

# Does family disagreement affect donation decisions by next of kin?

**Context**—Information about the relationship between family disagreement and donation decisions may facilitate development of strategies to help families resolve conflict and possibly increase donation consent rates.

**Objective**—To assess how family interactions influence next-of-kin decisions about organ donation.

**Design**—Semistructured survey.

**Setting and Participants**—Next of kin of potential donors (147 donors, 138 non-donors) from 1 organ procurement organization participated in a semistructured telephone interview, answering questions about the presence and influence of others during decision making related to organ donation.

**Results**—When others were actively involved in the donation decision (68%), disagreement about the donation decision occurred in 32% of cases. Compared with families initially in agreement, families not in agreement were less likely to donate ( $P < .001$ ), took longer to make a decision ( $P < .001$ ), and were less likely to make the same decision now ( $P < .001$ ). Family disagreement was significantly associated with having more family members involved in the discussion, characteristics of the deceased (younger age, not married, nonwhite race, fewer days in the hospital, trauma-related death), next-of-kin characteristics (less education, less favorable organ donation beliefs), not knowing the deceased's donation intentions, less satisfaction with the health care team, and perceptions of a less compassionate donation requester.

**Conclusions**—Family disagreement occurred in one-third of donation approaches when other family members were present. Such disagreement is most likely to contribute to donation refusal when the deceased's donation intentions are unknown. Recognizing and assessing the nature of family disagreement may increase donation consent. (*Progress in Transplantation*. 2008;18:179-184)

**James R. Rodrigue, PhD,**  
**Danielle L. Cornell, RN, BSN,**  
**Richard J. Howard, MD, PhD**  
Beth Israel Deaconess Medical Center,  
Boston, Massachusetts (JRR), LifeQuest  
Organ Recovery Services (DLC) and  
University of Florida (RJH), Gainesville,  
Florida

To purchase electronic or print reprints,  
contact:

The InnoVision Group  
101 Columbia, Aliso Viejo, CA 92656  
Phone (800) 809-2273 (ext 532) or  
(949) 448-7370 (ext 532)  
Fax (949) 362-2049  
E-mail reprints@aacn.org

Family members play a critical role in the organ donation process. When the deceased's donation intentions are documented, family members can confirm this intention and ensure that their loved one's wishes are carried out. Under these circumstances, organ procurement organizations (OPOs) are not obligated to formally request consent from next of kin because the OPO is legally authorized to carry out the intentions of the deceased. However, all OPOs engage the family in an active discussion of the deceased's documented intentions and solicit the family's acceptance and willingness to provide a past medical/social history. In most instances, family members make a donation decision that is consistent with the deceased's stated or documented intention.<sup>1-6</sup>

However, it is common for individuals to not have discussed their organ donation intentions with others.<sup>7,8</sup> When the deceased's donation intentions are not known

or documented, OPOs rely exclusively on the family (or legal next of kin) to make an informed choice about organ donation on behalf of the deceased. Research has shown that these decisions are influenced by a number of personal and contextual factors and are often more difficult for families.<sup>1,5</sup> Not knowing the deceased's donation wishes is what most often leads to donation refusal.<sup>5</sup> Consequently, public education efforts have stressed the importance of making a personal decision about organ donation and then sharing this decision with family members.

Whether or not the deceased's donation intentions are known, family members may have different attitudes and beliefs about organ donation. Although OPO coordinators seek the donation decision from the legal next of kin, the donation attitudes and beliefs of other family members and friends may be very influential in the decision-making process. Indeed, we previously reported

that organ donation is less likely when there is family conflict or when family members are not in complete agreement about the donation decision.<sup>5</sup>

The purpose of this study was to examine how family interactions at the time of the donation request influence organ donation decisions. Information about the relationship between family disagreement and donation decisions may facilitate the development of strategies to help families resolve conflict and possibly increase donation consent rates. Data reported herein are part of a larger study that examined multivariate predictors of organ donation decisions among next of kin.<sup>5</sup>

## Methods

### Recruitment Procedures

During a 4-year period, all legal next of kin who were approached by coordinators from one OPO in the southeastern United States were informed about the study. Specifically, after the donation decision, an OPO coordinator told the next of kin about the study and then gave them a laminated study information card, along with other informational handouts that are typically given to next of kin at this time. Next of kin who were interested in the study called a toll-free telephone number and spoke to a research assistant about the study purpose, its requirements, and time demands. Verbal consent was obtained and a semistructured telephone interview was conducted at a time that was convenient for the participant.

### Study Sample

We distributed 456 study information cards, which represented 67% of those approached by the OPO during the study period. Three hundred twelve (68%) next of kin made telephone inquiries and 285 (147 donors, 138 nondonors) completed the interview. Study participants were paid \$75.

We attempted to complete interviews near the time of the donation decision, while being respectful of the trauma experienced by grieving family members. This timing of the interviews was intended to limit the degree to which interview responses would be influenced by memory and decision-justification processes over time. Most (76%) of the next of kin were interviewed within 4 weeks of the donation decision.

### Data Collection and Measurement

All data were gathered via semistructured telephone interviews (mean duration, 42.3 minutes), which were conducted by research assistants who received extensive training in crisis management, grief and bereavement, organ donation request processes, and the protection of human research participants. Interview items represented 5 conceptual domains: characteristics of the deceased, next-of-kin characteristics, requestor characteristics, communication processes, and satisfaction with the

health care team. Those domains were based on previous research, theoretical considerations, recommendations of our advisory panel, and our own pilot work.<sup>1-3,9</sup>

Pertinent to this study, we asked participants whether and how many family members or others were present when organ donation was first mentioned, whether anyone else was involved in making the organ donation decision, whether family members had any disagreement about organ donation, and how any disagreement among family members was resolved. All study procedures were approved by the University of Florida's institutional review board.

### Statistical Analysis

Basic summary statistics were calculated for the questions pertaining to family member involvement. Univariate relationships were examined between these interview questions and the final donation decision, whether the next of kin would make the same donation decision again now, sociodemographic characteristics of the deceased, next-of-kin characteristics, and other contextual variables. We used *t* tests for continuous variables,  $\chi^2$  test for variables with 3 or more categories, and Fisher exact test for variables with 2 categories. Next, a logistic regression analysis was conducted to examine multivariate predictors of family disagreement. All data were analyzed by using the Statistical Package for the Social Sciences database (SPSS, Version 11, Chicago Illinois).

## Results

### Characteristics of the Sample

Deceased patients had a mean (SD) age of 46.1 (16.3) years, 56% were male, 78% were white, 44% were married, 35% had at least some college education, and 59% were employed at the time of death. Mean (SD) length of stay in the hospital before death was 6.5 (11.5) days. Forty percent ( $n = 114$ ) of the deaths were trauma-related. Next of kin had a mean (SD) age of 49.3 (13.2) years, and they were predominantly female (80%), white (78%), married (55%), employed (59%), and had a high school education or more (77%). Slightly more than half (52%) were registered organ donors. Next-of-kin relationship to the deceased was as follows: spouse (36%), parent (26%), adult child (21%), sibling (10%), and other (7%).

### Presence and Involvement of Others in Donation Decision Making

In most instances (73%,  $n = 209$ ), someone was with the next of kin when first approached about organ donation. In 99% of these cases, another family member (immediate or extended) was present, and in 40% a non-relative was present. A mean (SD) of 2.8 (3.0) family members and 0.9 (1.8) nonrelatives were with the next of kin at this time.

Table 1 Univariate associations between family agreement/disagreement and donation decision-making variables

Variable	Donation decision <sup>a</sup>		<i>P</i> from the Fisher exact test or $\chi^2$ statistic <sup>b</sup>
	Agreement (n = 132)	Disagreement (n = 61)	
Donation decision			<i>P</i> < .001
Donate	82 (79.6)	21 (20.4)	
Not donate	50 (55.6)	40 (44.4)	
Make same donation decision again			$\chi^2 = 21.8, P < .001$
Yes	116 (74.8)	39 (25.2)	
No	8 (29.6)	19 (70.4)	
Don't know	8 (72.7)	3 (27.3)	
Time taken to make donation decision, min			$\chi^2 = 27.2, P < .001$
≤15	96 (81.4)	22 (18.6)	
16-60	6 (35.3)	11 (64.7)	
61-120	8 (40.0)	12 (60.0)	
>120	22 (57.9)	16 (42.1)	
Given enough time to discuss donation decision			<i>P</i> < .001
Yes	109 (76.8)	33 (23.2)	
No	23 (45.1)	28 (54.9)	

<sup>a</sup> Numbers of participants are followed in parentheses by percentage of all respondents for that variable.

<sup>b</sup> For the Fisher exact test, only *P* values are calculated and reported; for  $\chi^2$  tests, both the test statistic and the *P* value are calculated and reported.

In 193 cases (68%), next of kin actively discussed the donation decision with others. Disagreement about the donation decision emerged in nearly one-third of these cases (32%, n=61). Disagreement was resolved by discussing it until everyone agreed on a decision (31%, n = 19), the legal next of kin asserting final authority (25%, n = 15), following another family member's strong opinion (25%, n=15), majority vote (10%, n = 6), next of kin abdicating the decision to another family member (5%, n = 3), or following the deceased's wishes (5%, n=3).

### Family Agreement/Disagreement and Donation Decision Making

As noted in Table 1, when family members disagreed about the donation decision, next of kin were less likely to consent to donation (*P* < .001), were less likely to say that they would make the same decision now (*P* < .001), took longer to make a donation decision (*P* < .001), and were less likely to feel that they were given enough time to make a decision (*P* < .001). When family members disagreed, donation consent was obtained only 26% of the time (vs 62% when family members were in agreement).

### Family Agreement/Disagreement, Sociodemographic Characteristics, and Contextual Factors

As Table 2 shows, family disagreement was more likely when more family members were involved in the discussion (*P* = .02), the deceased was younger (*P* = .003), not married (*P* = .03), and nonwhite (*P* = .01). Fewer days in the hospital (*P* < .001), trauma-related

death (*P* = .002), and not knowing the deceased's donation intentions (*P* < .001) were associated with more family disagreement. Family disagreement was also associated with several next-of-kin variables, including less satisfaction with the health care team (*P* < .001), lower education (*P* = .008), and less favorable beliefs about organ donation (*P* < .001). Finally, disagreement was more likely when someone other than a family member first mentioned donation (*P* = .02) and when the person making the formal donation request was seen as less compassionate (*P* = .02).

### Multivariate Predictors of Family Disagreement

Logistic regression analysis was used to examine the relative contributions of the deceased's characteristics, the next of kin's sociodemographic characteristics, and contextual factors in predicting family disagreement. Only those variables that had been shown to be statistically associated with family agreement/disagreement in the univariate analyses were included in the analysis. As noted in Table 3, the total model is statistically significant. The presence of more family members, not knowing the deceased's donation wishes, and less satisfaction with the health care team were all significant predictors of family disagreement.

### Discussion

The legal next of kin of a dying or deceased person are generally not alone when the option of organ donation is presented to them. Although some legal next of kin make a unilateral donation decision, we found that it is more common for them to seek consultation with others.

Table 2 Univariate associations between family agreement/disagreement, sociodemographic characteristics, and contextual factors

Sociodemographic or contextual characteristic	Donation decision <sup>a</sup>		<i>P</i> from the Fisher exact test or $\chi^2$ statistic <sup>b</sup>
	Agreement (n = 132)	Disagreement (n = 61)	
No. of others involved in discussion, mean (SD)	3.3 (4.2)	4.8 (3.8)	<i>t</i> = 2.38, <i>P</i> = .02
Age of deceased, mean (SD), y	45.2 (16.3)	37.8 (14.1)	<i>t</i> = 3.06, <i>P</i> = .003
Marital status of deceased			<i>P</i> = .03
Married	61 (77.2)	18 (22.8)	
Not married	71 (61.7)	44 (38.3)	
Race of deceased			<i>P</i> = .01
White	110 (72.8)	41 (27.2)	
Nonwhite	22 (52.4)	20 (47.6)	
Days in hospital, mean (SD)	8.9 (10.7)	4.1 (3.9)	<i>t</i> = 3.40, <i>P</i> < .001
Cause of death			<i>P</i> = .002
Trauma related	51 (57.3)	38 (42.7)	
Not trauma related	81 (77.9)	23 (22.1)	
Donation intentions of deceased			<i>P</i> < .001
Known	74 (85.1)	13 (14.9)	
Unknown	58 (54.7)	48 (45.3)	
Satisfaction of next of kin with health care team, mean (SD)	44.5 (6.2)	37.7 (7.2)	<i>t</i> = 6.73, <i>P</i> < .001
Education of next of kin			<i>P</i> = .008
≤High school	37 (56.1)	29 (43.9)	
College	95 (74.8)	32 (25.2)	
Organ donation beliefs of next of kin	67.7(10.7)	60.1 (12.9)	<i>t</i> = 4.27, <i>P</i> < .001
Person who first mentioned donation			$\chi^2$ = 8.37, <i>P</i> = .02
Personnel from organ procurement organization	28 (68.3)	13 (31.7)	
Professional not from organ procurement organization	62 (60.8)	40 (39.2)	
Family member	42 (84.0)	8 (16.0)	
Perceived compassion of requestor			$\chi^2$ = 8.32, <i>P</i> = .02
Very compassionate	93 (75.0)	31 (25.0)	
Somewhat compassionate	27 (61.4)	17 (38.6)	
Not at all compassionate	12 (48.0)	13 (52.0)	

<sup>a</sup> Except where mean (SD) is indicated, values are numbers of participants followed in parentheses by percentage of all respondents for that characteristic.

<sup>b</sup> For the Fisher exact test, only *P* values are calculated and reported; for  $\chi^2$  tests, both the test statistic and the *P* value are calculated and reported.

Indeed, the tragic loss of a loved one elicits both instrumental and emotional support from family members, relatives, friends, and significant others. Whether present at the hospital or not, this support system is likely to be drawn into discussions about important matters requiring resolution, including decisions about donating the loved one's organs. The presence of this support system has important implications for OPO coordinators who may be communicating primarily with 1 grieving family member, who then is left to disseminate information to others who may not be accessible to the OPO professional or medical staff. Moreover, our data show that family disagreement is significantly more likely as the number of others involved in the discussion increases. Therefore, those making the donation request should tactfully ask the next of kin who will participate in the donation discussion and make themselves available to answer questions that arise.

Although we found agreement about the donation decision in most instances, 32% of our next-of-kin participants reported some family disagreement about the initial donation decision. As we reported previously,<sup>5</sup> family disagreement is important to recognize and assess in light of its strong association with the final donation decision. The donation consent rate in the context of unresolved family disagreement was only 34% in our study, versus 62% when the family agreed on the donation decision.

Family members resolve their disagreement in a variety of different ways, some of which may not be optimal in obtaining consent for donation. For example, in the 15 cases with family disagreement in which the next of kin asserted his or her own position, donation occurred in only 5 instances. Similarly, in the 15 cases in which the next of kin followed an assertive family member's opinion, donation occurred only once. In contrast, consent for donation was obtained in

Table 3 Logistic regression model summary<sup>a</sup>

Variables	Total model		Individual variables
	$\chi^2$	% correct prediction	Odds ratio (95% CI)
	51.4 <sup>b</sup>	78.2	
Presence of more family members			1.17 (1.1, 1.4) <sup>c</sup>
Donation intentions of deceased unknown			0.43 (0.3, 0.8) <sup>b</sup>
Less satisfaction with the health care team			0.84 (0.7, 0.9) <sup>d</sup>

Abbreviation: CI, confidence interval.  
<sup>a</sup> -2 log likelihood for the constant-only model was 147.7. Hosmer-Lemeshow Goodness of Fit test: 6.1,  $P = .72$ .  
<sup>b</sup>  $P < .001$ .  
<sup>c</sup>  $P < .01$ .  
<sup>d</sup>  $P < .05$ .

75% of the cases when, despite initial disagreement, family members discussed it until consensus was reached.

The likelihood of family disagreement appears to be highest when the deceased's donation wishes are unknown, when the next of kin is less satisfied with the deceased's health care team, and when more family members and friends are invited to weigh in on the donation decision. When the deceased's donation wishes are not known, ambiguity and conflict about what the deceased would have wanted are more likely and, consequently, the decision may be influenced more by the donation attitudes and beliefs of individual family members and a guess about what the deceased might have wanted.<sup>10</sup> These data highlight the need for additional research on factors that influence donation communication and specific interventions that encourage individuals to share donation intentions with others.<sup>7,8,11-13</sup> Sharing such decisions not only makes it more likely that one's intentions are carried out, but reduces the likelihood of family disagreement and conflict at the time of death.

Previous research has shown that organ donation decisions are influenced by the family's relationship with the medical staff and their overall satisfaction with the health care provided to the deceased family member.<sup>1,2,5</sup> Findings from the current study also suggest that dissatisfaction with the health care team is associated with more disagreement among family members about donation. Some family members may be less likely to consider donation—and may argue this point strongly in the context of donation discussions—when they perceive that the health care team did not provide adequate medical care to their loved one, did not communicate effectively with the family, or did not show respect for the family. In-hospital OPO coordinators may be particularly helpful in attenuating any negative perceptions held by family members and in separating these perceptions from the donation discussion as much as possible.

Collectively, these findings suggest that OPO professionals may benefit from training in how to assess family dynamics, how to modify the donation approach on the basis of these dynamics, and how to help families reach consensus in a manner that both attenuates family stress and increases the likelihood of organ donation. For instance, in our OPO, coordinators and donor family advocates are now trained to do an assessment of family dynamics before being introduced to the family. They ask members of the health care team (eg, nurses, physicians, social workers, pastoral care) specific questions about family dynamics, key decision-makers regarding health care issues, history of previous disagreements around health care decisions and how these were resolved, and the nature of their interactions with the health care team generally. In some instances, disagreements about health care decisions represent long-standing conflict among family members; in other instances, they are simple philosophical or religious preferences that pertain specifically to the medical issue at hand. The nature of such conflict has important implications for how the OPO coordinator might approach the family with the option of organ donation.

On the basis of the information gathered, the OPO coordinator can make a determination regarding which family members will play the most active role in donation discussions, how to approach the discussion when the family/friend circle is large, what language might be most effective, and with whom primary eye contact should be made (ie, key decision makers). Customizing consent practices in this manner, based on family dynamics, may be important for donation to occur when some family disagreement is apparent.

### Limitations

Findings from this study should be interpreted within the context of several methodological limitations that we have noted in past publications. These relative weaknesses include using a self-selected sample,

recruiting participants from only 1 OPO, and a racially homogeneous sample. Of particular relevance to the current study, we simply asked next of kin whether there was disagreement about the donation decision, not about the extent or precise nature of the disagreement. Some of the disagreements most likely were very minor and brief. Some study participants told us about disagreements that were tense and uncomfortable for them, although we did not gather this type of information systematically.

### Acknowledgments

We thank the following individuals for their assistance in the preparation and/or conduct of this study: Shawna Ehlers, Kristin Gant, Shannon Jackson, Ian Jamieson, William Kanasky, Jonathan Lin, Kathleen MacNaughton, Charles McCluskey, Stephen Oelrich, William Pfaff, Olivia Puyana, Joseph Riley, Stephanie Toy, and the National Donor Family Council of the National Kidney Foundation.

### Financial Disclosures

This research was supported, in part, by a grant from the National Institute of Diabetes and Digestive and Kidney Diseases (DK55706) awarded to the first author.

### References

1. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA*. 2001;286:71-77.
2. Burroughs TE, Hong BA, Kappel DF, Freedman BK. The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosom Med*. 1998;60:156-162.
3. DeJong W, Franz HG, Wolfe SM, et al. Requesting organ donation: an interview study of donor and nondonor families. *Am J Crit Care*. 1998;7:13-23.
4. Martinez JM, Lopez JS, Martin A, Martin MJ, Scandroglio B, Martin JM. Organ donation and family decision-making within the Spanish donation system. *Soc Sci Med*. 2001;53:405-421.
5. Rodrigue JR, Cornell DL, Howard RJ. Organ donation decision: comparison of donor and nondonor families. *Am J Transplant*. 2006;6:190-198.
6. Sque M, Long T, Payne S. Organ donation: key factors influencing families' decision-making. *Transplant Proc*. 2005;37:543-546.
7. Guadagnoli E, Christiansen CL, DeJong W, et al. The public's willingness to discuss their preference for organ donation with family members. *Clin Transplant*. 1999;13:342-348.
8. Morgan SE, Miller JK. Beyond the organ donor card: the effect of knowledge, attitudes, and values on willingness to communicate about organ donation to family members. *Health Commun*. 2002;14:121-134.
9. Radecki CM, Jaccard J. Psychological aspects of organ donation: a critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychol*. 1997;16:183-195.
10. Siminoff LA, Lawrence RH. Knowing patients' preferences about organ donation: does it make a difference? *J Trauma*. 2002;53:754-760.
11. McDonald DD, Ferreri R, Jin C, et al. Willingness to communicate organ donation intention. *Public Health Nurs*. 2007;24:151-159.
12. Smith SW, Kopfman JE, Lindsey LL, Yoo J, Morrison K. Encouraging family discussion on the decision to donate organs: the role of the willingness to communicate scale. *Health Commun*. 2004;16:333-346.
13. Thompson TL, Robinson JD, Kenny RW. Family conversations about organ donation. *Prog Transplant*. 2004;14:49-55.

Copyright of Progress in Transplantation is the property of North American Transplant Coordinators Organization, Inc. (NATCO) and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.