

Explaining brain death: a critical feature of the donation process

To examine how a family's understanding of brain death may affect the decision to donate, an interview study was conducted with the immediate next of kin of 164 medically suitable organ donor candidates. Telephone interviews were conducted with members of both donor and nondonor families 4 to 6 months after the relative's death. Only 61% of the donor and 53% of the nondonor respondents said they had received an explanation of brain death. Few respondents reported that the hospital or organ procurement organization staff used visual aids to clarify or reinforce the information they were given. Next of kin who decided against donation had far less understanding of brain death than did those who decided in favor of it. Before making an organ donation request, healthcare providers must inquire about and address common misunderstandings people have about brain death. Healthcare teams should develop and be trained on a clear protocol for communicating with the families of patients who may be potential organ donors. (*Journal of Transplant Coordination*. 1997;7:14-21)

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The organ donation rate has remained relatively steady since 1988.¹ Although public attitudes toward donation are highly favorable, approximately half of the families asked to consider donating their relative's organs decline.² As a result, the list of Americans waiting for a transplant numbers approximately 50,000 and continues to grow.³ Each day, eight to nine people on the waiting list die because no suitable organ can be found.¹ It is therefore vital that we understand what affects a family's decision to donate their relative's organs.

Review of the Literature

For a medical practitioner, few things are more difficult than approaching families about donation. Because death has come unexpectedly, a hospital staff member or the coordinator from the regional organ procurement organization (OPO) is called upon to make the donation request under time-pressured and intensely emotional circumstances.⁴ Some have hypothesized that a key to the request process, and to a family's reaction to organ donation, is the family's understanding of brain death.^{5,7} To date, however, no empirical demonstration of a relationship between understanding of brain death and consent to donation has been made.

Brain death is a difficult concept for the lay public to grasp. Under the sponsorship of The Partnership for Organ Donation, the Harvard School of Public Health, and 17 OPOs, the Gallup Organization conducted a national survey in late 1992 of 6127 US adults to explore this issue and others.⁸ The depth of public misunderstanding was clear. Twenty-one percent of the respondents stated that it was possible for a brain-dead person to recover from his or her injuries, while an additional 16% were unsure whether this was true. (The survey's margin of error was 1.3%. A complete description of the methodology and a copy of the survey instrument are available upon request from The Partnership for Organ Donation.) These results varied by age, race/ethnicity, education, and household income (Table 1).

Families who consent to donation often do so without having all their questions about brain death answered. An interview study by the National Kidney Foundation found that one third of donor family respondents had wanted more information on brain death when making their decision.⁹ Similarly, Savaria et al¹⁰ reported that 15% of donor family respondents admitted they had consented to donation without a clear understanding of brain death.

To learn more about the donation request process,

Table 1 Belief in the possibility of recovering from brain death**

Response	Age %				
	18-24	25-34	35-44	45-54	55+
Strongly agree/ agree	28	25	20	16	18
Strongly disagree/ disagree	52	60	65	71	64
Don't know	19	15	15	13	17
Response	Race/ethnicity %				
	White	Black	Hispanic		
Strongly agree/ agree	19	33	29		
Strongly disagree/ disagree	65	55	54		
Don't know	16	12	17		
Response	Education %				
	High school or less	Some college	College graduate		
Strongly agree/ agree	24	19	15		
Strongly disagree/ disagree	60	67	70		
Don't know	17	14	15		
Response	Household income %				
	<\$25K	\$25K<45K	>\$45K		
Strongly agree/ agree	25	19	17		
Strongly disagree/ disagree	59	68	70		
Don't know	16	13	13		

* Question: "Do you agree or disagree with the following: It is possible for a brain-dead person to recover from his or her injuries." Totals may not equal 100% due to rounding error.

including how a family's understanding of brain death may affect the decision to donate, The Partnership for Organ Donation and the Harvard School of Public Health conducted telephone interviews with members of families who had been offered the option of donation.

Issues covered during the interviews included key hospital events, discussions with the OPO and hospital staff, and understanding of brain death. This article summarizes principal findings from the study related to the family's understanding of brain death and reviews their implications for hospital and OPO staff who must discuss brain death with families.

Method

Three OPOs (Delaware Valley Transplant Program, New Jersey Organ and Tissue Sharing Network,

and New York Regional Transplant Program) provided contact information on the legal next of kin of all medically suitable potential organ donors who had been referred to the OPOs from February 1 through September 30, 1994. For families that consented to donation, the legal next of kin was identified as the family member who signed the forms indicating consent to donate. For nondonor families, the legal next of kin was identified using the standard hierarchy that is in general use by OPO staff (ie, spouse, parents, children, siblings, and others).

Four to 6 months after their relative's death, the legal next of kin received a letter from the Harvard School of Public Health inviting them to participate in the study. An interviewer then made a follow-up telephone call to schedule an interview. To participate, a respondent had to speak English or Spanish and had to be 18 years or older (unless he or she was a parent of the deceased).

The interviews, which lasted from 30 to 60 minutes, covered a wide range of issues: how and when the donation request was made, what the family knew of the relative's wishes about donation, who was involved in making the family's decision, and knowledge and attitudes about organ donation and transplantation. The interview protocol included several questions about brain death. The initial questions focused on (1) whether brain death was explained, (2) how it was explained, (3) who explained it, and (4) when the explanation was given, relative to when the subject of organ donation was first presented. The interviewer further asked respondents whether they thought brain death had been explained in a way that they understood.

The respondents then answered three questions about brain death. The first question asked, "If a person is diagnosed as brain dead, are they in a coma or dead?" Next, the respondents indicated whether the following two statements were true or not true: "Someone who is brain dead is dead even though his or her heart is still beating," and "It is possible for a brain dead person to recover from his or her injuries."

After the series of questions on brain death, the interviewer provided all respondents with the following clarification: "Just for your information, brain death is death, and there is no hope of recovery when someone is brain dead."

Ensuring that the interviews were handled in a sensitive and appropriate manner was of paramount importance. The three female interviewers were selected on the basis of their prior training and experience with highly sensitive telephone interviews. If a respondent appeared to become unduly distressed, the interviewer gave the respondent the option of terminating the interview. At the end of the interview, the respondents were asked whether they wanted the name of a local bereavement counselor.

Two limitations of this study should be considered. First, a sizable number of potential respondents could not be located or declined to participate in the study. It is possible that their experiences differed from those of the respondents in important ways. Second, the respondents were recalling an event that occurred 4 to 6 months prior to the interview, which may have led to inaccurate recall of certain facts.

Results

The immediate next of kin of 378 medically suitable organ donor candidates were identified as potential study participants. One hundred twenty-one of the 160 (76%) who consented to the donation of their relatives' organs were located, and 102 (84%) of those agreed to be interviewed. One hundred seven of the 218 (49%) who denied consent were located, and 62 (58%) of those agreed to be interviewed. Only one respondent, a donor family member, prematurely terminated the interview. Sixty-three percent of donor and 69% of nondonor respondents asked for a referral to a local bereavement counselor ($\chi^2[1]<1$, ns).

Donor and nondonor respondents who chose not to be a part of the study gave similar reasons for refusal. Overall, 36% of those who declined to participate said they found it too difficult to discuss their relative's death, whereas another 53% simply said they did not want to participate or hung up the telephone. Only 11% refused to participate because they objected to organ transplantation. Insufficient information was available on those who declined to participate to gauge whether they differed in any important ways from the consenting participants.

Demographics

The donor and nondonor respondents were similar in gender, age, and relation to the deceased. Significant differences were seen, however, when comparing race/ethnicity, place of birth, and household income. A near-significant difference was found in education (Table 2). Nondonor respondents were significantly more likely to be a member of a racial or ethnic minority, to be born outside the US, and to report an annual household income under \$35,000.

Explanation of Brain Death

The respondents were asked, "Thinking back to the time when all of this happened, was the meaning of brain death ever explained to you?" Only 61% of the donor and 53% of the nondonor respondents answered affirmatively ($\chi^2[1]<1$, ns).

Of those given an explanation, 92% of donor and 85% of nondonor respondents said it had been done in a way that they could understand ($\chi^2[1]=1.14$, ns). Ninety-four percent of the nondonor respondents who

Table 2 Demographic profiles of the donor and nondonor respondents: relation to the deceased*

Relation to deceased	Respondent status		
	Donor %	Nondonor %	
Parent	14	23	$\chi^2(4)=7.86$, ns
Sibling	6	3	
Child	37	21	
Spouse	43	52	
Other	0	2	
Gender			
Male	39	31	$\chi^2(1)=1.23$, ns
Female	61	69	
Age (years)			
0-19	1	0	$\chi^2(3)=1.17$, ns
20-39	37	32	
40-59	47	50	
60+	15	18	
Race/ethnicity			
White	63	39	$\chi^2(3)=10.00$, $P<.02$
Black	13	27	
Hispanic	20	26	
Other	5	8	
Place of birth			
USA	78	61	$\chi^2(1)=5.61$, $P<.02$
Other	22	39	
Education (years)			
0-12	41	56	$\chi^2(1)=3.61$, $P<.06$
12+	59	44	
Household income			
\$0-34,999	42	59	$\chi^2(1)=4.22$, $P<.04$
\$35,000+	58	41	

* Totals may not equal 100% due to rounding error

were given an explanation identified a physician or resident as the person who explained brain death to them, compared with 82% of the donor respondents who received an explanation ($\chi^2[1]=2.94$, ns).

When brain death was explained to the family, few donor or nondonor respondents reported that the hospital or OPO staff used supportive materials to clarify or reinforce the information. Only 14% of the respondents who were given an explanation said that visual aids such as pictures or charts were used to help explain the concept. Additionally, only 19% of all respondents stated that they witnessed any of the medical tests that were done to establish whether their relative was brain dead.

Respondents were asked whether the explanation

of brain death they had received was given before, during, or after the conversation when the question of organ donation first was raised. Sixty-eight percent of the donor respondents and 78% of the nondonor respondents stated that the explanation came prior to the conversation about organ donation ($\chi^2[1]<1$, ns).

When asked whether they were given enough time to understand that their relative was brain dead before the medical staff brought up the idea of organ donation, 83% of the donor respondents said that they were given enough time, compared with 56% of the nondonor respondents ($\chi^2[1]=12.82$; $P<.0004$).

Understanding of Brain Death

Nearly all donor (95%) and nondonor (97%) respondents stated that their relative was brain dead ($\chi^2[1]<1$, ns). However, when respondents were asked a series of questions to investigate their understanding in more detail, it became clear that brain death was confusing to many, particularly to the nondonor respondents.

When asked whether a person diagnosed as brain dead is in a coma or dead, 28% of the donor respondents said the person was in a coma and 9% said they did not know. The comparable figures for nondonor respondents were 45% and 10%, respectively ($\chi^2[2]=5.26$; $P<.08$).

When asked whether it was true that someone who is brain dead is dead even though his or her heart is still beating, 12% of the donor respondents answered incorrectly and 8% did not know. The comparable figures for nondonor respondents were 27% and 13%, respectively ($\chi^2[2]=8.64$; $P<.02$).

Finally, when asked whether they agreed that people cannot recover when they are brain dead, 20% of donor respondents incorrectly disagreed with this statement and 6% did not know. The comparable figures for nondonor respondents were 52% and 14%, respectively ($\chi^2[2]=18.26$; $P<.0002$).

A summative index was formed of the three knowledge items, with respondents awarded 1 point for each item they answered correctly (range=0,3); internal reliability for the index was moderately high (Cronbach's $\alpha=.54$) (Table 3). Whereas approximately 80% of the donor respondents had a score of 2 or 3 on the index, only 52% of the nondonor respondents scored that well ($\chi^2[3]=21.8$; $P<<.01$). Cross-tabulations of the index score against several variables were run. To properly execute chi-square (χ^2) tests, scores on the index were dichotomized between those who answered all three knowledge items correctly ($n=64$) and those who did not ($n=100$).

Greater knowledge about brain death was associated with respondents having more than a high school education ($\chi^2[1]=5.11$; $P<.03$), being white ($\chi^2[1]=7.72$; $P<.006$), being born in the US ($\chi^2[1]=6.13$; $P<.02$), and

Table 3 Scores on the brain-death knowledge index for donor and nondonor respondents*

Index score	Donor n (%)	Nondonor n (%)
0	8 (8)	10 (16)
1	13 (13)	20 (32)
2	28 (28)	21 (34)
3	53 (52)	11 (18)

* The index was formed by assigning respondents one point for each of the three knowledge items they answered correctly. Totals may not equal 100% due to rounding error.

having income of \$35,000 or higher ($\chi^2[1]=9.02$; $P<.003$). Statistically significant associations were not found with gender, age, marital status, or religion of the respondent; whether the respondent worked in the healthcare industry; age of the deceased; or cause of death. Those who said that brain death had been explained to them did not show significantly greater knowledge about brain death compared with those who did not recall being given an explanation ($\chi^2[1]<1$, ns).

The difficulty many laypeople have in understanding the concept of brain death cannot be underestimated. A review of interview transcripts revealed that several months after facing their decision, many respondents, even those who agreed to donate their loved one's organs, expressed confusion about what brain death is. One 47-year-old man who consented to donate his wife's organs spoke for several respondents when he was asked whether a brain dead person is in a coma or dead: "They are dead. Well, they're not dead.... It depends on how you look at this."

Some respondents held out the prospect of their loved one's recovery. "There is the possibility," this same respondent stated. "I've been told that people diagnosed as brain dead do, in fact, spontaneously recover." A 32-year-old mother echoed that idea when speaking about donating her son's organs: "I thought that there was always a chance that he might come out of the coma." Several respondents stated that there was always the possibility of a "miracle."

The expression "brain death" apparently led some respondents to think in terms of only part of the person being dead. A 38-year-old woman who declined to donate her husband's organs answered this way when asked whether a brain-dead person is in a coma or dead: "I think a little of both.... [M]y emotions are telling me that [his brain is dead], but the rest of him is still alive until I do what I have to do."

What often contributed to the respondents'

confusion was the appearance of their loved one's body after brain death had been declared. One 20-year-old woman who agreed to donate her husband's organs indicated that he was in a coma: "I couldn't really understand it," she said. "When they touched his feet, his feet moved." A 30-year-old woman who donated her mother's organs stated, "She was breathing. Her heart was going.... They're telling you that she's dead, but she's still there."

Discussion

This study provides the clearest evidence to date that, in general, families deciding against donation have less understanding of brain death than do families deciding in favor of donation. At the time of their decision, a sizable number of donor respondents are confused about whether their relative is truly dead. Clearly, prior to making an organ donation request, healthcare providers must inquire about and address the common misunderstandings that people have about brain death.

It should be noted that just over half of the non-donor respondents answered correctly at least two of the three knowledge questions about brain death, yet they still decided not to give consent. This means, therefore, that the family's understanding of brain death is only one factor that affects the decision to donate.

Consider, for example, that nondonor respondents were significantly more likely to be a member of a racial or ethnic minority, to be born outside the US, and to report an annual household income under \$35,000. The study would have required a much larger sample to assess whether the association between poor understanding of brain death and refusal to donate would still emerge once these demographic variables were held constant. More research involving larger sample sizes drawn from additional areas of the country is warranted.

Need for Improving the Process for Explaining Brain Death

There is room for improvement in the process that healthcare teams follow in explaining brain death. Routinely, a physician should lead the family through a clear explanation of the brain injury their loved one suffered and how a diagnosis of death was made. Thirty-nine percent of donor respondents and 47% of nondonor respondents reported that they had received no such explanation.

Of the interview respondents who received an explanation, more than three fourths indicated that the explanation came prior to any conversation about organ donation, a sequence that seems preferable. Furthermore, nearly 9 out of 10 of these respondents said the explanation they had been given was understandable. Even so, nearly half of all

donor respondents and more than 80% of all non-donor respondents answered one or more basic questions about brain death incorrectly, thus bringing into question whether they truly understood that their loved one was dead. Clearly, a family's comprehension of brain death can no longer be judged merely by their ability to state, "My relative is brain dead." No family should be assumed to understand brain death, even if they claim that they do.

These findings underscore how important it is for healthcare team members to determine the family's understanding of brain death before making the donation request.⁹ If the family is merely echoing the term "brain death" without understanding its meaning, it is too early for the OPO coordinator or hospital staff to bring up the subject of organ donation.

Another issue is how much time the family is given to integrate their understanding of brain death and to absorb the fact of their relative's death. When asked whether they were given enough time to understand that their relative was brain dead before the medical staff brought up the idea of organ donation, only 56% of the nondonor respondents, compared with 83% of the donor respondents, said that they were given enough time.

As noted, respondents with certain demographic characteristics (eg, membership in a racial or ethnic minority, birth outside the US, annual household income under \$35,000) more often misunderstood brain death and were more likely to deny consent to donation. It must be emphasized, however, that those associations should not be construed to mean that any particular family will automatically respond negatively to donation. Rather, this information should be used to remind the healthcare team to be especially attentive to concerns that certain families might have and to take special care to meet their information and emotional needs. In some cases, working to build a rapport with these families and ensuring that they understand brain death and have absorbed the fact of their relative's death may require additional time.

Family Communication Protocol

The findings from this study suggest that new procedures for evaluating the family's real understanding of brain death and improved methods of explaining the concept are needed. To ensure that the subject of brain death is handled properly, healthcare teams should develop and be trained on a clear protocol for communicating with the families of patients who may be potential organ donors, from the initial communication of grave prognosis to the pronouncement of brain death and the organ donation request itself.

This study revealed that most explanations of brain death are given to families by physicians and medical residents. Therefore, it is critical that these

professionals develop specific skills and tools to communicate effectively about brain death. It is also essential that other team members know what they must do to clarify and reinforce what the families are told. Training on the protocol should be designed to ensure that all members of the healthcare team fully understand the legal and medical criteria for determining brain death¹¹ and are able to adjust their presentation in line with a family's particular situation and needs.

In designing the protocol, it is important to keep in mind that the unexpected loss of a relative, who only hours before was vital and fully functioning, is traumatic and overwhelming to nearly all families. Compounding their distress is the confusion created by the sight of their loved one lying in the hospital bed, warm to the touch and with good color, seemingly alive. At this critical time, the family's ability to process and act on information is greatly diminished.¹²

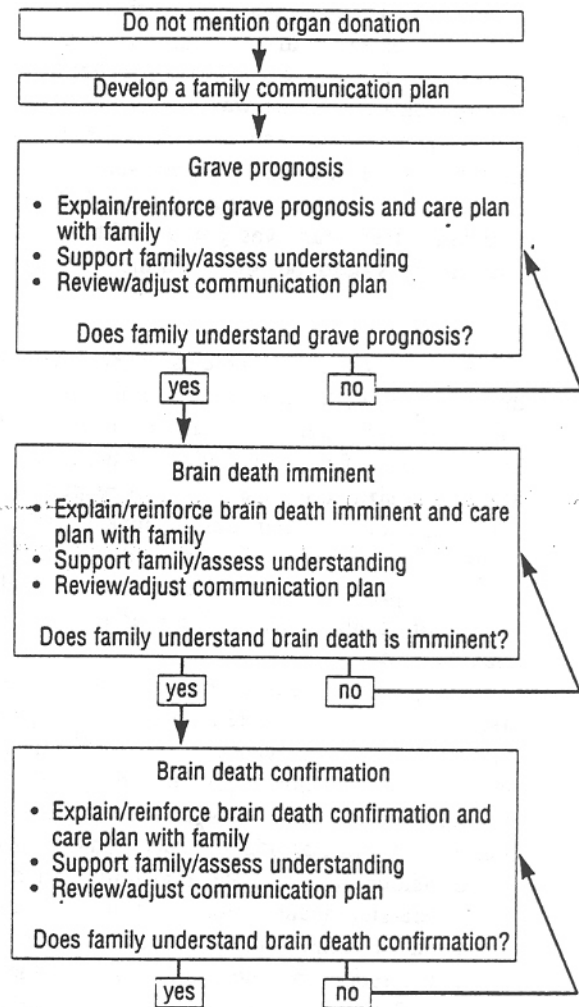
The published literature does not include formal protocols for communicating about brain death that are solidly grounded in theory or have been evaluated in practice. Nevertheless, past work by numerous researchers and practitioners suggests several elements that should be incorporated into newly developed protocols:

1. *Provide up-to-date information in small amounts.* The key is to make sure that facts about the patient's current condition and the care plan are understood before providing additional information (see Figure). It is especially critical to keep the family updated on any changes in clinical status that suggest the possibility of brain death.¹³

2. *Minimize the number of staff members who talk to the family about brain death.* This will help provide consistency in the messages conveyed, thereby enhancing the family's understanding of their relative's condition. It will also serve to strengthen the bonds of trust between the family and the healthcare team, which will be important should an organ donation request be required later.¹⁴

3. *Set aside time for families to ask questions.*¹⁵ It must be cautioned, however, that encouraging the family to ask questions is not a substitute for the healthcare team actively probing for areas of confusion on the part of the family. Due to their emotional distress, families cannot be expected to have organized their thoughts to formulate questions, nor can they always be aware of what they do not know.

4. *Choose words carefully when talking with the family about the patient's condition.* After brain death is declared, the healthcare team must declare with certainty that the patient is dead. It must be stated explicitly that brain death is not coma, that the patient will not recover, and that—even though the heart is still beating and the body is warm—the person is dead. This information must be stated simply, without obscure medical



Family communication protocol for explaining brain death

terms, acronyms, or other jargon that serve to confuse most families. The care given to the brain-dead patient should never be referred to as "life support." Better terms are "artificial" or "mechanical support."

5. *Use visual aids to describe the brain injury and clarify the concept of brain death.* Materials that are currently available include *The Brain Injured Patient Flipchart*¹⁶ and *The Injured Brain*.¹⁷ Both of these educational tools illustrate the anatomy of the brain, how traumatic injury can damage the brain, and how evidence of such damage can be obtained through standard medical tests. Using these or similar tools can help to ensure that the healthcare professional covers all essential information. Although these tools have been in use for several years among some OPO professionals and hospital staff, they should be evaluated more systematically to determine whether universal adoption is warranted.

Development of a brief educational videotape on brain death should also be considered. A carefully

crafted presentation can present the key facts while anticipating and then answering common areas of misunderstanding. Using a prerecorded message means that the information would be organized and presented in a clear, concise, and reliable way and at an appropriate instructional level. Importantly, such a videotape would serve as an adjunct to, not a substitute for, one-on-one counseling by the healthcare team. With the videotape concentrating on conveying basic facts about brain death, the team member could focus on answering the family's questions and attending to their emotional needs.

6. *Explain in simple terms what the medical equipment is designed to do.* From the family's perspective, the type of care that is given to someone who is brain dead in order to maintain the viability of the organs for transplantation may not seem very different from the care given to someone who is in a coma. To eliminate this potential source of confusion, staff must explain carefully what is being done and why. Because the brain-dead patient will appear to be breathing, and because cardiac monitors will show what appears to be a normal heartbeat, it is imperative for the healthcare team to explain how the medical equipment makes this possible when the patient is dead.

7. *Avoid talking to the patient once brain death has been declared.* It is common for nurses and other staff to talk to patients who are unresponsive, which may continue even after brain death has been declared.¹⁸ Members of the healthcare team may need to remind one another to be more conscious of this habit so that the message to the family about the patient's death is not undermined.

8. *Assess the family's understanding of brain death.* The present study suggests that assessing the family's understanding of brain death is not a straightforward matter. Many families state that their relative is brain dead without truly comprehending what that means. Healthcare professionals who regularly counsel families about brain death and organ donation must pool their experiences, identify the kinds of questions most likely to elicit the family's true perceptions, and then systematically incorporate them into an assessment tool.

9. *When feasible, bring the family to the patient's bedside to see the clinical tests that were done to test for brain death.* Doing this will reinforce in a concrete way what the family has been told. It also confirms for the family that the tests were done correctly and were properly interpreted. For some families, witnessing the tests and seeing for themselves what the healthcare team has sought to explain can bring home the reality of their loved one's death.¹⁹ Special care should be taken to help families anticipate and understand any spinal cord reflexes that might be

exhibited that otherwise could be misinterpreted as signs of life.

10. *Do not raise the subject of organ donation until the family fully understands that their loved one is dead and has had enough time to absorb their loss* (SL Gortmaker, CL Beasley, E Sheehy, et al, unpublished data, April 1991–December 1992).²⁰ In practice, this means that donation must not be mentioned until the healthcare team makes an assessment of the family and it is shown that moving to the next step, the donation request, is appropriate.

11. *Adopt a systematic protocol for withdrawing mechanical support or monitoring systems.* When the family decides to donate, or if the patient is unsuitable for donation, a systematic protocol for automatically withdrawing mechanical support or monitoring systems should be put into effect and the family should be informed of this fact. Asking the family to be a partner in any decision of this sort is a mistake. Doing so reinforces any lingering doubts family members might have about whether their loved one is truly dead and might raise fears that they have actively contributed to that person's death by agreeing to turn off the mechanical support system.

Conclusion

This study demonstrates a strong association between whether a family elected to donate and the next of kin's understanding of brain death, but it does not prove a cause-and-effect relationship between poor understanding due to faulty explanations and refusal to donate. Such a relationship could be established definitively through a randomized prospective trial that offers different communication approaches, establishes their impact on the family's knowledge, and compares donation rates.

The family's understanding of brain death is only one factor that affects the decision to donate. Many families of brain-dead persons do not understand the finality of brain death. They are left feeling confused about whether their relative was really dead or might have had even a remote prospect of recovery. Poor understanding of brain death is associated with significantly lower rates of consent to donate organs of the deceased. The procedures used by hospital and OPO staff to explain brain death appear to be inadequate.

Because families are frequently left with a poor understanding of brain death, a major implication of this study is that better protocols are needed for communicating with the families of brain-dead patients. How the explanation of brain death is given, how the family's understanding of their loved one's death is assessed, and how the family's questions are answered will spell the difference between good and substandard care. It may also spell the difference between higher and lower rates of consent to organ donation.

Acknowledgments

The authors thank Lisa Horowitz, Corinne Kulak, and Ellen Murachver for the careful (and caring) way that they conducted the family interviews; Barbara A Moeykens of the Harvard School of Public Health for her work in a pilot study of this investigation; and Andrea Poretsky for her contributions to data analysis.

This research was supported in part by a grant from the US Department of Health and Human Services Public Health Service, Health Resources and Services Administration, Division of Transplantation.

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