Family, friends, and faith: how organ donor families heal

Context—Understanding how organ donors' families recover from their grief can help organ procurement organizations improve consent rates and increase the number of deceased donor organs available for transplant.
Objective—To determine what helps the loved ones of deceased organ donors heal from their grief and loss, and to better understand families' needs during the consent process as a way of improving overall consent rates for organ donation.
Design, Setting, and Participants—Written survey of all organ and tissue donors' families in the San Diego and Imperial County (California) service area during 2006 and 2007.
Main Outcome Measures—Responses to the 20-question survey addressing factors that help healing from grief, as well as contextual information about the families' experience at the hospital and the consent process.
Results—Most respondents (84%) indicated that family support was the most helpful thing in dealing with their grief, followed by the support of friends (74%) and religious and cultural beliefs (37%). Most (75%) indicated that they agreed to donation so that something positive could result from their loss. Most respondents (93%) felt that they were given enough information to make an informed decision about donation, and 6% indicated that the donation process interfered with funeral or memorial arrangements. More than 95% understood that their loved one had died before they were approached for consent. Consistent with previous studies, 12% said they still had unanswered questions about aspects of donation, and 15% of respondents indicated that the discussion about organ donation added more emotional stress to their overall experience. (*Progress in Transplantation.* 2009;19:000-000)

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Each year in the United States, thousands of families are approached in one of the worst moments of their lives and asked if they wish to make their loved one an organ donor. In 2008, 7984 of those families said yes, which led to the transplantation of 27 867 organs.[1] In the past several years, the number of transplanted organs has grown significantly because of initiatives such as the Organ Donation Breakthrough Collaborative and targeted public awareness campaigns,[2] but the need for donated organs is still desperate. The number of people on the waiting list for an organ transplant in the United States could easily fill a Super Bowl–sized football stadium.[1]

The goals of this study were to determine what helps the loved ones of deceased organ donors heal from their grief and loss. We also hoped to better understand the needs of donors' families during the consent process as a way of improving overall consent rates for organ donation.

Review of the Literature

Few studies address the grief process of organ donors' families. Perhaps the most studied question has been whether the process of approaching a family for donation causes family members to experience additional stress. Stocks et al[3] and others have shown that the process of organ donation does not add stress or worsen the experience of such families. Cleiren and Van Zoelen[4] found that dissatisfaction with the hospital staff was more likely to adversely affect the grief process than organ donation. Other factors that worsened the experience of donor families included lack of privacy, feeling pressured or harassed into making a decision, or fear that they may not be following their loved one's wishes.[5]

Previous organ donation research studied attitudes toward donation, predictors of signing donor cards, distinguishing characteristics of donors versus nondonors, various demographics of donors' families, the attitudes of health care providers toward organ donation, why families say no to donation, and the various factors

that influence consent for donation of solid organs. Burroughs et al[6] even looked at whether families who consented or refused organ donation would do so again. They concluded that nearly 21% of their sample regretted their decision to donate and would not do so again, but they did not correlate this finding to any grief process. Thirteen percent of the families who refused donation said they would consent if given a second chance.

Conversely, the literature about how individuals and families respond to grief and loss in general is extensive. A simple combined search on the words "family" and "grief" on Google Scholar returns almost 120 000 hits. On Amazon.com, one can search books using the word "grief" and return more than 68 000 books that somehow address the subject. So much has been written about grief and bereavement that some scholars have questioned if we are overdiagnosing mental illnesses in the United States and thereby creating more serious problems, a so-called grief industry. Critics point to the crisis counseling model known as critical incident stress debriefing to illustrate how a method can be widely accepted across medical and psychological disciplines without any research-based evidence of its efficacy. Indeed, in the case of critical incident stress debriefing, studies are beginning to emerge that indicate that it may not be beneficial to those in crisis, and public safety agencies across the United States are discontinuing its use.[7]

Another area of grief and bereavement widely written about has been the Stage Theory of Grief. First proposed by Bowlby and Parkes and later adapted and popularized by Kubler-Ross, the stage theory of grief was used to describe a 5-stage response of terminally ill patients to awareness of their own impending death.[8] The theory became well known and accepted for all who grieve, again in the absence of any empirical investigation. The first and only (to date) empirical study of stage theory was published in 2007 by Maciejewski et al[9] and affirmed some, but not all, of the stage theory of grief. The study was helpful in normalizing almost all stages of the grieving process and pointed out that "complicated grief," or negative grief indicators that persisted beyond 6 months after the loss, might be more accurately described as "prolonged grief disorder." Among one of the many limitations of the study, the authors are quick to point out, is the fact that we may be trying to compare apples and oranges. Much academic work on the subject of grief is done in circumstances where the deceased died of natural causes, as opposed to the sudden loss, trauma, or violence that so often is a part of the experience of organ donor families.[9]

Methods

The study participants included all those families who had consented to organ and tissue donation in San Diego and Imperial counties (California) during the calendar years 2006 and 2007. The data were collected by using a self-administered survey of 20 questions that was mailed out to each family 3 months after donation. The survey did not ask for any identifying or demographic information. The survey was originally designed as a customer service improvement tool; the questions included the grief and bereavement experience relevant to this study as well as other related areas such as the consent process, satisfaction with hospital staff, and reasons why the family chose to donate. Because the instrument was not designed as a survey, approval of the institutional review board was granted retrospectively as was waiver of informed consent requirements since no identifying information was returned with the survey and participant confidentiality could be assured.

Because many of the questions had been used in previous surveys, they had been reviewed for content validity by a panel of experts including procurement coordinators, the executive director of the organ procurement organization (OPO), hospital development managers, and a donor family. A total of 945 surveys were mailed out during the period in question, with an 18% response rate (N=170). The form of the questions included multiple-choice, yes/no, and open-ended. Some questions used a modified Likert scale. Although these questions have been used in at least 2 previous studies, reliability has not been estimated for this survey.

Results

In the multiple-choice question central to this study, most respondents (84%) indicated that family support was the most helpful thing in dealing with their grief. Family support was followed by the support of friends at 74%, and religious and cultural beliefs at 37%. Ten other possible choices to this question ranged between 22% and 2% (Table 1). When asked why their family chose to donate, 75% indicated that they agreed to donation so that something positive could result from their loss. Additionally, 71% of respondents said they donated so someone else might have a better quality of life (Table 2). Twenty-eight percent said they donated because their loved one selected the organ donation option on his or her driver's license, but 50% said they donated because of a previous conversation with their loved one. Twenty respondents (16%) indicated that they or their family members required more information and assistance in seeking additional grief support.

Many of the other findings in this survey help to contextualize the results just described. For example, 74% of respondents felt that their loved one received the best possible medical care from hospital staff, and 83% felt they were treated respectfully by hospital staff. Most respondents (93%) felt that they were

Table 1 What has been helpful in dealing with your grief?

Response	%
Family support	84
Friend's support	74
Religious/cultural beliefs	37
Letters/resources from organ procurement organization	22
Receiving recipient information	18
Literature about grief and bereavement	13
Professional counseling	13
Support groups	8
Letters to and from organ recipients	7
Phone calls from staff at organ procurement organization	6
Talking with hospital staff	6
Volunteering in the community	4
Drugs and alcohol	2

given enough information to make an informed decision about donation, and only 6% indicated that the donation process interfered with funeral or memorial arrangements. More than 95% understood that their loved one had died before they were approached for consent. Consistent with several previous studies, 12% said they still had unanswered questions about some aspects of donation, and 15% of respondents indicated that the discussion about organ donation added more emotional stress to their overall experience.

Several open-ended questions asked for feelings and feedback on the families' experience of the process both during and after donation. A total of 372 comments returned, and these were manually coded for strongest expressions of feeling (n = 10), positive experience (87%) and negative experience (10%). The more common of the positive experience responses are summarized in Table 3. Negative experience responses are summarized in Table 4. Finally, strongest expressions of feeling are summarized in Table 5.

Table 2 Our family chose to donate because . . .

Response	%
Something positive could result from our loss.	75
It would help someone else have a better quality of life.	71
Our loved one could still have an impact on life.	58
Our loved one said he/she wanted to be a donor.	50
It was consistent with our loved one's life of helping others.	49
It would be a memorial to our loved one.	37
It was indicated on loved one's driver's license.	28
Other	.02
My loved one was registered on the Donate Life Web site.	.005

Table 3 Comments on nature of positive experience

"What your organization does is very special and very much needed. We were treated with incredible kindness and compassion by the organ transplant coordinator which is something that we will always remember. God bless you all."
"Making our son a donor has been a source of pride and joy."
"It was comforting to know that part of my husband benefited the living. It was what he wanted."
"We really appreciate all the kindness and caring that was given to our family."
"Personal faith was helpful in dealing with our grief."
"I am very pleased that I made the decision to donate."
"It was the right decision and I will become a donor when I die."
"I am happy that someone who received her organs will get a second chance to be happy as was her wish."
"Thank you for the opportunity to carry out one last act of generosity on my father's behalf."
"I am certainly happy that the opportunity to donate was offered."

Discussion

On the basis of findings from this study, we hypothesize that family, friends, and cultural/faith-based influences are the 3 primary factors in donor families' recovery from grief. These results are consistent with the findings of other studies and speak to the importance of allowing time for families and friends to come together at the time of death to begin their grief process. The study makes clear that spiritual and cultural needs are very important to families, and these needs should likewise be addressed by hospital and OPO staff. These needs can be addressed by involving hospital-based social workers and chaplains in donor cases, increasing OPO-based family services, and providing awareness training about the needs of donor families to bedside nurses in the intensive care unit. The work done by Jacoby et al[10] provides a useful framework for addressing these needs more effectively in 6 areas: contextual, behavioral, informational, emotional, environmental, and spiritual.

The question of whether the act of donation actually helps ease and/or shorten the grief process requires further study, but we feel that this study may lend support to that theory. It would also be important to understand the role of complicated grief in organ donation, and this study did not address that question. Families indicated that the main reasons they chose to

Table 4 Comments on nature of negative experience

Hospital charges (unrelated to organ donation)
Delay in time to get patient to operating room
Lack of support after donation
Consent process too long
Desire for more family privacy
In all phases of the process, need more time

donate were because they wanted something positive to result from their loss, and that they hoped that someone else might have a better quality of life. It would be helpful to the consent process to determine whether using this phrasing when approaching donor families would improve consent rates.

The finding that most donor families had enough information to make a decision and were generally satisfied with the treatment given their loved one by the hospital reinforces the work of Exley et al[5] and highlights the importance of having qualified OPO staff on site to evaluate both the needs of the patient's family and the appropriate time to approach for consent to donate. Indeed, it would appear that a "profile" could be constructed from this study of what factors identify a family that is highly likely to say yes to donation. These factors include (1) they understand that their loved one is dead (95%), (2) they have been given enough information about donation (93%), (3) they felt that the approach was made at an appropriate time (86%), (4) they were treated respectfully at the hospital (83%), (5) they felt that their loved one received good care (74%), and (6) they had previously discussed donation with the donor (50%). One finding inconsistent with previous research was that only 12% of the survey respondents said they would "not have done anything differently," as opposed to the 21% that Burroughs et al[6] found would not donate again. This area warrants further investigation.

The nature of negative experience in the comments, although small, deserves special attention. It is very important that OPOs recognize the role of customer service to donor families beyond the consent process. A team approach to caring for the family is vital and should include hospital-based resources (such as social workers and chaplains) as well as OPO-based family service coordinators. Ongoing problems, such as time delays between scheduled and actual operating room time, must be dealt with aggressively by the OPO, given the amount of pain that potentially can be inflicted on donors' families. Customer service tools, such as follow-up surveys, should be used regularly by the OPO community so that they know what these potentially damaging issues are in their service areas.

Table 5 Strongest expressions of feeling

"Very ecstatic"	"Totally supportive"
"Incredible kindness"	"Exceptionally patient"
"Extremely professional"	"Unexpectedly comforting"
"Very happy"	"Most frustrating" (billing issue)
"Great feeling"	"Tremendous anguish" (delays to operating room)

Given our small sample, limited geographical representation, and lack of demographic data, readers are cautioned against generalizing these findings. The fact that the survey was not designed to be a research tool is a further limitation.

In conclusion, this study has provided important information about what helps donors' families work through their grief process and how hospital and OPO staff can be more helpful in that process. It also helped define the basic steps that OPO staff should take before and during the consent process, as well as areas for improvement in the care of donor families. For many families, these times are among the most difficult that they will ever experience. By helping to meet the needs of their unique grief process, hospital and OPO staff can truly honor these families' heroic gift.

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