A Comparison of the Request Process and Outcomes in Adult and Pediatric Organ Donation

Laura A. Siminoff, PhD, Anthony J. Molisani, MPH, Heather M. Traino, PhD

abstract

BACKGROUND AND OBJECTIVES: Although existing studies suggest that factors affecting families' decisions regarding pediatric organ donation mirror those for adult patients, health professionals working in this area maintain that pediatric and adult decision-makers differ in significant ways. This study compared the request process, experiences, and authorization decisions between family decision-makers (FDMs) of adult and pediatric donors and non-donors.

METHODS: Perceptions of the donation request were collected via telephone interviews with 1601 FDMs approached by staff from 9 US organ procurement organizations (OPOs). Authorization regarding donation (ie, authorized/refused) was obtained from FDM reports and verified by using OPO records. Tests of association were used to estimate differences between FDMs of adult and pediatric patients. A logistic regression analysis was conducted to identify variables predicting FDM authorization.

RESULTS: FDMs of children were significantly more likely to authorize donation than were FDMs of adults (89.7% vs 83.2%; χ² = 6.2, P = .01). Differences were found between pediatric and adult families' initial feelings toward donation, donation-related topics discussed, communication behaviors and techniques used, perceptions of the request, and receipt and preference of grief information. The likelihood of FDM authorization increased with the number of topics discussed and communication skills employed during requests. Authorization was not predicted by patient age (ie, adult versus pediatric).

CONCLUSIONS: FDMs of children are willing to donate and experience no more psychological distress from the request for donation than do FDMs of adults. Communication emerged as a critical factor of family authorization, reinforcing its importance in requests for donation.

WHAT’S KNOWN ON THIS SUBJECT: Pediatric patients suffer higher mortality due to the shortage of transplantable organs. Factors influencing families’ donation decisions are similar for pediatric and adult patients. However, the general perception that families of pediatric patients are less willing to donate persists.

WHAT THIS STUDY ADDS: Communication emerged as a critical factor of family authorization, reinforcing its importance in the organ donation process. Patient age (ie, adult versus pediatric) was not predictive of family authorization.
Of the >120 000 persons awaiting solid organ transplantation, 1839 (1.5%) are pediatric candidates aged <18 years. Although they comprise a small portion of the total wait list, twice as many US pediatric patients die while waiting for a transplantable organ compared with adults (32.9% vs 16.5%). Furthermore, most organs donated by pediatric patients are allocated to adults. Although recent changes to allocation policies have led to decreased pediatric wait list mortality, these same policies have unintentionally reduced the number of living donors and therefore the number of organs available for transplantation for both adult and pediatric patients. Inquiry into the pediatric donation process and the specific factors influencing parental donation decisions should therefore be considered a national imperative. Research to date has suggested that a number of factors affect parental authorization, including knowledge of organ donation and favorable donation attitudes. For example, exposure to organ donation information, such as adequate knowledge of brain death, significantly predicts a favorable donation decision. In addition, the quality of communication between providers (both organ procurement organization [OPO] staff as well as health care professionals) and grieving families can influence authorization. Appropriately timed, high-quality requests that give families sufficient time to discuss and consider donation have been shown to lead to more favorable outcomes (ie, parental authorization). The donation decision may hinge on the professional and friendly demeanor of providers and their perception as being more trusting, sincere, sensitive, and respectful of the family. In addition, several qualitative studies indicate that families often view organ donation as a means of coping with the loss of a child, including giving meaning to the death and maintaining a connection with the deceased after the death. Empathy for other parents and children in need of transplants and an acknowledgment of the ability “to save another life” through donation also motivates some families to donate.

Although most existing studies have small sample sizes, their findings suggest that factors affecting families’ decisions regarding pediatric organ donation mirror those for adult patients. In contrast, health professionals working in this area maintain that pediatric and adult decision-makers differ in significant ways. To the best of our knowledge, no study to date has compared the authorization decisions of families of adult and pediatric patients. Using a large national sample, the present study explored similarities and differences in the request process, experiences, and authorization outcomes between family members approached about the donation of solid organs from adult and pediatric patients.

**METHODS**

**Overview**

Data were collected on consecutive requests for organ donation from January 2009 through March 2012 from 9 empanelled OPOs across the United States, including 1 in the Mid-Atlantic region and 2 each from the following areas: Northeast, Midwest, South, and Southwest. Family decision-makers (FDMs) of adult and pediatric patients were recruited by using a well-validated and accepted protocol. Recruitment packets describing the research were mailed to FDMs 2 months after the organ donation request for adult patients and 3 months for pediatric patients. An opt-out postcard included in each packet allowed for easy refusal. If the postcard was not returned within 2 weeks, FDMs were contacted by telephone to invite participation in the study. Of the 2232 contacted, 1601 (71.8%) FDMs agreed to the interview: 1369 (85.5%) were FDMs of adult patients, and 232 (14.5%) were FDMs of pediatric patients.

**Methods and Measures**

Data pertaining to FDMs were collected via semi-structured telephone interviews previously validated with this population. The interview collected sociodemographic data, relationship to the patient, and perceptions of the quality and content of the donation discussion. The initial response to the donation request was assessed by whether the FDM was surprised to have donation brought up (yes/no) and whether the FDM was originally favorable, unfavorable, or undecided toward donation. The reasoning behind FDMs’ initial attitudes toward donation and for the final donation decision was collected by using 2 separate open-ended questions.

The quality and content of communication occurring during the request were assessed by evaluating 2 distinct sets of skills: request-related and interpersonal. FDMs were asked to report on the requesters’ use (yes/no) of 28 specific request-related skills, such as expressing condolences and treating the FDM in a compassionate and caring manner. Requesters’ engagement in 24 interpersonal skills, including listening carefully to what the FDM had to say and summarizing to check for understanding, was evaluated on 5-point Likert scales (1 = never to 5 = always). The items of both request-related and interpersonal skills were positively correlated and exhibited high internal consistency reliability (Cronbach’s $\alpha = 0.93$ and 0.89, respectively). Composite scores for both constructs were created, with higher values reflecting requesters’ use of an increasing number of skills (range: 0–28) and more frequent behavioral engagement (range: 24–120). The content of the donation discussion was also assessed by using a series of dichotomous questions generated from the authors’ previous research ascertaining whether any of 17 donation-related topics were discussed (yes/no). For each
item, a follow-up question gauged whether the specific topic was of concern (or would have been of concern) to families while considering donation (yes/no).

A series of questions measured FDMs’ perceptions of the request process and comfort with the final donation decision. Two 7-point Likert-type items assessed the level of pressure felt regarding organ donation and satisfaction with the request process (1 = not at all to 7 = very much). Comfort with the donation decision was also assessed along the same 7-point Likert-type scale.

Respondents’ regret of the final donation decision was gauged in a single question asking whether the FDM would repeat the same decision made at the time of interview (yes/no). We assessed FDMs’ receipt (yes/no) and perceptions of grief support information and materials provided by OPO requesters (helpful/not helpful). A final question asked which coping aids would be most helpful in dealing with the patient’s death (eg, support groups, grief literature, literature for children, workshops on loss and healing).

The main outcome variable was the final donation decision (authorized/refused), which was collected in the FDM interviews and cross-verified by using OPO data. We posited that the type of patient (adult versus pediatric) would predict the donation decision, with the families of pediatric patients being more likely to authorize donation.

Analytic Plan

Descriptive statistics are reported to characterize the adult and pediatric samples. Dichotomous and categorical variables were analyzed by using contingency tables and the \( \chi^2 \) or Fisher’s exact test statistic, as appropriate. Independent-sample \( t \) tests were used to compare the means of adult and pediatric FDM responses to continuously measured variables. To assess the potential impact of the requester on the outcomes of interest, comparisons of patient status (adult/pediatric; \( P = .47 \)) and the final donation decision (donated/did not donate; \( P = .50 \)) were performed by requester; further details are not provided because no statistically significant differences were found. Finally, a logistic regression analysis was conducted regressing patient type (pediatric/adult), the number of topics discussed, and the number of communication behaviors and techniques requesters used during conversations about organ donation, as well as FDM satisfaction with the amount of time spent discussing donation, on FDM authorization (authorized/refused donation). All analyses were completed using SPSS version 22.0 (IBM SPSS Statistics, IBM Corporation, Armonk, NY).

RESULTS

Sample Characteristics

FDMs had a mean ± SD age of 47.4 ± 14.5 years. Most FDMs were female (69.0%), white (70.5%), married (72.4%), and Christian (94.4%). These characteristics are representative of the FDM population reported in earlier studies.9,13,21 A comparison of adult versus pediatric patients found significant sociodemographic differences. Compared with FDMs of adult patients, pediatric patient FDMs were, as would be expected, younger (41.1 vs 48.5 mean years; \( P < .001 \)) and a higher percentage were divorced or separated (19.9% vs 12.8%) or never married (17.3% vs 13.1%) (Table 1). The mean age of adult and pediatric patients was 49.0 and 14.0 years, respectively.

Donation-Related Attitudes

Overall, 84.1% of the sample authorized donation. FDMs of pediatric patients were significantly more likely to authorize donation than were FDMs of adult patients (89.7% vs 83.2%; \( \chi^2 = 6.2, P = .01 \)). (Table 1). Families of pediatric patients were also more likely to report a willingness to donate their own organs posthumously (90.5% vs 82.6%; \( \chi^2 = 9.8, P = .01 \)) and to raise the topic of donation (19.4% vs 13.6%; \( \chi^2 = 5.4, P = .02 \)) compared with FDMs of adults. However, no differences were found between pediatric and adult patient families and their surprise at having the topic of donation discussed (\( P = .51 \)) or their initial reaction to the organ donation request (\( P = .54 \)).

Differences were found in families’ rationale behind their initial feelings toward donation and the final donation decision (Table 2). Knowledge of the patient’s donation wishes accounted for more favorable initial reactions from FDMs of adult patients (31.0% vs 18.9%; \( \chi^2 = 9.8, P < .01 \)). Similarly, more FDMs of adult patients were initially unfavorable toward donation because they were unsure of the patient’s wishes (21.7% vs 2.4%; \( \chi^2 = 8.8, P = .003 \)).

Adult patient FDMs were more likely to cite a lack of relevant information about donation as a reason for feeling initially unsure about donation (23.8% vs 12.4%; \( \chi^2 = 3.992, P = .046 \)). Reasons behind families’ final donation decisions also differed based on patient age. A higher percentage of pediatric patient FDMs reported authorizing donation to help give meaning to the death (16.3% vs 11.4%; \( \chi^2 = 4.0, P = .05 \)) and to keep the patient alive in others (25.0% vs 14.3%; \( \chi^2 = 4.0, P < .01 \)). Of those refusing donation, pediatric patient families were more likely to express a desire to bury the patient whole (33.3% vs 8.3%; Fisher’s exact test, \( P < .01 \)). FDMs of adult patients were more likely to authorize donation to honor the patient’s wishes (44.8% vs 21.2%; \( \chi^2 = 40.5, P < .01 \)).

Content and Quality of the Donation Discussion

Significant differences were observed in the donation-related topics
requesters discussed with FDMs of pediatric and adult patients (Table 3). Specifically, discussion of the cost of donation (71.1% vs 64.3%; $^2 = 4.1, P = .04), ability to choose which organs to donate (78.4% vs 72.0%; $^2 = 4.2, P = .04), distribution of the donated organs (82.8% vs 73.0%; $^2 = 10.0, P < .01), and treatment of the patient's body during organ recovery (73.3% vs 66.5%; $^2 = 4.1, P = .04) were significantly more likely with FDMs of pediatric patients compared to adult patients. Requesters also displayed a greater frequency of request-related skills during discussions with families of children (25.7 vs 24.9 mean number of skills; $t = 2.7, P < .01$) (Table 4). Specifically, compared with adult patient FDMs, pediatric patient FDMs were more likely to report that the requester expressed condolences (99.1% vs 96.3%; $^2 = 4.9, P = .03$), made eye contact (96.1% vs 91.6%; $^2 = 5.7, P = .02$), explored and acknowledged individual concerns and worries about donation (87.9% vs 80.7%; $^2 = 6.9, P = .01$), ensured an understanding of the donation process (93.1% vs 87.9%; $^2 = 5.3, P = .02$), and clearly stated the next steps of the process (92.7% vs 84.7%; $^2 = 10.3, P < .01$). In addition, pediatric patient FDMs reported that requesters exhibited a greater number of interpersonal skills (110.4 vs 108.7; $t = 2.0, P = .05$), including listening carefully to what the family had to say (4.9 vs 4.8; $t = 2.5, P = .02$), treating the family in a friendly and courteous manner (4.9 vs 4.8; $t = 2.5, P = .01$), checking the FDM's understanding (4.3 vs 4.1; $t = 2.9, P = .01$), offering additional assistance (4.0 vs 3.8; $t = 2.3, P = .02$), exploring the source of expressed emotions (3.8 vs 3.5; $t = 2.4, P = .02$), and expressing empathy and support (4.8 vs 4.6; $t = 2.7, P = .01$) compared with FDMs of adult patients.

Perceptions of the Request and Final Donation Decision

No statistically significant differences were found in FDMs' feelings of pressure or harassment about organ donation, satisfaction with the request process, or comfort with the final donation decision (Table 2). Although a larger proportion of FDMs of adult patients reported regret about the final decision (7.4% vs 6.0%), the difference was not statistically significant. Comparable numbers of FDMs consenting and refusing donation expressed regret over the final decision: FDMs of adults, 47 versus 54; and FDMs of children, 7 versus 7.

Grief Support

FDMs of pediatric patients were more likely to report receipt of grief information (eg, books, pamphlets, videos, Web sites) (87.1% vs 77.4%; $^2 = 11.0, P < .01$). Most FDMs of both pediatric and adult patients found that the grief support information was helpful (61.0% vs 68.5%; $^2 = 4.8, P = .03$). When asked which coping aids would be most helpful in dealing with their grief, more FDMs of children endorsed support groups (35.3% vs 28.7%; $^2 = 4.2, P = .04$).

Predictors of Authorization

The results of the logistic regression analysis assessing whether patient type (adult or pediatric) was independently associated with the
donation decision are presented in Table 5. Patient type did not predict FDM authorization ($P = .13$) when controlling for communication factors. However, the odds of FDM authorization increased by 29% and 11% for each additional donation-related topic discussed (odds ratio: 1.3) and communication technique used by requesters during donation discussions (odds ratio: 1.1), respectively.

**DISCUSSION**

The need for pediatric donors is acute. Although it is commonly assumed that families of pediatric patients, compared with FDMs of adult patients, are more likely to refuse donation in an effort to “protect [the child] at all times” and belief that the child has been through enough, the results of the present study suggest that FDMs of children are more likely to donate (89.7% vs 83.2%). However, a closer look at the data suggests that the differences may lie in the differential communication practices of providers when dealing with the families of pediatric patients versus adult patients. The results of the logistic regression analysis revealed no independent relationship between pediatric status and FDM authorization. The content and quality of communication occurring during requests for donation emerged, rather, as significant predictors of family authorization. FDMs of pediatric patients reported higher frequencies of both request-related and interpersonal communication skills among requesters, and more donation-related and grief support information during requests. These behaviors may reflect the special attention and extra care that is provided to families facing the death of a child as well as providers’ beliefs that requests for pediatric donation are more likely to be met with refusals. Nonetheless, the findings support the paramount importance of the quality of the interaction between FDMs and requesters. Evidence of the provision of more intensive care and communication for pediatric cases can be found in other areas of health care. Multiple studies report more positive ratings of patient-provider communication and interaction for pediatric cases compared with adult cases.

The greater rate of organ donation discussions and sense of care observed with families of pediatric patients may stem from perceptions that the loss of a child is a more traumatic experience requiring more and better support than the loss of an adult family member. As such, the increased likelihood of family authorization to pediatric organ donation over adult organ donation in the United States may be partially due to providers assuming a greater role of beneficence and advocacy for parents and families of children and paying greater attention to the interests and values of the child’s caregivers.

The requesters’ approach to the provision of grief support materials supports this interpretation. Although most families interviewed found that the grief materials were helpful, families of pediatric patients were more likely to report receipt of grief materials than were families of adult patients. Moreover, although all families of nondonor children reported receiving grief materials, only two-thirds of FDMs of adult nondonors reported the same. Efforts to provide all families with

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**TABLE 3** Topics Discussed With Requester

<table>
<thead>
<tr>
<th>Topics Discussed</th>
<th>Donor Status Count (%)</th>
<th>Adult Mean (SD)</th>
<th>Pediatric Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of donation*</td>
<td>880 (64.3)</td>
<td>165 (71.1)</td>
<td></td>
</tr>
<tr>
<td>Patient’s donation wishes**</td>
<td>998 (72.9)</td>
<td>120 (51.7)</td>
<td></td>
</tr>
<tr>
<td>Ability to choose which organs to donate*</td>
<td>986 (72.0)</td>
<td>182 (78.4)</td>
<td></td>
</tr>
<tr>
<td>Treatment of patient’s body*</td>
<td>991 (66.5)</td>
<td>170 (75.3)</td>
<td></td>
</tr>
<tr>
<td>Distribution of donated organs*</td>
<td>990 (73.0)</td>
<td>192 (82.8)</td>
<td></td>
</tr>
</tbody>
</table>

*P < .05; **P < .01; ***P = .001.

**TABLE 4** Requesters’ Communication Techniques and Competence During Discussions With Adult and Pediatric FDMs

<table>
<thead>
<tr>
<th>Variable</th>
<th>FDM Count (%)</th>
<th>Adult Mean (SD)</th>
<th>Pediatric Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Request-related skills, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressed condolences*</td>
<td></td>
<td>1319 (96.3)</td>
<td>230 (98.1)</td>
</tr>
<tr>
<td>Addressed individual concerns and worries**</td>
<td></td>
<td>1105 (80.7)</td>
<td>204 (87.9)</td>
</tr>
<tr>
<td>Made sure the FDM understood the donation process*</td>
<td></td>
<td>1204 (87.9)</td>
<td>216 (93.1)</td>
</tr>
<tr>
<td>Made eye contact*</td>
<td></td>
<td>1254 (91.6)</td>
<td>223 (96.1)</td>
</tr>
<tr>
<td>Clearly stated the next steps of the donation process*</td>
<td></td>
<td>1160 (84.7)</td>
<td>215 (92.7)</td>
</tr>
<tr>
<td>Interpersonal skills, mean ± SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often did the requester listen carefully to what you had to say?*</td>
<td></td>
<td>4.78 ± 0.7</td>
<td>4.87 ± 0.5</td>
</tr>
<tr>
<td>How often did the requester have a negative attitude toward you?**</td>
<td></td>
<td>1.09 ± 0.5</td>
<td>1.05 ± 0.3</td>
</tr>
<tr>
<td>How often did the requester treat you in a friendly and courteous manner?***</td>
<td></td>
<td>4.84 ± 0.6</td>
<td>4.91 ± 0.4</td>
</tr>
<tr>
<td>How often did the requester summarize to check his or her understanding?****</td>
<td></td>
<td>4.09 ± 1.3</td>
<td>4.32 ± 1.1</td>
</tr>
<tr>
<td>How often did the requester offer to provide additional assistance?*****</td>
<td></td>
<td>3.77 ± 1.6</td>
<td>4.02 ± 1.4</td>
</tr>
<tr>
<td>How often did the requester explore the source of the emotion?******</td>
<td></td>
<td>3.47 ± 1.6</td>
<td>3.76 ± 1.6</td>
</tr>
<tr>
<td>How often did the requester express empathy and support?*******</td>
<td></td>
<td>4.62 ± 0.8</td>
<td>4.75 ± 0.7</td>
</tr>
<tr>
<td>How often did the requester check your understanding of the information he or she provided?********</td>
<td></td>
<td>4.22 ± 1.1</td>
<td>4.45 ± 0.9</td>
</tr>
</tbody>
</table>

*P < .05; **P < .01; ***P = .001.
information to help cope with the loss of a family member; adult or pediatric, may serve to engender trust in and increase public support of organ donation. In addition, family support is a highly valued component of the family approach for organ donation and, as this study found, supportive, caring communication is critical to securing family authorization. Therefore, request staff and health care providers must be trained to approach families of adult patients about the option of organ donation with the same sensitivity as they clearly show families of children. Indeed, the recommendations proposed by Bellali et al32 for pediatric organ donation, outlining the communication needed through all phases leading up to and after the request for donation, are appropriate for use with all potential donor families, including those of adult patients, and offer a starting place for future training efforts.

These results, however, also caution against a paternalistic attitude toward requesting organ donation from families of donor-eligible children. Specifically, FDMs of pediatric patients in this sample report levels of satisfaction with the request process and comfort with the donation decision on par with those reported by FDMs of adult patients. Moreover, fewer FDMs of children regretted the decision to donate. In retrospect, approximately one-half of FDMs authorizing donation wished they had not; the remainder refused to donate and later wished they had opted in favor of donation. Thus, few families of either adults or children appear to suffer psychological harm by being presented the option of donation. In fact, assuming too protective a stance with FDMs of children withholds the opportunity to help or save the life of another child through transplantation and any consolation this knowledge might bring.

Although the present study is the largest examination of pediatric organ donation to date and the first to compare the experiences of families considering adult and pediatric donation, several limitations constrain the generalizability of these findings. First, the sample overall was fairly homogeneous, consisting primarily of female, white, married, and Christian participants. Although representative of the entire US donor population, we were unable to examine the influences of sociodemographic differences. In addition, the donation rates, although significantly different between pediatric and adult cases, were relatively high among all groups. This finding results in a decreased sensitivity to detect factors predicting donation and a small subgroup of nondonors to be analyzed, particularly in terms of pediatric cases.

### CONCLUSIONS

As demonstrated by the present research, communication that achieves the dual goals of informing families faced with the option of organ donation (whether pediatric or adult) of the importance of and the need for donated organs and the key donation-related issues required for informed decision-making, and developing supportive trusting relationships with those families, increases the likelihood of authorization. Although we recognize the anguish caused by the loss of a child, families of adult patients often experience a similar magnitude of grief. Showing these families the same attention, tenderness of care, and compassionate communication may bring the rates of family authorization for adult organ donation closer to those observed for deceased children. Finally, although understandable, the protective stance taken toward families of pediatric patients may have the unintended consequence of refusing families the opportunity to help another child in need, reducing other families’ grief, and finding solace in the knowledge that the child’s death was not without meaning. A more positive and proactive approach is needed with these families to help ameliorate the shortage of transplantable pediatric organs.

### ABBREVIATIONS

FDM: family decision-maker
OPO: organ procurement organization

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**Potential Conflict of Interest:** The authors have indicated they have no potential conflicts of interest to disclose.

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**TABLE 5 Results of Logistic Regression on Donation Decision**

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric donor</td>
<td>1.519</td>
<td>0.889–2.595</td>
<td>.126</td>
</tr>
<tr>
<td>No. of topics discussed</td>
<td>1.289</td>
<td>1.229–1.352</td>
<td>.000*</td>
</tr>
<tr>
<td>No. of domain-specific techniques used</td>
<td>1.110</td>
<td>1.049–1.173</td>
<td>.000*</td>
</tr>
<tr>
<td>Average frequency of communication behaviors</td>
<td>1.539</td>
<td>0.962–2.462</td>
<td>.072</td>
</tr>
<tr>
<td>Satisfaction with amount of time spent discussing donation</td>
<td>1.008</td>
<td>0.885–1.149</td>
<td>.903</td>
</tr>
</tbody>
</table>

*Denotes significance at α = 0.05.
REFERENCES


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