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Pediatric Organ Donation: What Factors Most Influence Parents' Donation Decisions?

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Abstract

Objective—To identify factors that influence parents' decisions when asked to donate a deceased child's organs.

Design—Cross-sectional design with data collection via structured telephone interviews.

Setting and Participants—Seventy-four parents (49 donors, 25 non-donors) of donor-eligible deceased children who were previously approached by coordinators from one organ procurement organization (OPO) in the southeastern USA.

Main Results—Multivariate analyses showed that organ donation was more likely when the parent was a registered organ donor (OR=1.4, CI=1.1, 2.7), the parent had favorable organ donation beliefs (OR=5.5, CI=2.7, 12.3), the parent was exposed to organ donation information prior to the child's death (OR = 2.6, CI = 1.7, 10.3), a member of the child's healthcare team first mentioned organ donation (OR=1.4, CI=1.2, 3.7), the requestor was perceived as sensitive to the family's needs (OR=0.4, CI=0.2, 0.7), the family had sufficient time to discuss donation (OR=5.2, CI=1.4, 11.6), and family members were in agreement about donation (OR=2.8, CI=1.3, 5.2).

Conclusions—This study identifies several modifiable variables that influence the donation decision-making process for parents. Strategies to facilitate targeted organ donation education and higher consent rates are discussed.

Keywords

Organ donation; children; brain death; organ procurement; education

INTRODUCTION

Pediatric transplantation is a widely accepted life-saving intervention for children with end-stage organ failure. Approximately 1,600 pediatric transplants were performed in 2006, which represents 7% of all recipients.[1] Numerous studies highlight excellent clinical outcomes and improved quality of life for many patients.[2–8] Despite favorable outcomes and organ allocation policies that give special consideration for children, the scarcity of donated organs continues to be the primary factor limiting the field of pediatric transplantation.[9] The scarcity of donor

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organs is especially acute for children since organ size matters for liver, heart, and lung transplantation and there are not many size-matched deaths in younger children. As of December 20, 2006, 1,960 children under 18 years were awaiting solid organ transplantation in the United States, with 52% of them younger than 11 years.[1] Death rates of children on the waiting list vary by organ. Relative to adults, children on the kidney waiting list have lower death rates, while children on the heart transplant waiting list have substantially higher death rates.[10]

The general public is known to have very positive attitudes toward organ donation and transplantation.[11] Nevertheless, only about half of family members agree to donate the organs of a deceased loved one when confronted with this decision, although consent rates are higher in the Organ Donation Breakthrough Collaborative era.[12] Recent studies have shown that family members' decisions about organ donation are influenced by many factors, including whether the deceased's donation intentions are known.[13,14] Unlike adults, however, children and adolescents are less likely to provide first-person consent for organ and tissue donation. Therefore, parents of young children usually must make a donation decision in the absence of any direct knowledge about their child's donation intentions.

While the rate of donation consent across most solid organs is consistently higher if the deceased family member is a child,[10,15] little is know about the factors that most influence parents' donation decisions. The purpose of this study was to delineate modifiable factors that distinguish those parents who consented to versus refused donation. Information about their decision-making processes might help to inform the design and implementation of even more effective educational strategies and donation requests for this subgroup of potential donors. The data reported herein were collected as a substudy to a larger, recently published study on organ donation decisions.[14]

MATERIALS AND METHODS

Recruitment Procedures

A passive recruitment strategy was used. Over a 4-yr period, all parents of children less than 18 years who were approached by a coordinator from one organ procurement organization (OPO) in the southeastern United States were informed about the study following their donation decision. Parents who wanted to take part in the study were instructed to make a toll-free call to the research team for more information. During the call, the parent spoke to a research assistant who provided more information about the study, answered questions, requested study participation, and, for those desiring to participate, obtained verbal consent and scheduled an interview time.

Study Sample

One hundred twelve (68 donors, 44 non-donors) parents received information about the study. Of these, 81 (72.3%) called the research team and 74 (66.1%; 49 donors, 25 non-donors) completed telephone interviews. Five parents chose not to participate after speaking to a research assistant. Two parents expressed interest but did not keep two scheduled telephone interviews. All participants were paid $75.00. The 66.2% donation consent rate among participants in this study mirrors the 68% pediatric consent rate over a 10-year period at this OPO and the 67% pediatric consent rate nationally.[16]

It is important to emphasize that we attempted to complete interviews in close proximity to the donation decision, while being respectful of the trauma experienced by these grieving parents. This was done to limit the degree to which interview responses would be influenced by memory

and decision justification processes over time. Most (80%) of the parent interviews were done within four weeks of the donation decision.

Data Collection and Measurement

All data were gathered via semi-structured telephone interviews. Interview items were developed based on prior research, theoretical considerations, recommendations of our advisory panel, and our own pilot work. When more than one parent participated in the donation decision, we interviewed the one identified as the most active in the decision-making process. Interview items represented five conceptual domains: deceased characteristics, parent characteristics, requestor characteristics, communication processes, and satisfaction with the healthcare team (Table 1). Telephone (vs. face-to-face) interviews were done to be sensitive to the time and geographic limitations of families. The OPO participating in this study covers a wide geographic region. Additionally, a sizable proportion of parents reside in regions other than the one in which the child's death occurred. Both the passive recruitment strategy and data collection methodology were chosen after careful consideration by an advisory panel of donor families, OPO coordinators, transplant physicians, hospital administrators, and institutional review board members.

Mean interview duration was 48.6 minutes (range = 36 to 80). Interviewers were six research assistants who received several hours of training and behavioral rehearsal, as well as highly specialized education and training about the organ donation request process, grief and bereavement, crisis management, and the protection of human research participants. Study procedures were approved by the University of Florida Institutional Review Board.

Statistical Analysis

Univariate relationships between the interview items and the donation decision (donation or refusal) were examined using *t*-tests, Fisher exact tests, and χ^2 test. Logistic regression was used to examine the predictive relationship between modifiable variables that were statistically significant in the univariate analyses and the donation decision, while controlling for stable (i.e., non-modifiable) demographic characteristics. All data were analyzed using the Statistical Package for the Social Sciences database (SPSS, Version 11, Chicago IL).

RESULTS

Sample Characteristics

Deceased patients had a mean age of 9.5 yrs (±5.4; range, 1–17 yrs), 73.0% were male, and 79.7% were white. Of the 26 patients who had a driver's permit or license, 9 (34.6%) had a donor designation. Mean length of time in hospital prior to death was 4.7 days. Most common cause of death was head trauma (66.2%).

Parents had a mean age of 43.6 yrs (±11.7; range 18–61 yrs), and they were predominantly female (83.8%), white (82.4%), married (60.8%), employed (74.3%), and had a high school education or less (70.3%). More than half (60.8%) were registered organ donors.

Donation Decision and Child Characteristics

Children who were hospitalized longer prior to death declaration were more likely to be donors (donor mean = 5.4 days, non-donor mean = 2.3 days; $t = 2.0$, $p = 0.05$). There was no difference in donation status based on patient gender, ($p = 0.58$), race ($p = 0.23$), age ($p = 0.09$), or cause of death ($p = 0.67$). Also, including only those with a driver's permit or license, we found that those with a donor designation on their license were not any more likely to become donors ($p = 0.26$).

Donation Decision and Parent Characteristics

As noted in Table 2, education, donor registration status, donation attitudes and beliefs, and knowledge of brain death were significantly associated with donation decision. Parents without any college education were more likely to donate their child's organs than those with at least some college education (83.3% vs. 58.0%, p = 0.05). Parents with an expressed intention (e.g., driver's license, donor card) to be an organ donor were more likely to donate their child's organs than those without such a designation (80.0% vs. 44.8%, p = 0.01). Those who consented to donation had significantly more favorable attitudes (p = 0.02) and beliefs (p = 0.002) about organ donation at the time of their child's death than those who did not donate. Finally, parents with a complete understanding of brain death were more likely to consent to organ donation (78.0% vs. 51.5%, p = 0.03). There was no difference in donation decision based on parent gender (p = 0.63), race (p = 0.12), employment status (p = 0.52), or marital status (p = 0.57).

Parents who consented to donation were more likely to have received information about organ donation or transplantation within the last 6 months than were non-donors (76.6% vs. 48.1%, p = 0.02). The most common informational sources were family member (71.1% vs. 51.3%, p = 0.001), friend (73.7% vs. 41.2%, p = 0.02), medical professional (28.6% vs. 64.3%, p = 0.03), newspaper or magazine (65.3% vs. 36.0%, p = 0.02), public service announcement (26.5% vs. 40.0%, p = 0.18), movie or television show (26.5% vs. 32.0%, p = 0.41), and community activity or event (22.4% vs. 12.0%, p = 0.22).

Donation Decision and Requestor Characteristics

As noted in Table 3, donation was more likely when a member of the child's healthcare team (69.2%) or a family member (83.3%) first raised the possibility of donation, than when it was first mentioned by an OPO coordinator (41.2%, p = 0.05). More familiarity with the professional who formally asked for donation consent was associated with a favorable donation decision (p = 0.001). Parents who consented to donation viewed the requestor as being more sensitive to the family's needs than those who chose not to donate (p = 0.0001). There was no difference in donation decision based on perceived compassion of the requestor (p = 0.47) or who made the formal donation request (p = 0.62).

Communication Processes

As noted in Table 4, parents were more apt to consent to donation when they perceived the timing of the donation discussion to be right (p = 0.02), when they felt they had sufficient time to discuss the donation decision with others (p = 0.05), and when there was no disagreement among family members about the decision (p = 0.001). There was no difference in donation decision based on when a brain death explanation was given (p = 0.23), how many other family members were involved in the discussion (p = 0.70), or how much time was taken by the family to make the decision (p = 0.59).

Satisfaction with Healthcare Team

Satisfaction was measured with 14 questions on a 4-point Likert scale, with possible scores ranging from 14 to 56. Higher scores indicated more satisfaction with the healthcare team. Specific questions asked about the degree to which parents were satisfied with the care received by their child before and after death, the medical staff's communication with the family about the child's medical status and prognosis, and the degree of respect shown by the medical team toward their child and family members. Parents who consented to donation reported more satisfaction with the healthcare team than those who did not donate (42.6 ± 8.2 vs. 36.6 ± 11.7, t = 2.6, p = 0.01). The majority of parents were content with their donation decision, although 5 (10.2%) of those who consented to donation would not make the same decision now and 4 (16.0%) parents now wished they had donated.

Multivariate Predictors

Logistic regression examined the relative contribution of modifiable variables in predicting the donation decision, while controlling for stable demographic characteristics. Only those variables that were statistically associated with donation in the univariate analyses were included. Sociodemographic characteristics were entered first, followed by variables that can be modified via donation education, changes in donation attitudes and beliefs, the donation approach and request, and OPO coordinator training. The following modifiable variables predicted favorable donation decision: parent registration as organ donor (OR = 1.4, CI = 1.1, 2.7), positive organ donation beliefs (OR = 5.5, CI = 2.7, 12.3), exposure to organ donation information prior to child's death (OR = 2.6, CI = 1.7, 10.3), first mention by a member of the child's healthcare team (OR = 1.4, CI = 1.2, 3.7), high requestor sensitivity (OR = 0.4, CI = 0.2, 0.7), sufficient time to discuss donation (OR = 5.2, CI = 1.4, 11.6), and family agreement (OR = 2.8, CI = 1.3, 5.2). The total model was statistically significant and predicted parents' donation decisions in 79.3% of the cases.

DISCUSSION

Organ donation consent rates tend to be higher in pediatric versus adult cases, but few studies have examined the factors that most influence parents' donation decisions. While findings from this study generally mirror those of similar studies involving adult donors,[13,14] they also highlight a few unique differences that may be specific to pediatric cases. Perhaps most importantly, it seems important for the child's healthcare team to be involved in the initial approach about organ donation, as parents are more likely to agree to organ donation when it is their child's physician, nurse, or other health professional (e.g., social worker, clergy) who first mentions the donation possibility. In a retrospective analysis of pediatric trauma cases, Vane et al.[17] found a substantially higher donation consent rate when a pediatric trauma physician discussed organ donation with family members. The close and frequent interactions in the distinctive setting of critically ill or injured children foster a level of trust that is especially important during the donation request process. Consistent with the Organ Donation Breakthrough Collaborative,[18] a collaborative approach (i.e., "team huddle") between the critical care team and OPO coordinator is now used by many OPOs throughout the U.S.

While there are many different ways to increase organ donation awareness, discussions with family members and friends were most likely to have a direct impact on actual organ donation decisions in the current study. This is consistent with one published survey in which parents were three times more likely to have favorable pediatric donation intentions when there had been a prior family discussion about organ donation.[19] Public education campaigns should continue to encourage people to become organ donors and to discuss this decision with all family members, including older children and adolescents.[20,21] We also found that print media coverage of transplant success stories was an important and effective strategy for increasing awareness of the benefits of both organ donation and transplantation, especially in donor parents. Newspaper and magazine articles that stress how donated organs made the triumph of transplantation possible would seem to have a particularly positive impact. Whatever the educational vehicle, exposure to favorable organ donation messages has the potential to ease the donation decision-making process for parents at a time of tragedy and heightened stress.

Complex belief systems about organ donation are influential at the time of donation decisions, especially when the deceased's intentions are unknown, which is typically so with pediatric cases.[14,22] For instance, donor parents in the current study were less likely to believe that organ donation would disfigure the child's body or delay funeral services and they were more likely to believe that organ donation would allow something positive to come from their child's death. The child's healthcare team and OPO coordinators should carefully assess parents' organ

donation beliefs and address them directly in a sensitive manner prior to making the formal donation request.[13,14]

The finding that less educated parents were more likely to agree to donation than those with more formal education contradicts prior research that found either a positive relationship between donation decision and education[21] or no significant relationship at all.[13,14] The current study is one the first to examine organ donation decisions in a pediatric context, which may explain this education finding. There may be subtle differences in how OPO requestors and healthcare providers approach parents with different educational backgrounds or levels of sophistication about organ donation and transplantation. Also, more educated parents may be more aware and affected by recent negative publicity about organ donation and transplantation in print media (e.g., black market for organs, ethical violations, etc.).

It is important to emphasize that the timing of this first mention relative to the discussion of brain death was not influential in the decision-making process of parents in this study, which is consistent with some of our earlier findings.[14] Also, Siminoff et al.[24] similarly found a weak relationship between the timing of the formal donation request and donation decisions. Some mention of organ donation prior to death declaration enhanced the likelihood of obtaining consent for donation. Nevertheless, separating the death declaration from the donation request (i.e., decoupling) is standard practice today and has been identified as a best practice through the Organ Donation Breakthrough Collaborative.[18] Our data do not suggest that we should alter the decoupling strategy, but simply highlight that other factors may be more influential in the donation decision-making process for parents.

Regardless of who first mentions organ donation, to maximize the likelihood of a favorable donation decision parents need to feel that the formal request is done in a way that is sensitive to the family's needs and that they are given ample time to make their decision.[13,14,25] It is important for donor parents to feel that the critical care team and OPO coordinator would be supportive of their decision no matter what it was, to have sufficient privacy to discuss donation with other family members, and to feel that the critical care team truly cares about the family and what they are going through. For instance, Weiss et al. [26] found that parents' perceptions of insensitivity by hospital staff or the OPO professional was a key factor in not consenting to donation among the 50% of parents who were initially undecided. In contrast, more positive interactions with healthcare professionals influenced favorable organ donation decisions among one-third of the undecided parents.

Most parents in our study were satisfied with their decision and would make the same one again. However, some donor and non-donor parents regretted their decision and reported emotional discomfort about this. Those who regretted consenting to donation reported being angry that one or more of their child's organs were transplanted into an elderly recipient, distress over reliving the death of their child when told that the recipient of his/her child's organ had died, or regret over having gone against the opinion of other surviving family members. Regarding those who now wished they had consented to donation, two parents regretted their decision after talking to other bereaved donor parents as part of a support group and one parent felt that her refusal to donate was inconsistent with her otherwise favorable organ donation attitudes (and what her child would likely have wanted). These feelings of regret, while small in number, should not be ignored and should remind us of the need to provide follow-up supportive services to families regardless of the donation decision.

This study has several limitations, including a small sample size, the inclusion of only one OPO, and a predominantly female and White parent sample. Study findings should be interpreted with these caveats in mind. Furthermore, almost all cases involved brain death, so it is difficult to know whether these same factors would influence parents' decisions in other

types of circumstances (e.g., cardiac death). This is a self-selected sample of parents who were willing to share their experiences. Those who chose not to participate in the study may differ from participants in important ways, but we were unable to collect sociodemographic information about nonparticipants in order to evaluate this possibility. While we conducted telephone-based interviews based on practical and ethical considerations by an advisory board, it is possible that face-to-face interviews might yield different participation rates and findings. Finally, although we attempted to conduct the interviews in close proximity to actual donation decision, the impact of recall bias must be acknowledged.

CONCLUSIONS

Higher rates of pediatric organ donation would extend and improve the lives of many more children and adults awaiting solid organ transplantation. Parents' organ donation decisions are influenced by a number of variables, including prior exposure to organ donation information, their own organ donation beliefs and behaviors, who first mentions the possibility of organ donation, interactions with the healthcare and OPO team, and family disagreement about donation. Public organ donation educational efforts should continue to target parents and their children to stimulate family discussions and to more favorably impact organ donation attitudes and beliefs. Also, a family's consideration of organ donation should be viewed as a process that is influenced as much by the family's general interactions with the child's healthcare providers as by the donation request itself (e.g., who asks, the timing, etc.). Finally, OPO coordinators should carefully monitor for family disagreement and intervene as necessary to address any misperceptions or myths about organ donation in individual family members, even those who may seem peripheral in the decision-making process.

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Table 1

The 5 Conceptual Domains and Corresponding Item Content

Domain	Item Content
Deceased's Characteristics	Sociodemographic Variables (sex, age, race, marital status, education, employment status) Donation Intentions (donation intention known or unknown, signed donor card, license donor designation, previous discussion regarding intention with next-of-kin participant, previous discussion regarding intention with someone else) Death Circumstances (cause of death, hospital days)
Next-of-Kin Characteristics	Sociodemographic Variables (sex, age, race, marital status, education, employment status, relationship to deceased) Donation Intentions (signed donor card, license donor designation, shared donation intention with others) Attitudes Toward Organ Transplantation (general transplant attitudes, would accept transplant if medically indicated) Attitudes Toward Organ Donation (general organ donation attitudes) Beliefs About Organ Donation (knowledge beliefs, religious beliefs, altruistic beliefs, attribitutional beliefs, beliefs about the medical profession) Knowledge of Brain Death
Requestor Characteristics	First Mention of Donation (OPO coordinator, physician, social worker, clergy, next-of-kin or family member, other) Donation Requestor (OPO coordinator, physician, social worker, clergy, next-of-kin or family member, other) Familiarity With Donation Requestor Perceived Sensitivity Perceived Compassion
Communication Processes	Timing of Initial Donation Discussion Given Enough Time to Make Donation Decision Given Enough Information to Make Informed Decision Involvement of Others in Donation Decision (family members, friends, clergy, medical staff) Brain Death Explanation Given Adequacy of Brain Death Explanation Timing of Brain Death Explanation (before donation discussion, same time as donation discussion, after donation discussion)
Overall Satisfaction with Health Care Team	Level of Satisfaction (perceived adequacy of care, communication with family about medical issues other than donation and brain death, respect for deceased and family members)

Table 2

Parent Characteristics: Significant Univariate Associations with Donation Decision

		Donation Decision		
		Yes (n=49)	No (n=25)	Statistical Analysis
Education, no. (%)	≤ High School	20 (83.3)	4 (16.7)	p=0.05[±]
	> High School	29 (58.0)	21 (42.0)	
Registered organ donor, no. (%)	Yes	36 (80.0)	9 (20.0)	p=0.01[±]
	No	13 (44.8)	16 (55.2)	
Attitudes Toward Organ Donation[*]		16.7 ± 2.9	14.1 ± 4.7)	t=2.5, p=0.02
Beliefs About Organ Donation[&]		76.0 ± 7.9	62.4 ± 10.6	t=3.2, p<0.002
Adequate Knowledge of Brain Death	Yes	32 (78.0)	9 (20.0)	p=0.03[±]
	No	17 (51.5)	16 (48.5)	
Exposed to Donation Information in Past 6 Months	Yes	36 (76.6)	11 (23.4)	p=0.02[±]
	No	13 (48.1)	14 (51.9)	

[±]Only p value is reported because Fisher's exact test does not yield formal test statistic or critical value.

[*]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.

Table 3

Requestor Characteristics: Significant Univariate Associations with Donation Decision

		Donation Decision		
		Yes (n=49)	**No (n=25)**	**Statistical Analysis**
Person Who First Mentioned Donation	OPO personnel	7 (41.2)	10 (58.8)	χ^2=7.3, p=0.05
	Non-OPO professional[¶]	27 (69.2)	12 (30.8)	
	Family member	15 (83.3)	3 (16.6)	
Family's Familiarity With Person Asking for Consent	Never met before consent Request	10 (38.5)	16 (61.5)	χ^2=14.0, p=0.001
	Met briefly before consent Request	18 (78.3)	5 (21.7)	
	Met several times before consent request	21 (84.0)	4 (16.0)	
Perceived Sensitivity[§]		2.6 (1.1)	1.5 (0.8)	t=3.9, p=0.0001

[¶]Includes physician, nurse, social worker, and hospital clergy/chaplain.

[§]Measured using 4-point Likert scale. Range = 1–4, with higher score indicating that the requestor was perceived to be sensitive to the family's needs.

Table 4

Communication Processes: Significant Univariate Associations with Donation Decision

		Donation Decision		
		Yes (n=49)	**No (n=25)**	**Statistical Analysis**
Perceived Timing of Donation Discussion	Timing was right	33 (78.6)	9 (21.4)	
	Should have occurred Earlier	4 (66.7)	2 (33.3)	χ^2=7.5, p=0.02
	Should have occurred later	12 (46.2)	14 (53.8)	
Given Enough Time to Discuss Donation	Yes	40 (72.7)	15 (27.3)	p=0.05[±]
	No	9 (47.4)	10 (52.6)	
Disagreement Among Family Members About Donation	Yes	11 (37.9)	18 (62.1)	p=0.001[±]
	No	38 (84.4)	7 (15.6)	

[±]Only p value is reported because Fisher's exact test does not yield formal test statistic or critical value.