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Family Initiated Discussions About Organ Donation at the Time of Death

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Abstract

Some family members initiate organ donation discussions before being approached by donor coordinators or healthcare providers. We examined differences between families that did versus did not initiate organ donation discussions and factors predicting donation consent among those families that self-initiated the discussion. Next-of-kin of donor-eligible individuals (147 donors, 138 non-donors) from one organ procurement organization completed a telephone interview. Seventy-three families (25.6%) first mentioned organ donation, and 54 (74%) of them consented to donation. Several characteristics of the deceased and next-of-kin were associated with whether family members initiated the donation discussion with donation coordinators or healthcare providers. Also, family mention of donation was more likely to yield consent when the deceased was younger (OR = 0.95, CI = 0.92, 0.99), next-of-kin was a registered donor (OR = 3.86, CI = 2.84, 6.76), and when family was more satisfied with the healthcare team (OR = 1.20, CI = 1.04, 1.39). Knowing the deceased's donation intentions and being exposed to positive organ donation messages are more likely to trigger families to raise donation with providers. OPOs and healthcare providers should work collaboratively to develop strategies for how best to respond to families who initiate this conversation.

Keywords

organ donation; organ procurement organization; donation consent; education

INTRODUCTION

The organ donation community has expended considerable resources to identify strategies most likely to yield a favorable organ donation decision at the time of death. Several studies have identified key modifiable variables that are associated with a higher likelihood of

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family members consenting to organ donation.^{1–6} These variables include knowing the deceased's donation intentions, favorable attitudes toward organ donation, the level of decision agreement within the family, and certain characteristics of the donation requestor.

Consent to organ donation is more likely when the family first raises the idea to healthcare providers.^{1–3} Siminoff et al.¹ found that families who first raised the issue were more likely to donate than those who did not (86% vs. 14%). Rodrigue et al.² similarly found that donation consent was most likely when families first raised the topic (74%) or were first approached by an OPO representative (72%), than when donation discussion was initiated by someone else (e.g., physician, nurse, clergy, or social worker, 34%). A study of parents of deceased children found even higher rates of donation when the topic was first mentioned by the family (83%).³ However, little is known about what characterizes those families that first raise the issue of donation. It is possible that these families have heard about and have more favorable attitudes toward organ donation than those who do not raise donation on their own. However, in the Siminoff et al.¹ and Rodrigue et al.^{2,3} studies, some families who first raised donation eventually refused to consent. It seems important to understand the factors contributing to donation consent or refusal in these families.

The primary purpose of this study was to examine differences between families who first raised the topic of organ donation and those who did not. For those families who raised donation, a secondary aim was to delineate factors distinguishing families who consented versus refused donation. We hypothesized that families who initiated dialogue about organ donation would be more likely to know the deceased's donation intentions, have more favorable attitudes about donation and transplantation, and have heard more organ donation messages (e.g., television, movies, public service announcements) than those families who did not raise the donation topic themselves. Also, we hypothesized that families who raised donation themselves but refused donation when formally asked would be less satisfied with the care their loved one received. Data reported in this study are part of a larger study that examined multivariate predictors of organ donation decisions among next-of-kin.²

METHODS

Participants, Recruitment and Data Collection

During a 4-year study period, families of donor-eligible deceased individuals were informed about the study. In all cases, next-of-kin who met with an OPO coordinator received a study information card at the end of the donation request process. The card contained information about the study and how to contact the research team for additional information or volunteer as a research participant. Trained research assistants provided study information to next-of-kin who called and obtained verbal informed consent from those who decided to take part in the study. A semi-structured telephone interview was either conducted immediately thereafter or scheduled to occur at time more convenient for the participant. Most interviews lasted between 35 to 60 minutes. All participants received \$75.

To reduce the influence of decision justification processes and memory bias, most interviews (76%) were conducted within a month of the donation decision. On average, participants completed the interview 13.7±9.1 days after the donation decision. The telephone interview was semi-structured and extensive in nature, comprised primarily of questions with forced-choice responses. Questions covered five key conceptual domains, including information about the deceased, next-of-kin, and requestor characteristics, communication processes surrounding the donation request, and the family's satisfaction with the medical care received by the deceased's and the associated healthcare providers. Organ donation attitudes were measured with 6 questions (e.g., *A person willing to be an organ donor is a hero*) using a 4-point Likert scale (range = 6–24), with higher scores

reflecting more positive attitudes. Organ donation beliefs were assessed with 22 questions (e.g., *I believed that donating my loved one's organs would allow something positive to come out of his/her death*) using a 4-point Likert scale (range = 22–88), with higher scores reflecting more positive beliefs. Pertinent to the current study's purpose, we asked each participant the following question: "Around the time of your loved one's death, who first raised the possibility of organ donation?" Response choices included family member, OPO coordinator, doctor, nurse, social worker, chaplain/clergy, or someone else. This study was approved by the University of Florida Institutional Review Board.

Statistical Analysis

All data were analyzed using the Statistical Package for the Social Sciences database (SPSS, Version 11, Chicago IL). Summary descriptive statistics were first calculated for the entire sample. Participants were then grouped into one of two groups: (1) donation was first raised by the participant or a family member, or (2) donation was first raised by someone unaffiliated with the family (e.g., OPO representative, nurse, physician, social worker, hospital clergy). Statistical tests (t tests for continuous variables, chi square or Fisher's exact test for categorical variables) examined whether these two groups differed on sociodemographic characteristics and any of the study measures. Next, for those families who first mentioned donation, we examined for differences between donors and non-donors. Significant univariate findings were then entered into a logistic regression analysis to identify multivariate predictors of donation consent after the topic was first raised by the family.

RESULTS

Sample Characteristics

The primary study sample included 147 donor and 138 non-donor next-of-kin, which represented an overall participation rate of 63%. The majority of the sample was female (80%) and either the spouse (36%) or parent (26%) of the deceased, with a mean age of 49.3±13.2 yrs. Most were White (78%; 16% Black), married (55%), employed (59%), did not graduate from college (77%), and self-identified as a registered organ donor (52%). Mean length of time between the loved one's death and study participation was 13.7 d (±9.1; range, 1–68). Time since death was not associated with the primary study outcomes ($p>0.05$).

Comparisons of Those Who First Mentioned Organ Donation vs. Those Who Did Not

Seventy-three families (25.6%) mentioned the possibility of organ donation before the topic was raised by a member of the healthcare team or an OPO representative. Of these families, 54 (74%) consented to donation. Of the 212 cases in which the family did not first mention donation, 93 (43.9%) consented to donation ($p < 0.0001$).

As highlighted in Table 1, next-of-kin were more likely to raise the topic of organ donation when the deceased loved one was younger ($p < 0.0001$), hospitalized longer ($p < 0.0001$), and had previous conversations about organ donation with either the next-of-kin (71% vs. 43%, $p < 0.0001$) or others (45% vs. 17%, $p < 0.0001$). Next-of-kin who raised donation first also were more likely to know that the deceased wanted to be an organ donor (62% vs. 41%, $p = 0.004$).

Next-of-kin who first mentioned organ donation were younger ($p < 0.0001$), more likely to be registered organ donors themselves (68% vs. 48%, $p = 0.004$), and had more favorable organ donation attitudes ($p < 0.0001$) and beliefs ($p < 0.0001$). In addition, they were more likely to have had an organ donation discussion with a family member (62% vs. 32%, $p <$

0.0001) or heard a public service announcement about organ donation (48% vs. 32%, $p = 0.02$) in the 6 months preceding the loved one's death.

Those who first mentioned donation were more likely to rate the requestor as very compassionate (82% vs. 56%, $p < 0.0001$) and to be more satisfied with their loved one's healthcare team ($p = 0.001$). None of the communication process variables (e.g., explanation of brain death, disagreement among family members) were significantly associated with who made first mention of donation.

First Mention of Organ Donation: Donors vs. Non-Donor Comparisons

As noted previously, 54 families who raised the topic of organ donation with healthcare providers eventually consented to donation, while 19 families did not. Table 2 summarizes the characteristics that distinguish these two groups of families. Donation consent was more likely when the deceased was younger ($p = 0.002$) and when it was known the deceased wanted to be an organ donor (65% vs. 53%, $p < 0.001$). Of the 73 families that first mentioned donation, 9 knew the deceased did not want to be an organ donor and in all of these cases the next-of-kin eventually refused donation. Also, all of the families who refused donation had a loved one who died of a non-trauma related cause (i.e., cerebrovascular, cardiovascular) ($p < 0.0001$).

Next-of-kin were more likely to raise the issue of donation and then consent to donation if they were older ($p = 0.017$), the deceased's parent ($p = 0.007$), and a registered organ donor (79% vs. 37%, $p = 0.001$). In addition, more favorable transplant attitudes ($p = 0.003$), organ donation attitudes ($p = 0.04$), and organ donation beliefs ($p < 0.0001$) were associated with consenting to donation. Finally, donation consent was more likely when there was no family disagreement about the donation decision (92% vs. 50%, $p = 0.004$) and when the next-of-kin was more satisfied with the deceased's healthcare team ($p = 0.007$).

First Mention of Organ Donation: Predictors of Donation Consent

Using only those variables that were significant in the univariate analysis, we conducted a logistic regression analysis to examine for significant predictors of consent among those who first raised the topic with healthcare providers. The total regression model was significant ($p < 0.0001$) and showed that younger donor age, next-of-kin being registered as an organ donor, and higher satisfaction with the deceased's healthcare team were significant predictors of consent when the family first raised the possibility of organ donation.

DISCUSSION

Federal regulations require hospitals to notify their OPO of all deaths so that an appropriate assessment of donor eligibility can be completed and the family can be informed about the option of organ donation. However, in some situations, family members have already thought about or discussed the possibility of organ donation and have raised the topic with healthcare providers before being approached by an OPO representative. Indeed, we found a quarter (26%) of the families we interviewed first mentioned the topic of organ donation to a member of the deceased's healthcare team. The majority (74%) of them later consented to donation, which is a finding consistent with our clinical experience. When families raise the topic of organ donation, it represents a unique opportunity to answer specific questions and to provide targeted information at a time the family feels is right.

Our study hypotheses were generally supported by the data. The majority of families who first mentioned donation knew their loved one wanted to be an organ donor or had prior conversations with them about organ donation. Family members who are aware of the deceased's donation wishes – both documented and then validated by discussions with

others – likely feel more comfortable in being proactive about ensuring wishes are honored. Nine families initiating organ donation conversations knew their loved one did not want to be an organ donor and they all refused to consent to donation. We did not specifically ask these next-of-kin why they initiated the donation dialogue, but it is possible that some wanted to ensure the deceased's desire not to be a donor was communicated to the healthcare team. Collectively, these data once again underscore the importance of documenting one's donation intentions and informing others about it.

Those with more favorable organ donation attitudes and beliefs were more likely to initiate organ donation discussions with healthcare providers. Not surprisingly, they were also more likely to be registered donors themselves, which was a salient predictor variable in the multivariate model. Public education efforts have focused largely on encouraging individuals to register as organ donors, to ensure their donation wishes are documented and honored at the time of death.^{7,8} However, in addition to encouraging a personal decision about organ donation, successful public education campaigns may also prime individuals to be more proactive about organ donation at the time of a family member's death. Indeed, families who first raised organ donation with healthcare providers were much more likely to have heard a public service announcement about donation and to have talked with family members about donation in the 6 months prior to their loved one's death.

Our data support the hypothesis that families, after initiating the donation dialogue, are more likely to consent to donation when they are satisfied with the deceased's healthcare team. Other research has shown this is an important determinant of donation consent.^{1,2,4,9} Families were more likely to initiate and consent to donation when they felt informed about their loved one's medical status, their loved one received optimal medical care, the staff took time to answer their questions, and healthcare providers cared about what the family was going through. While favorable attitudes toward organ donation and transplantation may trigger the family to discuss donation with healthcare providers, this is much more likely to occur – and lead to donation consent – when healthcare providers demonstrate respect, sensitivity, and empathy regarding the family's tragic circumstances.

An interesting finding is all families who initiated the donation discussion and subsequently refused to donate had loved ones who died of non-trauma causes. In contrast, all of the families whose loved ones died of trauma-related causes consented to donation, if they were the first to raise the topic. It is our clinical impression that the general public often associates organ donation with traumatic injury, so some families whose loved one's death was not caused by traumatic injury may not have considered the organs to be suitable for transplantation, even after being assured by medical and/or OPO professionals that some organs can be used for this purpose. Healthcare provider attitudes may also account for this finding, although such attitudes were not the focus of this study. Many healthcare providers express discomfort with the interface between end-of-life care and organ donation, and this may be particularly difficult in non-trauma cases.¹⁰

Clinically, it is important for OPOs to consider how they want non-OPO hospital personnel to respond to families who first initiate discussion about organ donation. We recommend that once the topic of donation has been broached by a family member, the family should be assured an organ donation expert will be contacted on their behalf to further discuss the family's questions and concerns. The hospital staff should then inform their local OPO of the family's interest in donation. In general, OPO personnel will have more experience and expertise in addressing common concerns and questions about organ donation and more time to spend discussing the topic with family members. In addition, they can more effectively disentangle the loved one's medical care from the donation decision. Nevertheless, members of the medical team can play an important role in supporting family

members through the difficult and emotionally exhausting process of coping with the death of a loved one and grappling with a donation decision. Hospital staff may benefit from training on how best to converse with family members when they express interest in donation, especially since some discussions will be initiated prior to OPO involvement. An informative, empathic, and supportive conversation with the family may be a critically important determinant of the eventual donation decision. Even if donation is not an option for the deceased, the opportunity for the OPO to answer questions and for the medical team to provide much needed emotional support may leave the family with a positive view of donation and/or the recovery process that may influence future donation decisions.

Findings from this study should be considered in the context of a few methodological limitations. Since we used a passive recruitment strategy, next-of-kin who chose to participate in the study may differ systematically on certain sociodemographic characteristics from those who did not participate. As noted previously, this is a single-center study and the degree to which these findings can be generalized beyond this particular region is unknown. Importantly, we did not ask next-of-kin to tell us why they initiated organ donation discussions with healthcare providers, which we would encourage in future studies on this topic. Finally, we should emphasize that this study was conducted at a time when the predominant OPO clinical practice was to obtain next-of-kin consent for donation, even when the deceased had an actionable donor designation or was on the registry. It is unknown whether these findings generalize to the current era in which the deceased's documented donation intention is prioritized over next-of-kin consent.

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Table 1

Significant associations with first mention of donation by family

Donation Decision Variables		First mention of organ donation [€]		Fisher's exact test, chi square (χ^2) statistic, or <i>t</i> test [¶]
		Next-of-Kin or Family Member (n = 73)	Health Provider or OPO (n = 212)	
Organ donation decision	Donate	54 (36.7)	93 (63.3)	p < 0.0001
	Not donate	19 (13.8)	119 (86.2)	
Characteristics of the deceased				
	Age	43.3±17.1	54.6±19.7	t = 4.4, p < 0.0001
	Days in hospital	10.6±14.6	5.1±9.8	t = 3.6, p < 0.0001
Previous donation discussion with next-of-kin	Yes	52 (36.4)	91 (63.6)	p < 0.0001
	No	21 (14.8)	121 (85.2)	
Previous donation discussion with others	Yes	33 (47.8)	36 (52.2)	$\chi^2 = 24.1$, p < 0.0001
	No	22 (16.8)	109 (83.2)	
	Don't know	18 (21.2)	67 (78.8)	
Donation intentions known by next-of-kin	Wanted to be donor	45 (34.4)	86 (65.6)	$\chi^2 = 11.3$, p = 0.004
	Did not want to donate	9 (26.5)	25 (73.5)	
	Donation wishes unknown	19 (15.8)	101 (84.2)	
Next-of-kin characteristics				
	Age	44.3±13.0	51.0±12.97	t = 3.8, p < 0.0001
Donor designation on license or registered donor	Yes	49 (32.9)	100 (67.1)	p = 0.004
	No	23 (17.6)	108 (82.4)	
	Organ donation attitudes [§]	16.8±2.9	14.7±4.0	t = 4.2, p < 0.0001
	Organ donation beliefs [§]	69.9±10.1	63.0±11.2	t = 4.6, p < 0.0001
Source of organ donation information in 6 months prior to loved one's death				
Discussion with family member	Yes	45 (39.8)	68 (60.2)	p < 0.0001
	No	28 (16.3)	144 (83.7)	
Public service announcement	Yes	35 (34.0)	68 (66.0)	p = 0.02
	No	38 (20.9)	144 (79.1)	
Requestor characteristics				
Perceived compassion of person who formally requested donation	Very compassionate	60 (33.7)	118 (66.3)	$\chi^2 = 16.6$, p < 0.0001
	Somewhat compassionate	7 (10.4)	60 (89.6)	
	Not at all compassionate	6 (15.0)	34 (85.0)	
	Satisfaction with healthcare team [*]	44.4±5.7	41.2±7.2	t = 3.4, p = 0.001

[€] Values expressed as no. (%) or mean ± standard deviation.

[¶] For Fisher's exact test, only p values are calculated and reported; for chi square and *t* tests, both the test statistic and p value are calculated and reported.

[§] Measured using 4-point Likert scale. Range = 6–24, with higher scores reflecting more positive attitudes toward organ donation.

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

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

Table 2

First mention of donation by family: Comparison of donors vs. non-donors

Donation Decision Variables	Donation Decision [€]		Fisher's exact test, chi square (χ^2) statistic, or <i>t</i> test [¶]	
	Donated (n = 54)	Refused (n = 19)		
Characteristics of the deceased				
Age	38.7±22.4	56.4±13.8	t = 3.2, p = 0.002	
Cause of death	Trauma	0 (0.0)	p < 0.0001	
	Non-trauma	30 (61.2)	19 (38.8)	
Donation intentions known by next-of-kin	Wanted to be donor	10 (22.2)	$\chi^2 = 32.6$, p < 0.0001	
	Did not want to donate	0 (0.0)		
	Donation wishes unknown	9 (100.0)		
Next-of-kin characteristics				
Age	46.5±12.2	38.3±13.5	t = 2.5, p = 0.017	
Relationship to deceased, no. (%)	Spouse	8 (72.7)	3 (27.3)	$\chi^2 = 14.2$, p = 0.007
	Parent	23 (100.0)	0 (0.0)	
	Child	14 (53.8)	12 (46.2)	
	Sibling	5 (62.5)	3 (37.5)	
	Other	4 (80.0)	1 (20.0)	
Donor designation on license or registered donor	Yes	42 (85.7)	7 (14.3)	p = 0.001
	No	11 (47.8)	12 (52.2)	
General transplant attitudes [‡]	11.4±1.9	9.6±2.9	t = 3.1, p = 0.003	
Organ donation attitudes [§]	17.2±2.5	15.7±3.5	t = 2.1, p = 0.04	
Organ donation beliefs ^{&}	72.5±7.4	62.6±13.1	t = 4.1, p < 0.0001	
Communication processes				
Disagreement among family members	Yes	3 (37.5)	5 (62.5)	p = 0.004
	No	35 (87.5)	5 (12.5)	
Satisfaction with healthcare team*	45.4±6.0	41.4±3.2	t = 2.8, p = 0.007	

[€] Values expressed as no. (%) or mean ± standard deviation.

[¶] For Fisher's exact test, only p values are calculated and reported; for chi square and *t* tests, both the test statistic and p value are calculated and reported.

[‡] Measured using 4-point Likert scale. Range = 4–16, with higher scores reflecting more positive attitudes toward transplantation.

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

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

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

Table 3

First mention of donation by family: Significant multivariate predictors of donation consent

Variables	Total Model		Individual Variables
	Chi-square	% correct prediction	OR (95% CI), p value
	29.1 ***	81.8	
Younger donor age			0.95 (0.92, 0.99), p = 0.014
Next-of-kin registered as organ donor			3.86 (2.84, 6.76), p = 0.001
More satisfaction with deceased's healthcare team			1.20 (1.04, 1.39), p = 0.013

⁻² Log Likelihood for the constant-only model was 48.2

p < 0.0001