Almost all the literature on soliciting organs for donation cites the ever-expanding gap between supply and demand. Currently, 16 patients per day die while awaiting an organ for transplantation.1 Because this gloomy trend most likely will only get worse, and because the federal government is becoming more involved in efforts to reverse it, organ procurement organizations (OPOs) have become strident in their efforts to alter the only significant factor they can affect: the consent of families of possible organ donors.

Early research on organ donation described attitudes of health-care professionals2-5 and the public at large6-8 and issues associated with the ethics of the industry.9,10 The investigation of attitudes of organ donors’ families came later11,12 but excluded information on the attitudes of families that did not consent to donation.

Much is known today about persons who consent to organ donation; however, the problem of why some persons do not consent is less understood. In 1995, at the inception of the study described here, nonconsenting (ie, nondonor) families were the subjects in only 2 reports.13,14 Dominquez-Roldan et al13 correlated religious or cultural beliefs and social attitudes with refusal to grant consent. Doubts about the exact moment of death and the need for the body to remain whole according to the family’s cultural or religious tradition were issues of concern for nondonor families. Pearson et al14 concluded that the most important predictors of consent were whether a discussion about donation had taken place before the person was asked to consent to donation of a family member’s organ and whether at least one of the deciding family members was willing to donate his or her own organs.

In addition to a lack of information about nondonor families, no instruments have been developed to assess families’ attitudes and beliefs about deciding whether to consent to organ donation. Reliable and valid instruments are necessary to survey large samples and generalize findings. Findings from large groups can help determine differences between donor and nondonor families and perhaps reveal if healthcare providers can somehow influence more families to agree to organ donation.

Primarily because of the dearth of understanding in the organ recovery industry of why families refuse to donate the organs of a deceased family member 40% to 50% of the time, we decided to do this study. The purpose of the study was to develop a tool to examine families’ attitudes and beliefs and to determine the predictive value of different factors in families’ decisions to donate or not donate the organs of their deceased family member.

METHODS
Survey Instrument

For the purposes of the study, a new instrument was developed by the research team to compare the attitudes of donor and nondonor families to the families’ decision to donate or not donate the organs of a deceased family member. Development of the 40 Likert-scaled items and 3 open-ended questions was based on content gathered from initial interviews with 4 nondonor families, the available literature, and the experiences of staff from the OPO. In order to test usability,
timing, and readability, a pilot test of the survey instrument was done with donor and nondonor families and with OPO staff members. Revisions to the survey were grammatical and not content related.

The revised tool was mailed to 545 donor and 201 nondonor families. Among the donor families, 300 (55%) returned the survey, whereas only 39 (19%) of the nondonor families did. Data gathered from these subjects were used to apply factor analysis to the items of the tool to establish the construct validity of the instrument. Factor analysis is a method for identifying clusters of related variables within an instrument. Each cluster or factor consists of items from the instrument that share similar qualities or attributes. When the clusters confirm proposed shared attributes (determined during development of the instrument), evidence of construct validity is provided.15

The reliability of the instrument was assessed by using the Cronbach \( \alpha \) for internal consistency. Internal consistency is a form of reliability that indicates the degree of homogeneity or likeness among the items in the same cluster or factor. Values range from 0 to 1, and higher Cronbach \( \alpha \) values indicate that items within a cluster are similar (internally consistent). In general, an \( \alpha \) greater than or equal to .70 is acceptable for a new instrument.16

The initial instrument consisted of 40 items rated on a 6-response Likert scale (strongly disagree to strongly agree). The factor analysis established the following 5 factors: trust and care, religious beliefs, decision doubts and conflicts, transplant beliefs, and pain and mutilation (Table 1). Three individual items did not cluster with the factors but did differ between the donor and nondonor groups and were included in the analysis. On the basis of the results of the factor analysis, the final tool consisted of 5 factors (31 items) and 3 individual items that did not load on any of the factors.

Factor 1 (trust and care) consisted of 12 items that involved being kept informed of the kin’s condition, trusting that the families were being told the truth, and being given enough time and information to make a decision. Factor 2 (religious beliefs) included 4 items referring to the families’ own and their kin’s religious beliefs about organ donation and the effect of donation on the afterlife. Factor 3 (decision doubts and conflicts) consisted of 11 items that referred to being conflicted about the finality of brain death, conflicts due to the input of family members, and the possibility for changing one’s mind about organ donation. Factor 4 (transplant beliefs) consisted of 2 items related to beliefs that organ transplantation was successful and worthwhile. Factor 5 (pain and mutilation) consisted of 2 items about the belief that the process of donating organs would result in pain and mutilation for the deceased.

Items 30, 31, and 32 stood alone and did not load on any factor. These items were “My decision was affected by what the deceased wanted” (item 30), “My decision was affected by the belief that the deceased would live on in someone else” (item 31), and “The cost of organ donation and who pays for it affected my decision” (item 32).

At the end of the survey were 3 open-ended questions: “If there was something you could change about your organ donation experience, what would it be?” “What do you believe was the most important factor in your decision?” “If you had to make the decision again, why or why not would you change your mind?” A question about changing one’s decision if faced with the situation again was included to probe a finding of the Partnership for Organ Donation,17 unpublished at the time, that one third of non-donors indicated that they would change their minds if given the opportunity.

Table 1 Descriptions of the factors in the survey instrument

<table>
<thead>
<tr>
<th>Factor</th>
<th>No. of items</th>
<th>Concept</th>
<th>( \alpha ) Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>12</td>
<td>Trust and caring</td>
<td>.87</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>Religious beliefs</td>
<td>.73</td>
</tr>
<tr>
<td>3</td>
<td>11</td>
<td>Decision doubts and conflicts</td>
<td>.74</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>Transplant beliefs</td>
<td>.80</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>Pain and mutilation</td>
<td>.64</td>
</tr>
</tbody>
</table>
Statistical Analysis

In addition to descriptive statistics, the data were analyzed by using multivariate analysis of variance, $\chi^2$ tests, and $t$ tests to compare the donor and nondonor groups across the demographic background, the 5 factors, and the 3 stand-alone items. A stepwise discriminant function analysis was done to determine the most predictive variables from the 5 factors and the 3 items that could be used to differentiate the donors from the nondonors. Discriminant analysis is used to make predictions about group membership (donor vs nondonor) by using several independent variables (5 factors and 3 items). Responses to the open-ended questions were examined for content and major themes expressed by the donor and nondonor respondents.

Sample

Approval for the study was obtained from the appropriate institutional review board. All persons who were approached for organ donation by participating OPO members were invited to participate in the study. Study protocol required a minimum of 4 months elapsed time since the death of the prospective subject’s family member before the subject was contacted.

Concomitant with the development of the survey, the research team recruited other OPOs to participate. OPOs in Texas, Arizona, Missouri, Wisconsin, and California agreed to participate, but the level of involvement of each OPO varied. Those in Arizona, Texas, California, and Colorado maintained a strong commitment and provided 96% of the sample. Those in Missouri and Wisconsin provided the remaining 4%.

RESULTS

Characteristics of the Sample

Of the 746 subjects mailed surveys, 339 responded. Among the respondents, 300 were donors and 39 were nondonors. Non-donors were less willing than donors to participate in the study. The rate of response from donor families was satisfactory; however, the voluntary response from nondonor families was very small ($n=20$). In order to increase the size of the nondonor sample, a financial incentive of $25, and eventually $50 was offered to families, resulting in an enrollment of an additional 19 nondonor families. We recognize that this process may have biased the results of the study, but we thought that it was critical to improve the response rate of nondonor families. Not all subjects responded to each question. The percentages in Tables 2 and 3 are based on the actual number of subjects who responded to each question. The percentages in Tables 2 and 3 are based on the actual number of subjects who responded to each question.

The majority of the respondents (79%) were Anglo-American; 11% were Latino, 3.5% were African-American, 3% were Asian, 2% were Native American, and 1.5% did not specify ethnicity (Table 2). The sample was relatively well educated; only 7% had less than a high school education, and 34% had graduated from college or had a college or postgraduate degree. Household income was $26,000/year or greater for 65% of the respondents.

The sample was predominantly female (65%). Among the respondents, 45% described a situation in which the deceased was a son or daughter; 35%, a spouse; and 20%, a parent, grandparent, or sibling. Causes of death included medical problems, 48%; motor vehicle accidents, 32%; and gunshot wounds/suicide, 19% (Table 3).

Demographic and Background Differences

The results of the $\chi^2$ and $t$ tests indicated no differences between the donor and nondonor subjects in the age of the deceased; the age, sex, educational level, income, and relationship of the respondent to the deceased; and ethnicity of the person initiating the subject of organ donation. Donor and nondonor groups differed significantly, however, in the ethnicity and religion of the respondent, the person who initiated the subject of organ donation, the cause of death, the presence of a donor card, and the timing of the request for organ donation (Tables 3 and 4).

The donation rate among all Anglo-Americans who responded to this question was 91%. Similarly, 81% of Latino subjects and 79% of the African-American, Asian-American, and Native American subjects agreed to organ donation. Subjects who indicated a religious affiliation were more likely to donate (Christian, 89%; Mormon,
Jewish, and other religions, 94%) than were subjects who claimed no religious preference or religious affiliation (73% donated).

When donation was mentioned first by a family member, the donation rate was 98%. Being approached for organ donation by a transplant coordinator or a physician also resulted in high donation rates (94% and 92%, respectively). Donation rates were significantly lower when the family was approached by a social worker (85%) or a nurse (77%). Significantly more subjects agreed to donate when donation was first mentioned to them either before (93%) or during (93%) the declaration of brain death than when donation was first mentioned after the family was told that the deceased was brain dead (84%).

When the deceased experienced death as a result of gunshot or suicide, consent for donation was more likely to occur (97%) than when death was due to a motor vehicle accident (89%) or medical causes (84%). Only 30% of all the respondents (n = 89) said that the deceased had a signed donor card. The presence of a donor card was associated with higher donation rates (96%) than was the absence of a donor card (84%).

Finally, the amount of time that elapsed between the time of the illness or injury and the time of being approached about organ donation differed significantly between the donor and nondonor groups. The elapsed time was significantly greater for the nondonors (mean, 52 hours) than for the donors (mean, 32 hours). Interestingly, nondonor families more often reported not having enough time to make the decision about donation.

Differences Between Donors and Nondonors

The 2 groups differed significantly in their responses to the questions in factors 1, 3, 4, and 5 and to items 30 and 31 (Table 5). Although both groups generally agreed, the donor group expressed...
stronger agreement that their decision was influenced by factor 1 (trust and care), factor 4 (transplant beliefs), and item 30 (My decision was affected by what I thought the deceased would have wanted) than did nondonors. Both groups disagreed with the statements in factor 3 (decision doubts and conflicts) and factor 5 (pain and mutilation fears); however, the donor group disagreed more strongly that these beliefs affected their decision to donate.

We found no significant differences between the groups in their responses to the questions in factor 2 (religion). Respondents related that neither their own religious beliefs nor those of the deceased on how treatment of the body after death affects afterlife influenced their decision about organ donation.

The 2 groups differed significantly in their responses to item 31 ($P<.001$). Nondonors disagreed that the belief that the deceased would live on in someone else affected their decision, whereas the donors agreed that this belief affected their decision.

Predictions of Decisions

For the stepwise discriminant function analysis, all 5 factors and

<table>
<thead>
<tr>
<th>Variable</th>
<th>Characteristic of family more likely to donate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity of the respondent</td>
<td>Anglo-American</td>
</tr>
<tr>
<td>Religious affiliation</td>
<td>Any religious affiliation</td>
</tr>
<tr>
<td>Person initiating subject of donation</td>
<td>Family member, physician, or organ procurement coordinator</td>
</tr>
<tr>
<td>Cause of death</td>
<td>Gunshot or suicide</td>
</tr>
<tr>
<td>Timing of request</td>
<td>Before or during declaration of brain death</td>
</tr>
<tr>
<td>Donor card</td>
<td>Signed donor card present</td>
</tr>
</tbody>
</table>
the 3 single items were used as predictors (Table 6). Factors 1, 2, 3, and 5 and items 30 and 31 were the best set of predictive variables. The final set of 6 variables produced a canonical correlation of .53, indicating a moderately strong relationship between the 6 independent variables and the decision about organ donation. In addition, the analysis indicated that the 6 variables could be used to classify each subject as a donor or a nondonor with an accuracy of 82.6%. Specifically, agreement was 83% between predicted and actual donors and 79.5% between predicted and actual nondonors. A subject’s response to item 31 (The belief that the deceased would live on affected my decision) was the strongest predictor of whether the subject would be among the donor group or the nondonor group.

Open-Ended Responses

In response to the open-ended question about what families would change about the donation experience, the donor families indicated that they would have liked (1) more information and/or contact with the recipients, (2) nothing to be changed, (3) more time to make the decision and/or be with the donor, (4) expedition of the organ recovery process, and (5) to change the feeling of having to “part and parcel” out their loved one. The nondonor families responded that the doctors should not have “tried to bring him back,” and they were upset by what they perceived to be unprofessional behavior of the staff, for example, persistence on the part of the OPO coordinator even “after it was obvious we didn’t want to participate” and “a lack of compassion shown by some of the staff.”

In response to the question about what they thought was the most important factor in their decision, the donor families said it was the “gift of life” (“parts of my son live on, I hope” or “giving a chance for life or better health to someone else”). They also indicated that they thought they were following the wishes of the deceased (“my wife would have wanted me to”). Other donor families cited personal experiences in working with organ donation as a healthcare professional or having a strong belief in the value of organ donation.

The nondonor families indicated that donating the organs of a child went against their “parental instincts to protect her at all times.” They also noted the deceased “had been through enough trauma and felt like the surgery would prolong the process.”

When asked if they would change their mind if they had to make the decision again, most of the donor families indicated they would change nothing because they had given the gift of life or had followed either the donor’s wishes or their own beliefs. Although a few indicated they would have changed their mind, 1 person indicated she would have changed her decision because she had not realized it was against her religion and also because she had been “treated so bad by the coordinator—I still suffer from the way she hurried me.”

Most of the nondonor families also would not have changed their decisions. One subject stated, “I felt that if he would have wanted to donate his organs, he would have told me or put it on his drivers

| Table 5 | Characteristics with significant differences between donor and nondonor families |
|---------|---------------------------------|---------------------------------|-----------------|-----------------|-----------------|
| Variable| Donors                          | Nondonors                       |
|         | Mean   | SD    | Mean   | SD    | Mean   | SD    |
| Factor 1, trust and care | 5.2    | 0.87  | 4.7    | 0.94  | .001* |
| Factor 2, religious beliefs | 2.2    | 1.26  | 1.9    | 1.17  | .26  |
| Factor 3, decision doubts and conflicts | 2.3    | 0.91  | 2.8    | 0.83  | .003* |
| Factor 4, transplant beliefs | 5.5    | 0.82  | 5.1    | 0.96  | .003* |
| Factor 5, pain and mutilation | 1.4    | 0.87  | 2.5    | 1.47  | .26  |
| Item 30, what deceased wanted | 5.2    | 1.53  | 4.3    | 2.11  | .002* |
| Item 31, live on after death | 4.3    | 1.87  | 1.9    | 1.47  | .001* |
| Item 32, cost of donation | 2.3    | 1.82  | 1.9    | 1.59  | .15  |

<table>
<thead>
<tr>
<th>Table 6</th>
<th>Discriminant analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual</td>
<td>Predicted No. (%)</td>
</tr>
<tr>
<td>Donor</td>
<td>249 (83)</td>
</tr>
<tr>
<td>Nondonor</td>
<td>8 (20.5)</td>
</tr>
</tbody>
</table>

*Variables in the model were factors 1, 2, 3, and 5 and items 30 and 31. Numbers in parentheses are percentages. Overall accuracy = 82.6%. Canonical correlation = .53; P < .001.
license.” Only 1 nondonor indicated he or she would have made a different decision and stated, “better understanding of the process . . . we would donate if ever faced with the decision again.”

DISCUSSION
The development of a new instrument to measure attitude and beliefs with respect to organ donation was an important part of this study. The final tool had fair to excellent reliability coefficients and evidence of both content and construct validity as indicated by factor analysis. This tool fills a void in quantitative instruments that help OPOs better understand some of the family issues associated with decisions about organ donation.

This study was unique because it included subjects from multiple OPO sites who had been contacted about the possibility of organ donation. The response rate for the donor families was low, but a 55% response rate or lower is common in survey research. Of greater concern were the initial nondonor response rate and the difficulty of recruiting nondonor families. The poor response rate of nondonor families and the need to offer financial incentives for participation to some nondonor families may be limitations to the generalizability of the findings from the study. The reason for the reluctance of nondonor families to participate in the study was never discovered. We postulate that perhaps family members who have already said no are more likely than those who said yes to refuse to participate in a study that makes them think about an emotionally painful situation once again.

The differences in donation rates between Anglo-Americans and other ethnic groups is supported by the results of other studies and may represent some generalized mistrust by non-Anglos of the Anglo-American-dominated healthcare system. Age of the donor was not a significant factor between donation and nondonation, contrary to the findings of Gortmaker et al, who found that family members were more likely to donate if the donors were less than 50 years old.

The finding that religious affiliation was associated with higher donation rates (regardless of which specific religion was named) may be associated with a strong spiritual belief or a belief in an afterlife or may represent the altruistic doctrines of many religions. On the other hand, the donor and nondonor groups did not differ significantly on the religion factor (that their own or the family member’s religious beliefs affected the decision). This factor played a small but significant role in the discriminant analysis. The more strongly the respondents disagreed with the influence of religion, the less likely they were to donate. Perhaps the religious beliefs were less important than an overall sense of spirituality.

Of those surveyed, the response to organ donation was more positive when an OPO coordinator or a physician rather than a nurse approached the next-of-kin. In contrast, in the Partnership Study, success rates were lower when a physician approached the family. In the study by Ehrle et al, consent rates were better for OPO staff members because staff members have the commitment to donation, the experience and the time to work with families, and extensive knowledge of brain death. Perhaps both physicians and nurses should consider partnering with OPO staff to observe approach methods to improve the consent rates for donation. Siminoff found that when the initial response to donation request was unsure or negative, the family more often denied permission. Thus, it becomes imperative to involve the OPO staff at the onset for maximum beneficial outcome.

The timing of the request for organ donation relative to the pronouncement of brain death was also significant. Previous research indicated that “decoupling” the donation request from the pronouncement of death improves donation rates. In our study, however, donation rates were higher when donation was first mentioned before or during the pronouncement of brain death and lower when families were approached after being informed of brain death. The subjects in our study may have used the early mention of donation as an opportunity to “rehearse” the ensuing situation and prepare for the possibility of donation. Although evidence is insufficient to refute the benefits of decoupling,
our findings indicate that introducing the subject of organ donation early in the encounter (planting the seed) may be useful. When a loved one died as a result of a violent death (eg, gunshot) or suicide, the next-of-kin was more likely to consent to donation than when death was due to a medical cause or even a motor vehicle accident. In the study by Walker et al,

similar findings were attributed to the younger age associated with violent deaths. The responses to the open-ended questions support the notion that the family members of persons who experienced violent deaths attempted to make sense out of a senseless tragedy by consenting to donation.

The importance of having a signed donor card cannot be underestimated. Both quantitative data and the responses to the open-ended questions support the need for family members to follow the intentions of their loved ones and the belief that the donor card was the most explicit means of conveying that belief to the family members. In fact, in the absence of a signed donor card, the family members tended to default to no. They thought that if the deceased desired to donate his or her organs, a signed donor card would be present.

CONCLUSIONS

Because of the disparities between our findings and those available in the literature, it appears that there is no magic bullet or easy remedy for the vexing problem of families’ denying consent for donation. Increasingly clear, however, is the importance of families discussing this option among themselves, a finding that lends increasing support to public education efforts. Also apparent is the importance of including the OPO staff early in the potential donor situation and of clear communication between hospital and OPO staff about how, when, and by whom the family should be approached for donation. It may not be problematic for physicians to mention donation early in the process of pronouncing brain death. The consensus among both donor and nondonor families that they need more time to be with their loved ones and to decide about their options is a clear call for all involved to listen more carefully to families’ needs.

Acknowledgments

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