Family terminated treatment before brain death, No. (%)	54 (67.5)	26 (32.5)	<.001
Trauma-related cause of death, No. (%)	67 (34.9)	125 (65.1)	.002
Family Attitude Scale toward donation, mean (SD)‡	19.2 (3.4)	21.6 (2.7)	<.001
Median (IQR)	20.0 (17.0-22.0)	22.0 (20.0-24.0)	
Family willing to donate own organs, No. (%)	92 (30.4)	211 (69.6)	.001
Family believed their religion encourages donation, No. (%)	7 (17.5)	33 (82.5)	<.001
HCP comfort level answering questions about organ donation, mean (SD)§	8.8 (1.6)	9.3 (1.5)	<.001
Median (IQR)	9.0 (8.0-10.0)	10.0 (9.0-10.0)	
Family had enough information regarding patient's donation wishes, No. (%)	112 (37.5)	202 (64.3)	<.001
Family knew if patient had a donor card, No. (%)			<.001
Knew patient did have card	8 (10.7)	67 (89.3)	
Did not know	41 (38.7)	65 (61.3)	
Knew patient did not have card	133 (55.6)	106 (44.4)	
Family thought patient wanted to donate, No. (%)	32 (13.6)	203 (86.4)	<.001
Explicitly discussed donation with patient, No. (%)	59 (34.1)	114 (65.9)	.002
Family initial response to first request for organ donation, No. (%)			.001
Favorable	195 (80.6)	47 (19.4)	
Undecided	33 (46.5)	38 (53.5)	
Unfavorable	10 (9.4)	97 (90.6)	

*IQR indicates interquartile range; HCP, health care practitioner.

†Significance level for a 2-tailed test of the null hypothesis of independence of the factor with the donation outcome using a χ^2 test or the Fisher exact test when the independent variables have 3 or more categories or 2 categories, respectively, and a 2-tailed Wilcoxon rank-sum test of the null hypothesis in which there is no difference in the median scores.

‡Measured on a 5-item Likert Scale. Scale range: 5-25, with higher scores indicating more positive attitudes toward donation.

§Measured on 10-point rating scale. Scale range: 0-10, with higher scores indicating greater comfort discussing donation with families.

vs 44.0%, $P = .002$). However, when HCPs mentioned that donation had the potential to help others, families were more likely to donate (72.3% vs 27.7%, $P = .001$). Having more discussions about donation itself, discussing more topics of concern to the families, and having more questions answered were all associated with consent to donate ($P < .001$) (Table 2).

Multivariable Analysis of Factors Associated With Consent to Organ Donation

Asking for organ donation is a complex task entailing a number of factors that may or may not be relevant for every situation. To better understand the independent effects of these factors on the eventual donation decision, individual variables were aggregated into 7 categories (factors) representing different aspects of the donation process (Box). The effects of the individual components comprising each factor were discussed above. Six of the 7 factors, along with the donation decision, form the basis of the log-linear regression analysis. The resulting model uses a hierarchical technique such that all single factors occurring in statistically significant interaction terms are kept in the model. TABLE 3 exhibits the interrelationships between the 6 major factors and the outcome variable of donation. The model indicates that there were also significant relationships between the 6 factors themselves.

Results of the multivariable analysis reveal that 4 factors were directly related to the donation decision: (1) prerequisite characteristics, (2) who raised issue of donation and spoke to family, (3) OPO request-related variables, and (4) topics discussed with the family. Prerequisite variables were strongly associated with the decision to donate. Families' sociodemographics, attitudinal characteristics, and prior knowledge of the patients' wishes were included in this cluster. Families who fit the profile of being more positive about donation were over 7 times more likely to donate (adjusted odds ratio [AOR], 7.68; 95% con-

Table 2. Association of Request Process and Content With the Organ Donation Decision*

	Donation		P Value†
	No	Yes	
Family understanding of brain death/treatment, mean (SD)‡	4.4 (1.4)	4.8 (1.4)	.004
Median (IQR)	4.0 (3.0-5.0)	5.0 (4.0-6.0)	
Point when family believed patient had died, No. (%)			.001
When heart stopped	53 (60.2)	35 (39.8)	
Confused about when patient died	33 (43.4)	43 (56.6)	
When told patient was brain dead	96 (37.5)	160 (62.5)	
Socioemotional/communication variables, No. (%)			.002
Family felt harassed or pressured to make a decision concerning donation	29 (65.9)	15 (34.1)	
≥1 HCPs not caring or concerned	30 (56.6)	23 (43.4)	.04
Family surprised to be asked about donation	62 (66.0)	32 (34.0)	<.001
Family and HCP agreed on how the family responded to the initial request for donation (congruence)	56 (28.4)	141 (71.6)	<.001
Who raised issue of organ donation and spoke to family			<.001
Optimal Request Pattern Scale, mean (SD)§	4.4 (2.2)	6.3 (2.2)	
Median (IQR)	4.0 (2.0-7.0)	7.0 (5.0-8.0)	
First person to ask family was identified as the person who was the important requestor, No. (%)	129 (56.3)	100 (43.7)	<.001
Family raised issue of organ donation, No. (%)	14 (14.3)	84 (85.7)	<.001
OPO request-related variables			<.001
Time spent with OPO, mean (SD), min	0.8 (1.4)	3.6 (1.7)	
Median (IQR)	0 (0-2)	4.0 (3.0-5.0)	
Family asked about organ donation before speaking with OPO, No. (%)	121 (74.7)	41 (25.3)	<.001
Timing of organ donation discussion, No. (%)			.09
When was donation requested			
Same time as family told of patient's death	84 (48.8)	88 (51.2)	
After family told of patient's death	37 (44.6)	46 (55.4)	
Before family told patient dead	61 (37.0)	104 (63.0)	
Organ donation mentioned while brain death tests conducted	36 (34.6)	68 (65.4)	.04
Topics discussed with family by HCPs			<.001
Costs of donation, mean (SD)	0.3 (1.0)	3.0 (2.3)	
Median (IQR)	0 (0-0)	4.0 (0-5.0)	
Impact of donation on funeral, mean (SD)	1.6 (1.3)	3.0 (2.3)	<.001
Median (IQR)	1.0 (1.0-2.0)	2.0 (1.0-5.0)	
Body parts that can be donated, mean (SD)	0.3 (0.6)	1.6 (1.2)	<.001
Median (IQR)	0 (0-0)	2.0 (1.0-2.0)	
No. of questions asked by family, mean (SD)	0.4 (0.9)	0.8 (1.2)	<.001
Median (IQR)	0 (0-0)	0 (0-1.0)	
Total No. of discussions regarding organ donation, mean (SD)	2.0 (1.8)	2.4 (1.6)	<.001
Median (IQR)	1.0 (1.0-2.0)	2.0 (1.0-3.0)	
Total No. of all items discussed, mean (SD)	2.5 (2.3)	7.2 (3.6)	<.001
Median (IQR)	2.0 (1.0-4.0)	7.0 (4.0-10.0)	
No. of issues of concern to family, mean (SD)	3.1 (2.6)	8.1 (4.0)	<.001
Median (IQR)	2.0 (1.0-4.0)	8.0 (5.0-11.0)	
HCP told family she/he was required to ask about donation, No. (%)	65 (56.0)	51 (44.0)	.002
HCP said donation helps others, No. (%)	26 (27.7)	68 (72.3)	.001
Discussed disfigurement, No. (%)	14 (18.7)	61 (81.3)	<.001
Assured family donation would not cost them anything, No. (%)	8 (5.1)	149 (94.9)	<.001

*IQR indicates interquartile range; HCP, health care practitioner; and OPO, organ procurement organization.

†Significance level for a 2-tailed test of the null hypothesis of independence of the factor with the donation outcome using a χ^2 test or the Fisher exact test when the independent variables have 3 or more categories or 2 categories, respectively, and a 2-tailed Wilcoxon rank-sum test of the null hypothesis in which there is no difference in the median scores.

‡Measured on a 10-point rating scale by an independent reviewer.

§Cases scored (1-9) by how closely they followed the optimal request pattern, obtained by regressing different request patterns to the outcome variable, donation.

Table 3. Log-Linear Regression Hierarchical Model of the Relationship Between the Donation Decision and Factors Describing the Donation Process (n = 420)*

Significant 2-Way Interactions in Model	AOR (95% CI)
Prerequisite (factor 1)—donation	7.68 (6.55-9.01)
Topics discussed (factor 6)—donation	5.22 (4.32-6.30)
OPO related (factor 5)—donation	3.08 (2.63-3.60)
Who raised issue (factor 4)—donation	2.96 (2.58-3.40)
Prerequisite—family understands BD (factor 2)	2.69 (2.39-3.02)
Prerequisite—topics discussed (factor 6)	3.81 (3.17-4.58)
Prerequisite—socioemotional (factor 3)	2.98 (2.66-3.34)
Family understands BD (factor 2)—OPO related (factor 5)	1.63 (1.45-1.84)
OPO related (factor 5)—topics discussed (factor 6)	7.71 (6.48-9.18)
OPO related (factor 5)—who raised issue (factor 4)	5.32 (4.64-6.10)
Who raised issue (factor 4)—socioemotional (factor 3)	2.09 (1.86-2.34)

*Factors are defined in the Box. Factors were examined in relation to each other and the donation decision. Only statistically significant interactions are reported. AOR indicates adjusted odds ratio; CI, confidence interval; OPO organ procurement organization; and BD, brain death.

fidence interval [CI], 6.55-9.01). After controlling for other variables, an optimal request pattern (a health care provider other than a physician making the initial request followed by discussion with an OPO coordinator) ensured that the family was almost 3 times as likely to give consent compared with other patterns (AOR, 2.96; 95% CI, 2.58-3.40). Organ procurement organization request-related factors also were associated with a 3-fold likelihood of donating. Families who had two-thirds more contact with OPO staff were 3 times as likely to donate irrespective of other factors (AOR, 3.08; 95% CI, 2.63-3.60). Finally, the number of topics and the kind of topics discussed were also strongly associated with the donation decision. Families who had more topics of interest discussed with them and who had more conversations about organ donation were over 5 times more likely to donate even when controlling for other factors such as initial response to the donation request (AOR, 5.22; 95% CI, 4.32-6.30) (Table 3).

COMMENT

There is no “magic bullet” that will improve organ donation rates. This study identified a number of factors that influence family consent to organ donation. First, we must acknowledge that most families have some knowledge of organ donation and most have some preconceived attitudes about it. Thus,

what we have termed *prerequisite* variables—characteristics that individuals bring with them to the decision process—play a significant role in how the request is received and processed by family members making these decisions. Of note, families of patients who were younger, male, and who died from trauma were more likely to donate as were families who were white, were more positive about organ donation, and who believed the patient would have wanted to donate. Families who met with HCPs who rated themselves as generally more comfortable answering families' questions about donation were also more likely to donate. These variables were the strongest influences on the consent to donate.

These prerequisite variables are significant determinants of donation, suggesting the need for increased educational efforts to help inform the public about organ donation. Current emphasis has been on the benefits of transplantation, which is the proximal outcome of donation. However, little public education has centered on the donation process itself, which could prepare individuals for this potential life event. Since it is not reasonable to expect that family decision makers can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress of a loved one's death, prior education is the best mechanism we may have to inform the

public and prepare families for an organ donation request. Further research might focus on how best to convey the important information and increase the effectiveness of public education campaigns.

There remains significant room for improvement in the request process. First, a good relationship between families and the HCPs caring for the patient can smooth the way for a donation request. Second, our results suggest that families are more likely to donate if they are prepared that a request will be made; conversely, families who reported greater surprise were less likely to donate. One better approach may be to regularly assess the family's beliefs regarding their loved one's likelihood of survival and not bring up organ donation until the family members acknowledge their loved one's terminal status.

Health care practitioners making donation requests must learn how to ask appropriately. Our results suggest that asking apologetically or mentioning that one is legally required to ask is likely to result in a refusal. In addition, we found that the more time spent discussing the issue and the more information discussed, the more likely the family was to donate, even when controlling for variables such as the family's initial reaction to the request.

Our data suggest that most HCPs are poor judges of who wants to donate. Health care practitioners were correct in their assessments in less than half the cases. When HCPs believed the family was negatively disposed toward donation, they spent less time discussing donation. Moreover, families whom the HCP thought were unfavorably disposed regarding donation were less likely to talk to the OPO staff. An excellent way to avoid this pitfall is to establish a standard practice of always calling the OPO to meet with the families of potential donors.

Our data strongly indicate that involvement of the family with a professional from the OPO is critical. The time spent with the OPO coordinator was a strong factor associated with the decision to donate. Ensuring that all po-

tential donor families meet with an OPO representative, whether or not the HCP believes the family will donate, may increase the number of organs donated. Our results provide empirical data in support of the Health Care Financing Administration (HCFA) regulations requiring contact of the OPO when a potential organ donor is identified.

Our results further suggest that HCPs should limit their role to ensuring that the OPO staff is called early in the process and work under the direction of the OPO staff to optimize the donation request. Further research should investigate whether the role of the HCP should be limited to simply the introduction of the family to the OPO staff person.

Incomplete or inaccurate information about the donation process may limit consent. The psychological literature on donation stresses the relationship between allaying individuals' fears regarding the donation process and the propensity to consent to donation.²³⁻²⁷ Our results indicate that family members want information about the costs of donation, which organs can be donated, and the effect of donation on the funeral arrangements (especially disfigurement of the body)—topics that HCPs might be reluctant to raise. We suggest that HCPs should introduce these issues and address any possible concerns or fears directly. Many of our respondents reported concerns or misinformation about these issues, which they did not share or discuss with any of the HCPs or OPO staff at the hospital. Discussion and correction of common fears and misinformation about organ donation should be part of the organ donation request process.

Several limitations of our study should be acknowledged. First, the study took place in northeastern Ohio and southwestern Pennsylvania. Neither region has significant numbers of Hispanic or Asian ethnic minorities. Moreover, although we had an overall high response rate, donor families were more likely to participate than nondonor families, and nondonor families were more likely to be ethnic minorities. Second, the study relied on HCPs' and families'

recollections of the donation request and may involve some recall bias. However, family members' and HCPs' responses regarding the conversations were similar, suggesting that recall was accurate. Third, the number of OPO staff involved in the study was too small to characterize aspects of successful OPO requests. However, the Association of Organ Procurement Organizations and United Networks for Organ Sharing are currently conducting research into this subject. Finally, current HCFA regulations require that each hospital notify its local OPO about imminent deaths and that only trained HCPs or the OPO staff approach families about donation. Pennsylvania passed similar legislation in 1994, the year we began data collection, but the findings from Ohio did not differ (data available on request). This leads us to conclude that interventions promoting better coordination between HCPs and OPOs, as well as request processes tailored to families' decisional needs, are still needed.

The shortage of organs for transplantation has reached a critical stage. Our study points to the need for large rigorously conducted intervention studies to determine the characteristics of successful requests. These studies could test the various elements of the request process and would provide guidance to policy makers and practitioners as they attempt to increase the numbers of solid organs available for transplantation.

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