

# Interaction of organ donor families and recipients

An exploratory descriptive study of donor families and recipients of cadaveric organs was done to determine their feelings about direct contact with each other. Direct contact was desired by 70% of donor families and 75% of recipients. Donor families wanted to see firsthand the benefit of the transplant to another person. Recipients primarily wanted to express gratitude. Both groups think they have a right to meet. Although both think these interactions should be professionally regulated and facilitated, they do not think the transplant center or the organ procurement organization is responsible for the outcome of a meeting. Donor families and recipients think the process should be gradual with prior correspondence. On the basis of our findings, we have developed a list of suggested guidelines to use when facilitating an interaction. (*Journal of Transplant Coordination*, 1996;6:191-195)

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**D**irect interaction between organ donor families and transplant recipients is a subject that evokes an emotional response from transplant professionals. Historically, transplant programs and organ procurement organizations (OPOs) have prohibited contact between recipients and donor family members, primarily under the guise of patient confidentiality. Transplant professionals, as the result of personal or secondhand anecdotal stories, were concerned that either the family members or the recipients might pressure the other in some inappropriate or unethical manner.

A review of the literature yielded little, if any, relevant data. A 1971 paper<sup>1</sup> reported that two donor families each met their respective heart transplant recipients, at mutual request, and the meetings appeared to be meaningful for all parties. A more recent study<sup>2</sup> on interaction between bone marrow recipients and their donors showed that donors want information about recipients' outcomes, whether or not the recipient has died. Using a less scientific format, several television talk shows have recently shown donor families and recipients meeting with what appears to be a beneficial outcome. Because this subject is becoming more prominent in both the public and transplant communities, requests for direct contact are increasing. We think that decisions about such contact should be based on research, rather than hearsay or speculation.

The purpose of our study was to determine the

feelings of donor families and recipients about direct contact, which can include telephone or personal interaction or both. We explored each group's perception of the role transplant professionals should play in direct interaction. In addition, we addressed some logistical issues, including when and where to meet, and who should initiate contact.

## Methods

We used an exploratory descriptive design because no previous studies have been published on this topic. The participants included persons who had received cadaveric transplants and family members who had donated organs from their brain-dead next of kin within the service area of the Organ and Tissue Acquisition Center of Southern California. Data were collected through a survey questionnaire we designed. The questionnaire was reviewed for content validity by a panel of experts that included procurement coordinators, members of donor families, and transplant recipients. It was mailed to 367 donor families and 898 recipients along with a cover letter that explained the purpose of the study and assured anonymity and a self-addressed stamped envelope for returning the completed form. The required five types of answers: yes/no, multiple choice, rank order, Likert-type scale, and open-ended. Similar questionnaires were mailed to donor families and recipients, and both versions contained questions about contact between donor families and recipients; opinions on timing, place, and

regulation of meeting; ownership of the organs after transplantation; and demographic information. Responses to the questionnaire were described in frequency distributions and through content analysis.

## Results

Of 367 surveys mailed to donor families, 95 were returned, a response rate of 26%. In the recipient population, 248 of 898 surveys were returned, a 28% response rate. Fifty percent of donor families and 41% of recipients had donated or had received organs, respectively, within the preceding 2 years. Table 1 gives the remaining demographics of each group.

Desire for direct contact with their counterparts was reported by 70% of donor families and 75% of recipients; meeting in person was desired by 65% of donor families and 69% of recipients. An interest in telephone communication was reported by 60% of both groups.

### Donor Families

Respondents were asked to list in order the reasons why they would or would not like to meet. For

the majority of donor families (61%), the primary reason was to see firsthand the benefit of the transplant to another person. For 29%, the primary reason was to connect with a part of their loved one through the recipient. For 100%, receiving compensation was the least motivating reason to meet the recipients. Some respondents noted that they considered that option offensive, and others deleted the option from the survey altogether. When donor families were asked why they would not like to meet the recipients, the two primary reasons were as follows: "The identity of the recipient is unimportant to me" (48%) and "Do not want to relive a painful part of my life" (39%).

### Recipients

Recipients overwhelmingly (93%) reported that being able to say thank you was their primary reason for wanting contact. Curiosity to find out as much as possible about the donor was a distant second (4%). Recipients reported three main reasons why they did not desire contact with donor families: Some recipients (37%) felt uncomfortable about being alive while the donor families' loved one was dead. Others (36%) did not want to have contact because they thought they would make the donor family relive painful memories. Thirteen percent feared that the donor family might want some involvement in the recipient's life. Older recipients reported a degree of uneasiness about their age, especially when the donor was younger.

### Logistics of Direct Contact

The survey addressed some logistical considerations of direct interaction such as when and where to meet. The length of time after donation or transplantation was not a factor in determining when to meet for 39% of donor families and 36% of recipients. Whereas 27% of donor families and 32% of recipients thought 1 year after donation or transplantation was an appropriate time, the remainder of each group thought periods less than 1 year were appropriate. Both groups were asked, "Who should initiate contact?" In response, 58% of donor families and 56% of recipients did not think it mattered. Interestingly, 40% of donor families thought the recipient should initiate contact, whereas 32% of recipients thought the donor's family should initiate contact. When asked where a meeting should take place, 76% of donor families and 83% of recipients thought a location other than the home of either of the two parties was preferable (Figure 1). Using the OPO or hospital cafeteria as a meeting location may be a difficult choice for the donor family, who may not have been to a hospital since the death of their loved one.

Respondents were asked, "If a meeting takes place, should there be a facilitator present?" Of donor

Table 1 Demographics of respondents to a survey on meetings between organ donor families and transplant recipients

Characteristic	Donor families		Recipients	
	n	%	n	%
Sex				
Female	64	67	124	50
Male	31	33	124	50
Age (years)				
19-30	4	5	19	8
31-40	18	21	33	14
41-50	25	29	56	24
51-60	22	26	63	27
61-77	17	20	59	26
Race				
White	68	80	182	83
Hispanic	8	9	20	9
Black	5	6	9	4
Asian	4	5	9	4
Time since donation or transplantation (years)				
< 1	26	28	42	17
1-2	20	22	58	24
2-3	18	19	45	18
3-4	20	22	31	13
4-5	7	8	22	9
> 5	2	2	46	19

Percentages may not add up to 100% because of rounding. Other numbers may not add up to 95 (donor families) or 248 (recipient families) because some recipients did not answer every question.

families, 44% thought a facilitator should be present, 44% were impartial to a facilitator's presence, and 12% were opposed. Recipients were more inclined to want a facilitator (51%); 35% did not think the presence of a facilitator mattered, and only 14% thought a facilitator should not be present.

Of those surveyed, only 5% of donor families and 3% of recipients had had direct interaction. Although direct contact was rare, a considerable amount of information about the other party had been obtained through alternative sources (Figure 2). Exchange of written correspondence has had more acceptance than direct contact among transplantation professionals. Of donor families, 10% reported sending a letter or card to the recipient, and 33% acknowledged receiving correspondence. These data support the recipient's responses: 38% had sent correspondence to their donor's family, and 5% acknowledged receiving correspondence.

Some transplant professionals have thought that issues of ownership might be a concern during direct interaction between donor families and recipients. The overwhelming response from both donor families (90%) and recipients (85%) was that after donation or transplantation, the organ belongs to the recipient. Only 3% of donor families and 7% of recipients thought that the organ belonged to the donor. Seven percent of donor families and 8% of recipients thought it belonged to neither donor nor recipient.

The final seven questions of the study required Likert-type scale responses (Table 2) that explored the participant's feelings about the meeting process. Donor families and recipients shared some opinions. Both groups agreed that the meeting process should be gradual with prior correspondence. Both donor families (60%) and recipients (59%) agreed that transplant professionals should regulate meetings. More than 50% of both groups think they should

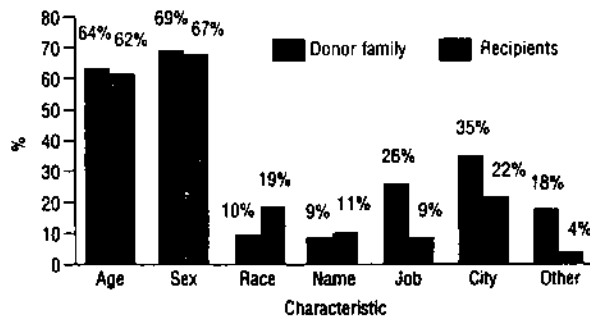


Figure 2 Information organ donor families and transplant recipients know about one another before meeting

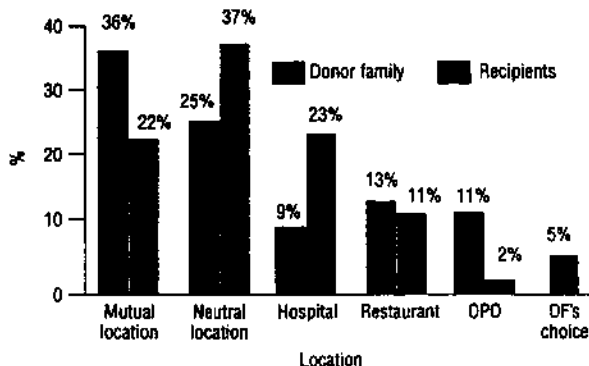
receive some counseling before they meet. Both donor families (93%) and recipients (89%) think that neither the transplant center nor the OPO is responsible for the outcome of a meeting.

**Discussion**

Our results overwhelmingly show that donor families and recipients would like to have direct contact. Given the desire of the donor families to see the benefits of transplantation first-hand and the recipients' desire to express thanks, it is not surprising that both groups preferred a personal meeting to a telephone conversation. Donor families and recipients not only desire contact, they think they have a right to meet even if their transplant professional advises against it. A clear message from both parties is that they do not think that transplant professionals should be able to prohibit contact. Paradoxically, the majority of both parties think that transplant professionals should, in some way, facilitate and regulate meetings. Both groups are in favor of a gradual process that includes correspondence and some counseling before the meeting. Donor families and recipients gave similar responses to questions about when such a meeting should take place and about to whom the organs belong after transplantation.

Not all of the responses were similar. An ironic finding is that although more than half of the respondents in both groups thought that it did not matter who initiated contact, those who did express an opinion overwhelmingly thought the other party should initiate contact. The reluctance to initiate contact may account for the discrepancy seen in correspondence rates. Virtually all recipients reported that being able to express thanks was their primary motivation for direct interaction. Yet, slightly more than one third of the recipients had sent some form of correspondence to their donor's family.

Future research should include outcomes of actual meetings, transplant professionals' attitudes toward interaction, and a duplication of this study with different participants. The large discrepancy in attitudes



OPO, Organ procurement organization; DF, donor family

Figure 1 Places for meetings between organ donor families and transplant recipients.

about initiation of contact is also an area that merits more research. Lives being saved by complete strangers is a phenomenon unique to transplantation. A donor's family and the recipient or recipients are strangers to each other, creating a situation in which the transplant professional has both the ability and the responsibility to regulate the amount of information and contact between the two groups. In light of this responsibility, we suggest the following guidelines, which can be used by transplant professionals when facilitating interaction.

### Suggested Guidelines

At our OPO, direct interaction begins with anonymous correspondence. At the time of donation, the donor's family receives a packet of materials that includes a brochure titled *Writing to Transplant Recipients*, which provides guidelines and explains the initial need for anonymity. Our local clinical coordinators and social workers are provided similar brochures titled *Writing to Donor Families* for distribution to their patients. The OPO and transplant programs act as a conduit for any correspondence received. The local transplant professionals do not normally edit correspondence, but they may contact a letter's author or intended recipient and explain their concerns about the appropriateness of the letter. This contact gives the author the option to rewrite the letter or the letter's recipient the option to receive the letter

as is. If both parties express an interest to meet during their correspondence, the responsible OPO coordinator will consult with his or her clinical counterpart to facilitate a meeting according to the following guidelines:

- Both parties must express interest in meeting and must sign a waiver authorizing the OPO or transplant program to release names and telephone numbers to the other party.
- Both parties should have corresponded and exchanged generalities such as age, gender, and cause of death of the donor before the meeting. Similarly, the age, gender, and disease of the recipient must be known.
- Both parties, during a mandatory telephone call with the facilitator, should discuss their expectations of direct interaction. The needs of both parties may be satisfied by a single meeting, though some choose to stay in contact over an extended period.
- The timing of the meeting is often determined by the need for prior correspondence. Grief, recuperation, and the logistics of exchanging several letters can take up to 6 months; thus, direct contact is a gradual process.
- Both parties should agree on the location of the meeting, and the residence of either party should be avoided.
- A facilitator is recommended for the meeting to help break the ice and provide a safety net, of sorts, to

Table 2 Likert-type scale responses to statements about meetings between organ donor families and transplant recipients

Statement	Respondent	Response (%)				
		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Meeting should take place gradually with prior correspondence	Donor family	21	52	17	10	0
	Recipient	15	43	32	7	3
Donor families and recipients should receive counseling prior to meeting	Donor family	18	33	38	8	3
	Recipient	18	43	25	11	3
Donor families and recipients have a right to meet even if transplant professionals advise against it	Donor family	28	29	23	11	10
	Recipient	19	30	20	19	12
Transplant professionals should regulate meetings between donor families and recipients	Donor family	23	37	25	10	5
	Recipient	24	35	22	10	9
Donor families have a right to meet the recipients	Donor family	21	19	23	20	16
	Recipient	14	29	23	22	12
Recipients are obligated to meet their donor's family	Donor family	4	4	23	43	26
	Recipient	7	23	20	36	14
The transplant center and organ procurement organization are not responsible for the outcome of a meeting	Donor family	47	46	3	2	1
	Recipient	37	52	9	1	1

both parties. Facilitators are not required to stay for the entire meeting, but they should be available.

### Conclusions

Requests from donor families and recipients for direct interaction will continue to increase. We hope that objective evaluation, and not a knee-jerk response, will guide the decision-making process. Direct interaction enables donor families to see first-hand the benefit of their donation and provides recipients the opportunity to express gratitude. We think that meeting the needs of donor families will have a beneficial effect on their experience, making them even stronger advocates of donation and transplantation. Once both parties have agreed to meet, donor families and recipients agree that the transplant center and OPO are not responsible for the outcome of a meeting. The key point in this process is the need for

mutual interest. Our opinion and the informal policy of our OPO can best be summarized in the eloquent words of an anonymous respondent, "If both parties are willing to meet, I just don't see any bad outcome except not to meet at all."

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