



# PERCEIVED SUPPORT AMONG FAMILIES DECIDING ABOUT ORGAN DONATION FOR THEIR LOVED ONES: DONOR VS NONDONOR NEXT OF KIN

By Liva Jacoby, PhD, MPH, and James Jaccard, PhD

**CE** 1.25 Hours

### Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

1. Identify at least 2 types of information that family members found to be helpful when considering organ donation for a brain-dead relative.
2. Describe bereavement care.
3. Discuss at least 3 reasons why relatives did not consent to donation for their loved ones.

To read this article and take the CE test online, visit [www.ajconline.org](http://www.ajconline.org) and click "CE Articles in This Issue." No CE test fee for AACN members.

This article is supplemented by an *AJCC* Patient Care Page on page 462.

©2010 American Association of Critical-Care Nurses  
doi: 10.4037/ajcc2010396

**Background** Families' experiences in the hospital influence their decisions about donating organs of brain-dead relatives. Meeting families' support needs during this traumatic time is an obligation and a challenge for critical care staff.

**Objectives** (1) To elicit family members' accounts of various types of support received and perceived quality of care for themselves and their loved ones when they made the donation decision, and (2) to examine the relationship between these factors and the families' donation decision.

**Methods** Retrospective telephone interviews of 199 families from different regions of the country were completed. Aside from demographic data, the survey addressed perceptions of informational, emotional, and instrumental support and quality of care.

**Results** One hundred fifty-four study participants consented to donation; 45 declined. White next of kin were significantly more likely than African Americans to consent. Specific elements of reported support were significantly associated with consent to donate. Donor and nondonor families had differing perceptions of quality care for themselves and their loved ones. Receiving understandable information about organ donation was the strongest predictor of consent.

**Conclusions** Specific supportive behaviors by staff as recounted by family members of potential donors were significantly associated with consent to donation. These behaviors lend themselves to creative training and educational programs for staff. Such interventions are essential not only for next of kin of brain-dead patients, but also for staff and ultimately for the public as a whole. (*American Journal of Critical Care*. 2010;19:e52-e62)

**R**esearch undertaken during the 1990s on the effects of families' hospital experiences on their decisions about organ donation for a relative generated compelling evidence regarding the significance of families' satisfaction with hospital care, their understanding of brain death, and the timing of the donation request (decoupling).<sup>1-5</sup> Results of research since 2000 have largely supported these findings and provided new insights, such as the importance of families' being given time to bring up concerns with staff, receiving clear information about their relatives' condition and the organ donation process, not being pressured to make a decision, and being shown respect and compassion.<sup>6-12</sup>

Also emerging from this research is evidence regarding the emotional experiences of next of kin in relation to their donation decision. Based on their extensive research with donor and nondonor families in the United Kingdom, Long, Sque and colleagues<sup>13-16</sup> describe how the emotional upheaval for acutely bereaved families and the lack of clarity regarding brain death while faced with the image of their relative "breathing" engendered dissonance and distress that adversely affected families' decision making and complicated their grieving over time. Research in other countries has produced similar findings.<sup>17,18</sup>

Research with donor and nondonor next of kin in the United States has cited, among a number of reasons for not donating, emotional exhaustion and inadequate staff sensitivity and compassion to address families' suffering.<sup>19,21</sup>

The option of organ donation is a topic in discussions about end-of-life care between hospital staff and patients' families. As such, physicians and nurses, especially in critical care settings, play vital roles in communicating with and supporting families of potential organ donors.<sup>22-27</sup> Evidence suggests that critical care nurses may experience emotional and moral distress when simultaneously caring for brain-dead patients and their grieving families.<sup>28-32</sup> Thus, the decision-making process not only is emotionally wrenching

for next of kin of eligible organ donors but may also constitute a precarious time for nursing staff, who are presented with exceptionally difficult demands.

Although existing research often refers to the needs of patients' families for "support" and to their "perceived quality of hospital care" in relation to their donation decision, little attention has been given to families' perceptions of the particular nature and elements of supportive behaviors and quality care. In order to optimally serve family members during their crisis, as well as aid nursing staff with their demanding obligations, it is essential for staff to have a more nuanced understanding of families' support needs and of what "quality of care" in these unique situations entails than what current evidence provides. Furthermore, such information is warranted if it can bring to light modifiable ways of increasing rates of consent for organ donation. Toward this end, focus groups and a survey were undertaken with donor and nondonor family members to gain insights into their perceptions of various aspects of support and quality of care during the donation approach and decision-making processes. This article describes findings from the survey; focus group results are reported elsewhere.<sup>11</sup>

## Objectives

The aims of the survey were twofold: (1) to elicit family members' accounts of various types of support received and their perceived quality of care for themselves and their loved ones during the time they made the donation decision and (2) to examine the relationship between those factors and the families' decision about organ donation.

## Methods

### Data Collection Procedures

The survey was part of a study undertaken during a 6-year period that covered regions of 6 organ procurement organizations (OPOs) in the Northeast,

Reasons for not donating include emotional exhaustion and inadequate staff sensitivity and compassion.

### About the Authors

**Liva Jacoby** is an associate professor in the Department of Medical Education and the Alden March Bioethics Institute at Albany Medical College in Albany, New York. **Jim Jaccard** is a professor in the Department of Psychology at Florida International University in Miami.

**Corresponding author:** Liva Jacoby, PhD, Alden March Bioethics Institute, MC153, Albany Medical College, 47 New Scotland Ave, Albany, NY 12208 (e-mail: jacobyl@mail.amc.edu).

Midwest, and Midsouth of the United States. The study included 326 families who constitute the population for the present survey. Owing to the large geographical study areas, telephone interviews were selected as the optimal method of data collection. A second reason for choosing this method was to maintain relative anonymity for the respondents. Six individuals with interviewing experience related to sensitive topics were recruited and trained during a 1-day workshop. Aside from using the survey to practice interviewing, training included presentations about the organ donation process, brain death criteria, grief and bereavement, and the protection of human subjects. One Spanish-speaking interviewer was available for participants wishing to be interviewed in Spanish. Interviews lasted an average of 45 minutes. Respondents were offered \$50 for their participation. The study was approved by the institutional review boards at the academic institutions affiliated with the participating OPOs.

Potential survey participants received a letter from their OPO 8 to 10 months after the death of their relative informing them about the nature and purpose of the study and that they would be receiving a telephone call from a member of the research staff to ask if they were willing to take part in the study. Within 5 days, calls were made by the interviewers to review the study and its purposes, answer family members' questions, obtain verbal consent, and if consent was given, to set up a convenient time for the interview. Interviewers asked for a family member who had played a significant role as a decision maker about donating their loved one's organs. Respondents were told they could end the interview at any time. No one chose to terminate the interview before completion. At the end of the interview, participants were given information about bereavement services in their area.

Of the 326 letters mailed to potential respondents, 44 (13.5%) were returned as undeliverable. Of the remaining 282 persons who were called, 23 (8.2%) could not be located or were not reachable after 3 attempts. Sixty persons (21.3%) refused to participate when contacted. Reasons given by those who refused were similar for donor and nondonor groups and were primarily related to difficulties talking about their relative's death. A total of 199 persons (70.6% of those who were called) were successfully interviewed. Respondents and nonrespondents were comparable in terms of their relationship to the deceased; most were mothers. Other sociodemographic factors were not available for nonrespondents. The proportion of nondonor next of kin who could not be located or who refused to

participate was 36.4%, compared with 21.8% for donor family members. Of the final sample of 199 participants, 154 (77.4%) had consented to donation.

### The Instrument

A 65-item structured survey questionnaire was developed by the researchers based on prior research and theoretical work, results from focus groups with donor and non-donor family members,<sup>11</sup> recommendations from donor families, and pilot testing. Survey items consisted of close-ended nominal-level questions and 3- and 4-point Likert scales. The survey was pilot tested with mothers of organ donors; the pilot test did not result in any substantive changes. A test-retest was undertaken with 8 persons (staff members of 1 of the participating OPOs) 1 week apart, producing a reliability of 98%.

The questionnaire addressed the following: background characteristics of the respondent and the deceased, perceived support, perceived quality of care for the family and the patient, and perceptions of the decision-making experience. Questions about support were grouped into 3 dimensions of social support: emotional, instrumental, and informational.<sup>33</sup> Emotional support was defined by behaviors such as listening, reassurance, demonstration of understanding, acceptance and nonabandonment, and physical touch; instrumental support was measured by meeting physical needs for comfort; and informational support addressed understandable information about organ donation and brain death, as well as having enough time to make an informed decision. A fourth dimension of social support referred to as "appraisal support" was not addressed in this study. Perceived quality of care was operationalized by perceived demonstration of compassion, respect, and dignity toward family members and toward the patient.

The social support items and their convergent and reliability properties are reported in the Results section.

### Analysis

Univariate analysis was first conducted to provide descriptive statistics for the donation decision as well as the core potential predictors of that decision. Multivariate logistic regression was then used to predict binary donation decisions by using the various predictors in a single equation, along with demographic and other covariates. Although many

No one chose to terminate the interview before completion.

Of the 199 participants, 77.4% consented to organ donation for their loved ones.

**Table 1**  
Demographic characteristics of 199 survey respondents

Characteristic	No. (%) of respondents
Relationship to deceased	
Parent	80 (40.2)
Spouse	78 (39.2)
Child	21 (10.6)
Sibling	14 (7.0)
Other relative	6 (3.0)
Sex	
Male	72 (36.2)
Female	127 (63.8)
Race/ethnicity	
White	150 (75.4)
African American	31 (15.6)
Other	11 (5.5)
No information	7 (3.5)
Marital status	
Single	26 (13.1)
Married	73 (36.7)
Divorced/separated	30 (15.1)
Widowed	70 (35.2)
Education level	
<High school (<12 y)	24 (12.1)
Completed high school	48 (24.1)
Some/completed college	107 (53.8)
Graduate degree	20 (10.1)
Annual income level, \$	
<25 000	64 (32.2)
25 000-44 999	47 (23.6)
45 000-75 000	42 (21.1)
>75 000	39 (19.6)
No information	7 (3.5)

**Table 2**  
Characteristics of the deceased, donation wishes, and families' donation decision

Characteristic	No. (%) of patients		$\chi^2$
	Donors (n = 154)	Nondonors (n = 45)	
Sex			0.8 <sup>a</sup>
Male	87 (56)	23 (51)	
Female	67 (44)	22 (49)	
Age, y			11.0 <sup>b</sup>
≤35	71 (46)	12 (27)	
>35	82 (53)	33 (73)	
No information	1 (<1)		
Stated wishes			13.7 <sup>c</sup>
Wished to donate	26 (17)	3 (7)	
Wishes not stated	84 (55)	40 (89)	
Wishes unknown	25 (16)	1 (2)	
No information	19 (12)	1 (2)	

<sup>a</sup> Not significant

<sup>b</sup>  $P = .01$ .

<sup>c</sup>  $P = .003$ .

different hospitals were involved in the study, only 8 hospitals had 5 or more study participants. The analyses included adjustments for clustering due to hospital through the inclusion of relevant dummy variables. The SUDAAN statistical software package, version 10.0, was used for the analysis.<sup>34</sup>

## Results

### Demographic Characteristics of Survey Participants

Slightly more than half (55.8 %,  $n = 111$ ) of the respondents were from the Northeast, 28.6 % ( $n = 57$ ) from the Midsouth, and 15.6 % ( $n = 31$ ) from the Midwest. As Table 1 shows, close to two-thirds of the participants were women and most were white. About one-third of respondents were either married or widowed. Slightly more than two-thirds had more than 12 years of education and a household income that exceeded \$25 000. Respondents were primarily a parent of the deceased, followed by a spouse, an adult child, and a sibling.

### Characteristics of the Deceased

Age of the deceased ranged from 1 month to 89 years, with a mean (SD) of 39.3 (19.4) years. Most were between 45 and 54 years of age. Slightly more than half (55.3%,  $n = 110$ ) were males. Racial/ethnic background corresponded to that of the next of kin. Ninety-eight percent ( $n = 195$ ) had been hospitalized in an intensive/critical care unit. Length of stay varied from less than 1 day to 28 days, with a mean (SD) of 3.4 (9.4) days. Age was the only characteristic that differed significantly with respect to the deceased's donation status: donors were younger than nondonors (Table 2).

### Comparisons of Donor and Nondonor Next of Kin

**Families' Donation Decision.** As noted earlier, a total of 77.4% ( $n = 154$ ) of the respondents agreed to donate their relative's organs. Whether consent was given or not, the primary decision maker was most often a parent (45.7%,  $n = 91$ ), followed by a spouse (31.7%,  $n = 63$ ), a child (12.6%,  $n = 25$ ), and a sibling (10.1%,  $n = 20$ ).

**Demographic Background.** Demographically, donor and nondonor respondents differed only with respect to racial background. Among those who consented, 85.9% ( $n = 128$ ) were white, 11.4% ( $n = 17$ ) were African American, and 2.7% ( $n = 4$ ) represented other racial/ethnic groups. (Data on racial/ethnic background were missing for 7 participants; Figure 1).

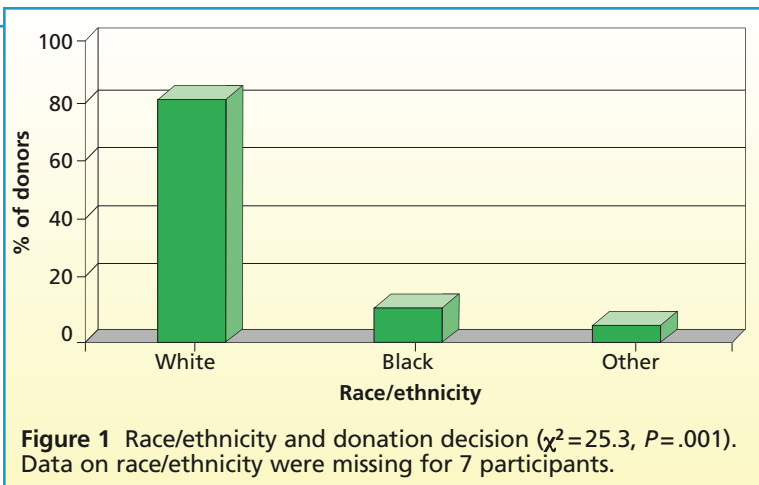
**Families' Perceptions of Their Decision.** Donor and nondonor families differed significantly in their perceptions of how difficult their decision had been,

with 60.4% (n = 93) of donors and 42.2% (n = 19) of nondonors stating that the decision had not been difficult at all ( $\chi^2 = 9.7$ ;  $P = .02$ ). Conversely, 11.0% (n = 17) of those who consented to donation and 26.7% (n = 12) of those who declined described their decision as “very difficult.” Asked if they would make the same decision again, donor and nondonor next of kin also differed considerably in that 90.3% (n = 139) of donors compared with 57.8% (n = 26) of nondonors answered affirmatively (Figure 2). Nondonors were not only more likely to regret their decision but also expressed more uncertainty about the decision they had made.

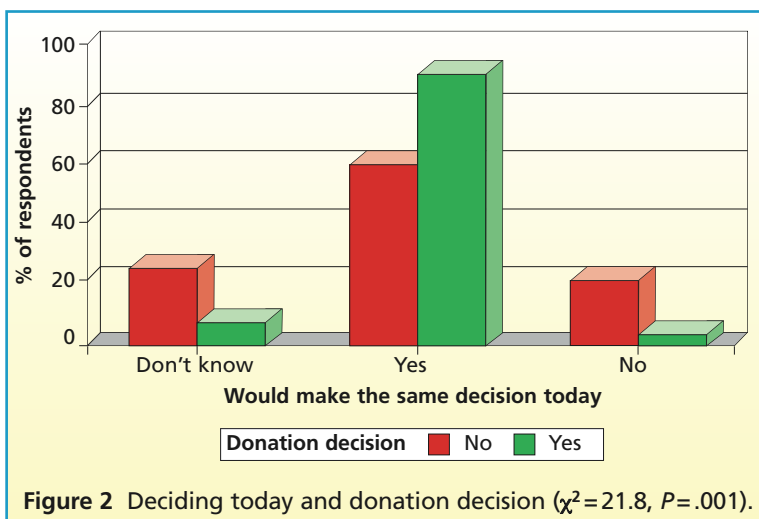
*Wishes of the Deceased.* Almost half of the respondents (48.2%, n = 96) reported that their loved one had talked about organ donation sometime during their lives. This variable did not affect the families’ decision. Of the entire sample, 14.6% (n = 29) were aware that their relatives had formally stated their donation wish by signing a donor card, their driver’s license, or signing up on a donor registry. Families were more likely to consent to donation when their relative had already formally expressed his or her wish. The same applied when families did not know if their loved ones had stated such wishes (Table 2). Wishes of the deceased were included as a variable in the logistic regression analysis.

*Perceived Emotional Support.* Several questions were asked regarding respondents’ accounts of specific aspects of emotional support. Five items were of particular interest, with more than 50% of participants giving positive answers: (1) a staff member or volunteer was present who showed understanding of what they were going through (85.9%, n = 171); (2) a staff member or volunteer was there in case they needed them (83.9%, n = 167); (3) someone was present who listened to them (78.9%, n = 157); (4) a staff member or volunteer let them know that their feelings were normal (68.7%, n = 136); and (5) a volunteer or staff member gave them hope that they could go on (54.8%, n = 109). A comparison of donors and nondonors on these support elements showed that significantly higher proportions of donor family members recounted having had someone present who showed understanding, who listened, who was there in case of need, and who gave them hope to go on (Table 3). Differences between donors and nondonors with respect to someone having let them know that their feelings were normal approached statistical significance ( $P = .05$ ).

The 5 emotional support items were averaged to yield an overall index of emotional support for the logistic regression analyses. The items had an alpha coefficient indexing internal consistency of 0.70.



**Figure 1** Race/ethnicity and donation decision ( $\chi^2 = 25.3$ ,  $P = .001$ ). Data on race/ethnicity were missing for 7 participants.



**Figure 2** Deciding today and donation decision ( $\chi^2 = 21.8$ ,  $P = .001$ ).

*Perceived Instrumental Support.* Instrumental support was assessed by means of the following 2 items: (1) physical necessities in terms of being provided with blankets, shower facilities, or toiletries and (2) food and/or drinks. Significant differences based on donor status were found in the area of physical necessities, with 62.3% (n = 96) of donors vs 40.0% (n = 18) of nondonors responding that they had been given such support (Table 3). No differences were found between groups with respect to being provided with nutritional items.

The physical comfort items showed a correlation of 0.30 (based on a phi coefficient) and were averaged to form an index of instrumental support.

*Perceived Informational Support.* At first, 2 general questions were asked of families regarding informational support: whether they were informed about the status of their loved ones and what to expect related to treatments and/or prognosis, and whether someone had been available to ask questions of hospital and/or OPO staff for them. In response to the former, 87.4% (n = 174) of the respondents

**Table 3**  
Families' perceived support and quality of care by donation decision

Type of support	Donors (n = 154)	Nondonors (n = 45)	$\chi^2$
Emotional, No. (%) of patients			
Shown understanding	137 (89)	34 (76)	6.1 <sup>a</sup>
Someone there to listen to me/us	129 (84)	28 (62)	1.7 <sup>b</sup>
Someone there if needed	135 (88)	32 (71)	12.6 <sup>c</sup>
Given hope to go on	96 (62)	15 (33)	10.8 <sup>d</sup>
Instrumental, No. (%) of patients			
Physical necessities	94 (61)	18 (40)	7.10 <sup>e</sup>
Informational, score, <sup>f</sup> mean (SD) $t$			
Understandable information about brain death	2.76 (0.49)	2.47 (0.69)	-2.68 <sup>c</sup>
Enough time to understand brain death before making decision	2.68 (0.59)	2.07 (0.96)	-4.03 <sup>d</sup>
Understandable information about organ donation	2.91 (0.29)	2.22 (0.77)	-5.70 <sup>d</sup>
Adequate information about organ donation to make informed decision	2.85 (0.45)	2.07 (0.88)	-5.89 <sup>d</sup>
Quality of care, score, <sup>g</sup> mean (SD)			
Care for loved one			
Loved one treated with compassion	3.81 (0.52)	3.53 (0.86)	-2.60 <sup>d</sup>
Loved one treated with dignity/respect	3.79 (0.57)	3.58 (0.83)	-1.91 <sup>h</sup>
Care for family			
Family treated with dignity/respect	3.78 (0.59)	3.49 (0.94)	-2.46 <sup>d</sup>
Family's religious/spiritual values were respected	3.72 (0.75)	3.40 (0.10)	-2.18 <sup>d</sup>

<sup>a</sup>  $P = .04$ .  
<sup>b</sup>  $P = .003$ .  
<sup>c</sup>  $P = .002$ .  
<sup>d</sup>  $P = .001$ .  
<sup>e</sup>  $P = .01$ .  
<sup>f</sup> Score: 1 = not at all understandable, 2 = somewhat understandable, and 3 = quite understandable.  
<sup>g</sup> Score: 1 = not at all, 2 = somewhat, 3 = quite, 4 = very.  
<sup>h</sup>  $P = .27$  (not significant).

gave an affirmative answer. Having had a friend or relative present who asked questions of staff was mentioned by 39.7% (n = 79). These 2 variables were not significantly associated with the families' donation decision.

Two key and specific elements of informational support were then assessed: information about brain death and information about organ donation.

**Information About Brain Death:** Notable differences based on donor status were found regarding information on brain death, with 79.2% (n = 122) of donors and 57.8% (n = 26) of nondonors stating the information had been "quite understandable," and 73.4% (n = 113) vs 48.9% (n = 22) asserting they had been given adequate time to understand brain death before considering organ donation. On a scale of 1 = "not at all understandable," 2 = "somewhat understandable," and 3 = "quite understandable,"

means were 2.76 for donors vs 2.47 for nondonors for understandability of the information and 2.68 for donors vs 2.07 for nondonors for having enough time to understand before making a decision (Table 3). Although only 6.5% (n = 10) of consenting next of kin felt that the amount of time for decision making was "not at all adequate," the corresponding proportion among nondonors was 42.2% (n = 19;  $\chi^2 = 35.4$ ;  $P < .001$ ).

The two informational support items had a correlation of 0.46 and were averaged to form a general index of provision of adequate information about brain death for the logistic regression analysis.

**Information About Organ Donation:** In response to the question regarding the adequacy of information about organ donation in order to make an informed decision and the extent to which this information was perceived as understandable, donors were significantly more likely than nondonors to report that the information had been adequate and understandable. Proportions were 90.0% (n = 137) for donors vs 42.2% (n = 19) for nondonors and 90.3% (n = 139) for donors vs 42.2% (n = 19) for nondonors, respectively. Mean scores (range = 1-3) were 2.91 for donors vs 2.22 for nondonors for understandability of the information and 2.85 for donors vs 2.07 for nondonors for having been given adequate information to make an informed decision (Table 3).

The 2 informational items showed a correlation of 0.77 and were averaged to form an index of provision of adequate information about organ donation for the logistic regression analyses.

**Perceived Quality of Care for Loved One and for Family.** Families' perceptions of quality of care for their loved ones was assessed by the extent to which they felt that the patient was treated with compassion, dignity, and respect. Donor and nondonor family members differed significantly in their perceptions of compassionate care for their relatives. On a scale of 1 to 4 (with 4 being the most positive rating), mean scores were 3.81 for donor family members and 3.53 for nondonor family members (Table 3). Perceptions of the deceased having been treated with dignity and respect did not differ significantly according to the donation decision.

With regard to quality of care for themselves, family members who consented to donation more commonly felt that they had been treated with dignity and respect (means = 3.78 for donor family members vs 3.49 for nondonor family members) and that their religious/spiritual beliefs were respected (means = 3.72 for donor family members vs 3.40 for nondonor family members; Table 3). The 4

**Table 4**  
Correlations between donation decision and dimensions of social support

	Donation decision	Informational support about organ donation	Informational support about brain death	Emotional support	Instrumental support
Donation decision	—	0.548 <sup>a</sup>	0.349 <sup>a</sup>	0.286 <sup>a</sup>	0.209 <sup>a</sup>
Informational support about organ donation		—	0.513 <sup>a</sup>	0.253 <sup>a</sup>	0.105 <sup>a</sup>
Informational support about brain death			—	0.297 <sup>a</sup>	0.189 <sup>a</sup>
Emotional support				—	0.462 <sup>a</sup>
Instrumental support					—

<sup>a</sup>  $P = .01$ .

quality-of-care items were averaged to yield an overall index of perceived quality of care, yielding an alpha coefficient of 0.87.

### Logistic Regression Analyses

Table 4 presents intercorrelations between the 3 dimensions of support and the donation decision. The correlations reported are point biserial correlations. All of the support dimensions were significantly correlated with the donation decision. Informational support about organ donation had the highest correlation ( $r = 0.55$ ,  $P = .01$ ), followed by informational support about brain death ( $r = 0.35$ ,  $P = .01$ ), emotional support ( $r = 0.29$ ,  $P = .01$ ) and instrumental support ( $r = 0.19$ ,  $P = .01$ ). When the variables were entered simultaneously into the logistic regression with the demographic (characteristics of respondents and the deceased), and hospital covariates, only informational support about organ donation yielded a statistically significant logistic coefficient (coefficient = 2.68, exponent of coefficient = 14.61, 95% confidence interval of exponent = 5.14-41.51).

To further elucidate this relationship, we calculated observed conditional probabilities of consent to donate as a function of informational support about organ donation (scale range = 1-3) by computing the proportion of respondents who consented to donate at a given score on the informational support scale. For those with a score of 1 ( $n = 9$ ), the proportion donating was 0%; for those with a score of 1.5 ( $n = 11$ ), the proportion was 45%; for those with a score of 2.0 ( $n = 14$ ), the proportion was 29%; for those with a score of 2.5 ( $n = 17$ ), the proportion was 82%; and for those with a score of 3.0 ( $n = 148$ ), the proportion was 89%. The data indicate a dramatic decrease in decisions to donate at scores less than 2.5. Perceived quality of care and the known prior

wishes of the deceased to be a donor did not yield statistically significant logistic regression coefficients.

### Discussion

Families who are approached about organ donation for their relatives have to make their decision during profoundly stressful circumstances. Findings from this study advance our understanding of families' experiences with and perceptions of particular elements of emotional, informational, and instrumental support and quality of care during these traumatic circumstances. Moreover, the analysis illuminates the association between the particular aspects of support and quality of care on the one hand and the families' decision about donation on the other.

Meeting families' support needs during the donation decision-making process is a challenge as well as an obligation for staff caring for eligible organ donors. Yet critical care practitioners often have inadequate communication skills and knowledge related to organ donation and brain death.<sup>22,29,35,36</sup> As noted earlier, they may also have ambivalent feelings about such issues. In combination, these factors have the potential to influence staff confidence and comfort and, in turn, prevent them from providing effective support to families and from facilitating the decision-making process.

Our multivariate analysis showed that the strongest predictor of consent to donation is informational support about organ donation. Previous research has shown families' emphasis on their desire that such factual information be conveyed with compassion and sensitivity, suggesting a convergence of informational and emotional support.<sup>11,13</sup>

**Nondonors were more likely than donors to regret their decision.**

Family members who consented to donation more commonly felt that they had been treated with dignity and respect.

The relationship between families' consent, receiving understandable information about organ donation and brain death, and having been given sufficient time to make their decision mirrors the results of earlier research. The importance of family decision makers being provided with adequate informational support is underscored by longitudinal studies revealing that unanswered questions about aspects of the organ donation process complicated families' grief.<sup>13,17</sup>

Regardless of their decision about donation, slightly more than one-third of participants reported having had a relative or friend act as a messenger between them and hospital or OPO staff. As Thelen<sup>37</sup> notes, nurses often serve as the intermediaries between families and physicians in end-of-life situations. The importance of this nursing role is accentuated when the issue of organ donation requires information be added to end-of-life conversations with next of kin. Yet various constraints limit nurses in fulfilling this role on a continuing basis, necessitating the involvement of informal caregivers.

The notable differences found between donors and nondonors in the domain of emotional support related to 4 particular elements: having had someone there to listen to them, having had someone there to show understanding, having had someone there to give them hope to go on, and having had someone there just in case of need. As noted earlier, previous research has addressed the emotional turmoil experienced by families during the donation decision process. However, only 1 empirical study<sup>38</sup> was found—and it was limited to parents of brain-dead children—that recommends particular staff behaviors that may address parents' emotional needs. Such behaviors included giving parents the

The strongest predictor of consent to donation is informational support about organ donation.

opportunity to be at their child's bedside and to say goodbye. The authors' other recommendations were stated in general terms related to providing emotional support and developing trusting relationships with patients' families. Our findings move this area of inquiry forward by identifying more precise elements of emotional support and their association with consent to donation. Moreover, our findings bring into focus how hospital staff can respond optimally to families' emotional needs and through that process facilitate the families' decision making. Similarly, our results suggest that

specific instrumental support in the form of physical comfort—also amenable to staff intervention—is associated with consent to donation.

The significant differences between donor and nondonor families' perceptions of quality of care in terms of compassion, respect, and dignity for their loved ones and themselves warrant attention from the perspective of medical and nursing practice and education. How can these elements of quality of care translate into specific staff behaviors and be incorporated into skills training for relevant staff? We believe that principles of bereavement care—a central tenet of palliative care—are applicable in this context for staff training about providing support to families of brain-dead patients as well as support strategies for staff.<sup>39</sup>

Evaluation of the aforementioned differences between donor and nondonor families sheds light on the nature of the decision-making experience itself. Nondonors were considerably more likely to describe their decision as "very difficult" and to state that they would make a different decision if in the same situation again. They also tended to express more uncertainty about their decision. The latter findings, which are consistent with those of Rodrigue et al,<sup>40</sup> highlight what may have been lost opportunities in obtaining consent from families and underscore the need for careful examination by OPO and hospital staff. Such examination should address strategies to reduce the potential for regrets and uncertainties among families by optimally meeting their needs for support.

## Limitations

Limitations of this study pertain to its retrospective nature, relying on respondents' memory of past events. Respondents' recall of events and facts may have been inaccurate. Another limitation is that nonrespondents could have differed from respondents on key background characteristics, thus weakening the generalizability of the study findings. Furthermore, the sample had limited racial and ethnic diversity. Another limitation pertains to the fact that some survey items were generated in a pilot study undertaken with mothers of donors only.

## Conclusions

Our findings give us a deeper and more nuanced understanding of families' experiences with support and quality of care and of the particular elements most predictive of consent to donation than was available from previous research. Gaining new insights into the "texture" of informational, emotional, and instrumental support and quality care



helps us define modifiable elements of care that can be incorporated into professional educational programs. Innovative programs with simulated training and role playing constitute recent advances in this area.<sup>41,42</sup> Such educational interventions must comprise components about support of and strategies for critical care nurses, in particular, to cope with the stress they may experience when caring for prospective organ donors and their families. We argue that such educational programs not only will benefit bereaved families facing the donation decision and critical care staff caring for them and their loved ones but, ultimately, will improve the health of the public as a whole through increased rates of organ donation and transplantation.

#### ACKNOWLEDGMENTS

We extend our thanks to the survey participants for their courage and generosity and thank the interviewers for their skillful interviewing. We gratefully acknowledge the cooperation of the participating OPOs and the assistance of all project staff and volunteers who made the study possible.

#### FINANCIAL DISCLOSURES

This study was supported by grants 1 H39 OT 00007 and 1 H39 OT 00119 from the Office of Special Programs, Division of Transplantation, Health Resources and Services Administration, US Department of Health and Human Services.

#### eLetters

Now that you've read the article, create or contribute to an online discussion on this topic. Visit [www.ajconline.org](http://www.ajconline.org) and click "Respond to This Article" in either the full-text or PDF view of the article.

#### REFERENCES

- DeJong W, Franz HG, Wolfe SM, et al. Requesting organ donation: an interview study of donor and non-donor families. *Am J Crit Care*. 1998;7(1):13-23.
- Franz HG, DeJong W, Wolfe SM, Payne D, Reitsma W, Beasley C. Explaining brain death: a critical feature of donation. *J Transpl Coord*. 1997;7(1):14-21.
- Gortmaker SL, Beasley CL, Sheehy E, et al. Improving the request process to increase family consent for organ donation. *J Transpl Coord*. 1998;8(4):210-217.
- McNamara P, Beasley C. Determinants of familial consent to organ donation in the hospital setting. In: Cecka PI, Terasaki JM, eds. *Clinical Transplants*. Los Angeles, CA: UCLA Tissue Typing Laboratory; 1997:219-229.
- Evanisko MJ, Beasley CL, Brigham LE, et al. Readiness of critical care physicians and nurses to handle requests for organ donation. *Am J Crit Care*. 1998;7(1):4-12.
- Rodrigue JR, Cornell DL, Howard RJ. Organ donation decision: comparison of donor and nondonor families. *Am J Transplant*. 2006;6:190-198.
- Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA*. 2001;286(1):71-77.
- Siminoff LA, Mercer M, Arnold R. Families' understanding of brain death. *Prog Transplant*. 2003;13(3):218-224.
- Rocheleau C. Increasing family consent for organ donation: findings and challenges. *Prog Transplant*. 2001;11(3):194-200.
- Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant*. 2001; 15:39-47.
- Jacoby L, Breitkopf CR, Pease E. A qualitative examination of the needs of families faced with the option of organ donation. *Dimens Crit Care Nurs*. 2005;24(4):183-189.
- Long T, Sque M, Addington-Hall J. What does a diagnosis of brain death mean to family members approached about organ donation? A review of the literature. *Prog Transplant*. 2008;18(2):118-125.
- Sque M, Long T, Payne S. Organ donation: key factors influencing families' decision-making. *Transplant Proc*. 2005;37: 543-546.
- Long T, Sque M, Addington-Hall J. Conflict rationalization: How family members cope with a diagnosis of brain stem death. *Soc Sci Med*. 2008;67:253-261.
- Long T, Sque M, Payne S. Information sharing: its impact on donor and nondonor families' experiences in the hospital. *Prog Transplant*. 2006;6(2):144-149.
- Sque M, Payne S, Macleod Clark J. Gift of life or sacrifice?: key discourses to understanding organ donor families' decision-making. *Mortality*. 2006;11(2):117-132.
- Kesselring A, Kainz M, Kiss A. Traumatic memories of relatives regarding brain death, request for organ donation and interactions with professionals in the ICU. *Am J Transplant*. 2007;7:211-217.
- Macdonald ME, Liben S, Cohen RS. Signs of life and signs of death: brain death and other mixed messages at the end of life. *J Child Health Care*. 2008;12(2):92-105.
- Exley M, White N, Martin J. Why families say no to organ donation. *Crit Care Nurse*. 2002;22(6):44-51.
- Rodrigue JR, Cornell DL, Howard RJ. Pediatric organ donation: what factors most influence parents' donation decisions? *Pediatr Crit Care Med*. 2008;9(2):180-185.
- Siminoff LA, Mercer MB, Graham G, Burant C. The reasons families donate organs for transplantation: implications for policy and practice. *J Trauma*. 2007;62:969-978.
- Williams MA, Lipsett LA, Rushton CH, et al. The physician's role in discussing organ donation with families. *Crit Care Med*. 2003;31(5):1568-1573.
- Aulisio M, DeVita M, Luebke D. Taking values seriously: ethical challenges in organ donation and transplantation for critical care professionals. *Crit Care Med*. 2007;35(2suppl): S95-S101.
- Daly BJ. End-of-life decision making, organ donation, and critical care nurses. *Crit Care Nurse*. 2006;26(2):78-86.
- McCoy J, Argue PA. The role of critical care nurses in organ donation: a case study. *Crit Care Nurse*. 1999;19(2):48-52.
- Ingram J, Buckner E, Rayburn A. Critical care nurses' attitudes and knowledge related to organ donation. *Dimens Crit Care Nurs*. 2002;21(6):1-8.
- Phillips Riley L, Coolican MB. Needs of families of organ donors: facing death and life. *Crit Care Nurse*. 1999;19(2):53-59.
- Sque M, Payne S, Vlachonikolis I. Cadaveric donor transplantation: nurses' attitudes, knowledge and behavior. *Soc Sci Med*. 2000;50:541-552.
- Elpern EH, Covert B, Kleinpell R. Moral distress of staff nurses in a medical intensive care unit. *Am J Crit Care*. 2005;14(6):523-530.
- Dodd-McCue D, Tartaglia A, Veazey K, Streetman P. The impact of protocol on nurses' role stress. *J Nurs Admin*. 2005;35(4):205-216.
- Pearson A, Robertson-Malt S, Walsh K, Fitzgerald M. Intensive care nurses' experiences of caring for brain dead organ donor patients. *J Clin Nurs*. 2001;10:132-139.
- Day L. How nurses shift from care of a brain-injured patient to maintenance of a brain-dead organ donor. *Am J Crit Care*. 2001;10(3):306-312.
- Heany CA, Israel BA. Social networks and social support. In: Glanz K, Rimer BK, Lewis FM, eds. *Health Behavior and Health Education: Theory, Research and Practice*. 3rd ed. San Francisco, CA: Jossey-Bass; 2002.
- RTI International. SUDAAN home page. <http://www.rti.org/sudaan/page.cfm/AboutSUDAAN>. Accessed June 9, 2010.
- DuBois J, Anderson E. Attitudes toward death criteria and organ donation among healthcare personnel and the general public. *Prog Transplant*. 2006;16:65-73.
- Collins T. Organ and tissue donation: a survey of nurse's knowledge and educational needs in an adult ITU. *Intensive Crit Care Nurs*. 2005;21:226-233.
- Thelen M. End-of-life decision making in intensive care. *Crit Care Nurse*. 2005;25(6):28-37.
- Bellali T, Papazoglou I, Papadatou D. Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive Crit Care Nurs*. 2007;23:216-225.

39. Lloyd-Williams M, Morton J, Peters S. The end-of-life care experiences of relatives of brain dead intensive care patients. *J Pain Symptom Manage*. 2009;37(4):659-664.
40. Rodrigue JR, Cornell DL, Howard RJ. The instability of organ donation decisions by next-of-kin and factors that predict it. *Am J Transpl*. 2008;8:2661-2667.
41. Williams MA, Lipsett LA, Shatzer JH, et al. Experiential, interdisciplinary training in end-of-life care and organ donation [abstract]. *Crit Care Med*. 2001;28(suppl):A204.
42. Jacoby L, Crosier V, Pohl H. Providing support to families considering the option of organ donation: an innovative training method. *Prog Transplant*. 2006;16(3):247-252.

---

To purchase electronic or print reprints, contact The InnoVision Group, 101 Columbia, Aliso Viejo, CA 92656. Phone, (800) 899-1712 or (949) 362-2050 (ext 532); fax, (949) 362-2049; e-mail, [reprints@aacn.org](mailto:reprints@aacn.org).

**CE Test** Test ID A1019052: Perceived Support Among Families Deciding About Organ Donation For Their Loved Ones: Donor vs Nondonor

**Next of Kin.** Learning objectives: 1. Identify at least 2 types of information that family members found to be helpful when considering organ donation for a brain-dead relative. 2. Describe bereavement care. 3. Discuss at least 3 reasons why relatives did not consent to donation for their loved ones.

1. Research was conducted in the 1990s regarding the effects of a family's hospital experiences on decisions for organ donation for a family member. The research showed that most families were affected by which of the following?
  - a. Their satisfaction with hospital care and their understanding of brain death
  - b. The patient's prior decision to donate and the family's past experiences in a hospital
  - c. Their satisfaction with hospital care and the patient's prior decision to be a donor
  - d. Their past experience in a hospital and their satisfaction with hospital care
2. Which of the following factors were found to affect a family's decision about organ donation?
  - a. Physician support of the patient's organ donation and family support from care coordination
  - b. Clear information about the organ donation process and about the family member's condition
  - c. Family support from care coordination and an understanding that their relative is being made comfortable
  - d. Clear understanding of a family's needs for emotional support and communication prior to donation
3. In the United States, research on donor and nondonor next of kin indicates which of the following is a primary reason for not donating?
  - a. Emotional exhaustion and inadequate staff sensitivity and compassion in addressing the family's emotional suffering
  - b. Donation is not addressed with the family or the patient during or prior to the time of death
  - c. The organ donor specialist approaches the family about donating but the physician does not support it
  - d. Death of the patient is unexpected and the family is unwilling or unable to discuss donation options
4. Evidence suggests that the challenge of dealing with brain-dead patients and their grieving families may result in critical care nurses experiencing which of the following?
  - a. Job related burn out
  - b. Moral distress
  - c. Inadequate sensitivity
  - d. Over involvement with families
5. Identify 1 factor that affects critical care practitioners' ability to provide effective support to families and facilitate their decision-making process in organ donation?
  - a. Lack of time to spend with relatives due to patient care duties
  - b. Inadequate knowledge related to organ donation and brain death
  - c. Lack of support by physicians to approach relatives about organ donation
  - d. Organ donation staff failure to include care staff in communication with relatives
6. The multivariate analysis in this study showed that the strongest predictor of consent to donate is which of the following?
  - a. Compassion from the health care staff
  - b. Quality patient care
  - c. Informational support about organ donation
  - d. Physician support and compassion
7. Longitudinal studies showed that which of the following factors complicates family grief?
  - a. Lack of compassion and quality care for their relative
  - b. Lack of time to grieve and make decisions
  - c. Physician pressure to make timely decisions about care
  - d. Unanswered questions about aspects of organ donation
8. An empirical study that was limited to brain-dead children found which of the following behaviors may address a parent's emotional needs?
  - a. Time to go home and rest at night to prevent exhaustion
  - b. Time with family support resources provided by the hospital
  - c. Opportunity to be at the child's bedside to say goodbye
  - d. Opportunity to spend time with other relatives visiting the child
9. Donor and nondonor families' perceptions of quality of care can best be addressed by improving staff training, education, and skills in which of the following?
  - a. Organ donation
  - b. Bereavement care
  - c. Family support
  - d. Brain death
10. Bereavement care can include which of the following?
  - a. Support strategies for staff of brain-dead patients
  - b. The process physicians use for brain-dead patients' care
  - c. The family's involvement in the dying patient's care
  - d. Education provided on bereavement to families
11. In the study's results about the stated wishes of the deceased, which of the following was more likely to occur?
  - a. Wishes to donate were stated
  - b. Have no information on wishes
  - c. Wishes were unknown
  - d. Wishes were not stated

Test ID: A1019052 Contact hours: 1.25 Form expires: September 1, 2012. Test Answers: Mark only one box for your answer to each question. You may photocopy this form.

- |                               |                               |                               |                               |                               |                               |                               |                               |                               |                                |                                |
|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|--------------------------------|--------------------------------|
| 1. <input type="checkbox"/> a | 2. <input type="checkbox"/> a | 3. <input type="checkbox"/> a | 4. <input type="checkbox"/> a | 5. <input type="checkbox"/> a | 6. <input type="checkbox"/> a | 7. <input type="checkbox"/> a | 8. <input type="checkbox"/> a | 9. <input type="checkbox"/> a | 10. <input type="checkbox"/> a | 11. <input type="checkbox"/> a |
| <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b    | <input type="checkbox"/> b     | <input type="checkbox"/> b     |
| <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c    | <input type="checkbox"/> c     | <input type="checkbox"/> c     |
| <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d    | <input type="checkbox"/> d     | <input type="checkbox"/> d     |

Fee: AACN members, \$0; nonmembers, \$10 Passing score: 8 Correct (73%) Category: A, Synergy CERP B Test writer: Brenda Hardin-Wike, RN, CNS, MSN, CCNS

**AMERICAN  
ASSOCIATION  
of CRITICAL-CARE  
NURSES**

**For faster processing, take this CE test online at [www.ajconline.org](http://www.ajconline.org) ("CE Articles in This Issue") or mail this entire page to: AACN, 101 Columbia, Aliso Viejo, CA 92656.**

**Program evaluation**

	Yes	No
Objective 1 was met	<input type="checkbox"/>	<input type="checkbox"/>
Objective 2 was met	<input type="checkbox"/>	<input type="checkbox"/>
Objective 3 was met	<input type="checkbox"/>	<input type="checkbox"/>
Content was relevant to my nursing practice	<input type="checkbox"/>	<input type="checkbox"/>
My expectations were met	<input type="checkbox"/>	<input type="checkbox"/>
This method of CE is effective for this content	<input type="checkbox"/>	<input type="checkbox"/>
The level of difficulty of this test was:		
<input type="checkbox"/> easy <input type="checkbox"/> medium <input type="checkbox"/> difficult		
To complete this program, it took me _____ hours/minutes.		

Name \_\_\_\_\_ Member # \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Country \_\_\_\_\_ Phone \_\_\_\_\_ E-mail address \_\_\_\_\_

RN License #1 \_\_\_\_\_ State \_\_\_\_\_

RN License #2 \_\_\_\_\_ State \_\_\_\_\_

Payment by:  Visa  M/C  AMEX  Check

Card # \_\_\_\_\_ Expiration Date \_\_\_\_\_

Signature \_\_\_\_\_

The American Association of Critical-Care Nurses is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. AACN has been approved as a provider of continuing education in nursing by the State Boards of Nursing of Alabama (#ABNP0062), California (#01036), and Louisiana (#ABN12). AACN programming meets the standards for most other states requiring mandatory continuing education credit for relicensure.