

CHAPTER 21

Determinants of Familial Consent to Organ Donation in the Hospital Setting

Patrick McNamara and Carol Beasley

*The Partnership for Organ Donation
Boston, Massachusetts*

Despite the dramatic success and growing need for transplantation therapy, its growth and availability are tightly constrained by the shortage of suitable organs for transplant. The Partnership for Organ Donation has attempted to take a systematic, research-driven approach to improving organ availability, focusing on those parts of the donation system we believe can be most readily improved, and where the increases in donation will be largest. We have focused the majority of our efforts on the problem of helping OPOs and hospitals to maximize donation rates among brain-dead potential donors.

Published estimates of underlying donor potential in the US suggest that less than half of the nation's donor potential is currently being realized. Only approximately 5,400 potential donors become donors each year (1) while estimates of potential range from a low of about 7,000 to a high of about 15,000 (Fig. 1). Extrapolating from detailed chart review data in Pennsylvania, Nathan, et al (2), estimated national potential to be between 10,000 and 14,000 annually. Evans, et al (3), estimated national donor potential to be between 6,900 and 10,700 cases per year, an estimate that probably significantly underestimates donor potential since this study excluded non-traumatic deaths. Relying on medical records review in hospitals across 4 regions of the US, and including both traumatic and non-traumatic deaths in our analyses, we estimated the pool to be between 12,600 and 15,100 potential donors annually (4).

In order to understand the dynamics of this "realization problem" more thoroughly we have focused our research on 4 interrelated issues:

1. Where is existing potential concentrated?
2. Where in the donation process is existing potential lost?
3. What factors influence family consent rates?

4. How can organ procurement organizations (OPOs) and hospitals use the answers to these questions to maximize donation rates?

Where is Existing Potential Concentrated?

Large community and university affiliated hospitals and major trauma centers are more likely to treat patients at high risk for brain death. Thus, we hypothesized that existing donor potential would be concentrated in large and intermediate bed-size hospitals. In a recent study (5) designed to test this hypothesis and to develop an algorithm which generates accurate estimates of regional potential, we conducted medical records reviews (MRR) in a stratified random sample of 89 hospitals in 3 OPO regions ranging from very large to very small hospitals.¹ Extrapolating from the random sample to the

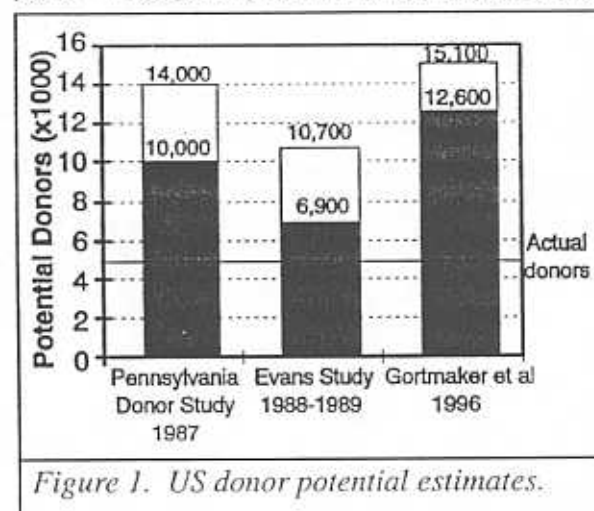


Figure 1. US donor potential estimates.

¹ These included California Transplant Donor Network (CTDN), LifeSource Upper Midwest OPO (LifeSource), and Washington Regional Transplant Consortium (WRTC). Statistical analysis was performed by faculty from the Harvard School of Public Health.

full compliment of hospitals served in the 3 regions we estimated that hospitals with 350 beds or more accounted for 11% of the hospitals but contained 38% of the potential donors. Intermediate bed-size hospitals (150-349 beds) represented 26% of the hospitals and 49% of potential donors; and smaller hospitals of 150 beds or less constituted 63% of the hospitals but only 13% of the potential donors (Fig. 2). Furthermore, the data collected in the random sample indicated that the larger hospitals were not realizing higher donation rates (actual donors/medically suitable potential) than smaller hospitals. So not only were potential donors concentrated in larger hospitals, unrealized donors were also concentrated in the larger institutions. These data suggest that efforts to maximize existing potential should initially focus on the largest hospitals since these will contain nearly 90% of the existing potential.

Where in the Donation/Procurement Process is Existing Potential Lost?

To become an organ donor a brain-dead patient needs to be recognized as a potential donor by hospital staff. Next the family needs to be informed of and accept the death of their relative. Finally donation must be offered to the family who then must consent before donation can proceed (Fig. 3). Breakdowns can occur at any of these stages. In a recent retrospective MRR review of 916 cases where patients were suitable candidates for organ donation, we found that only 299 of these became donors (for a donation rate of 33%) (4). Of the 617 cases of potential donors who did not become donors, 326 (36%) were due to family refusal to consent. Families were not given the option to donate (i.e. were not asked) in 156 cases (17% of total) despite evidence in the medical record that the potential donor had been

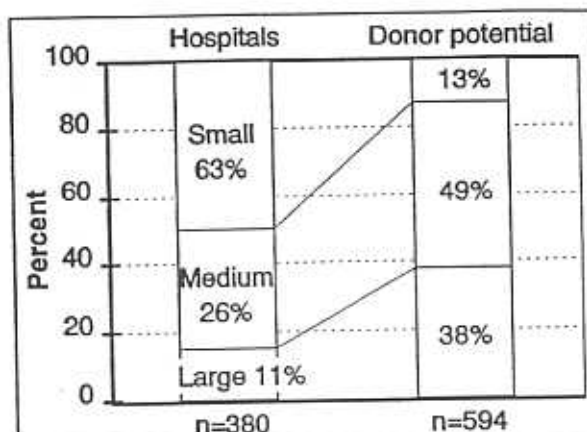


Figure 2. Estimated distribution of donor potential by hospital size (5). Hospitals: small= ≤ 150 beds, medium=150-349 beds, large= ≥ 350 beds.

diagnosed as brain dead. Ninety-four potential donors (10% of total), on the other hand, were never identified as brain dead in the record, despite clinical findings consistent with brain death. In 41 cases (4% of total) donation did not occur for other reasons, including situations when cardiac arrest occurred before donation could proceed or when medical examiners refused to release cases (Fig. 4). These data are consistent with the findings of Siminoff, et al (6), who estimated that 13% of potential organ donors were not properly identified and their families were not approached for donation. Both studies found that family refusal to donate was the principal reason for non-donation. In the Siminoff study, 54% of families declined organ donation when it was offered; in the Gortmaker study (4), the corresponding figure was 52%.

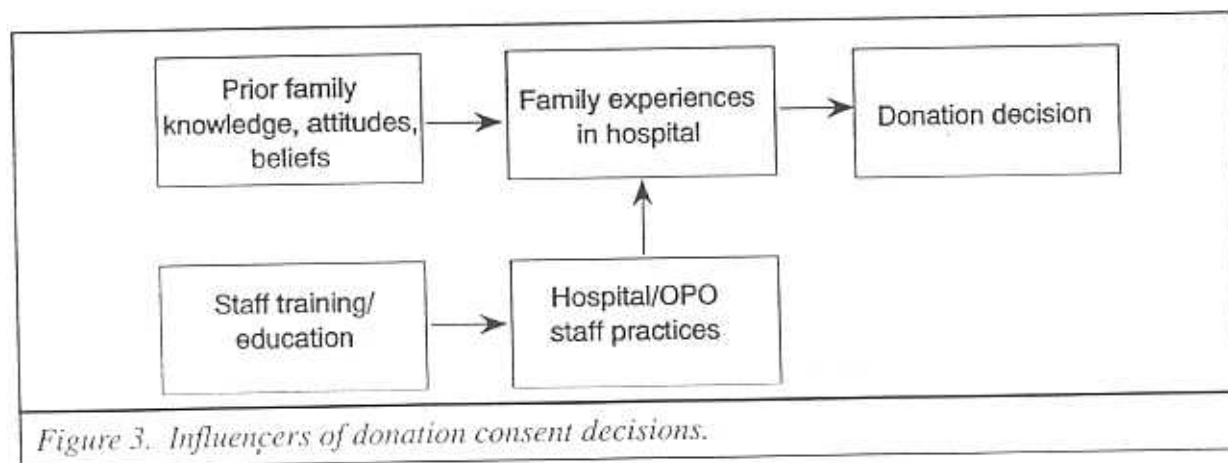
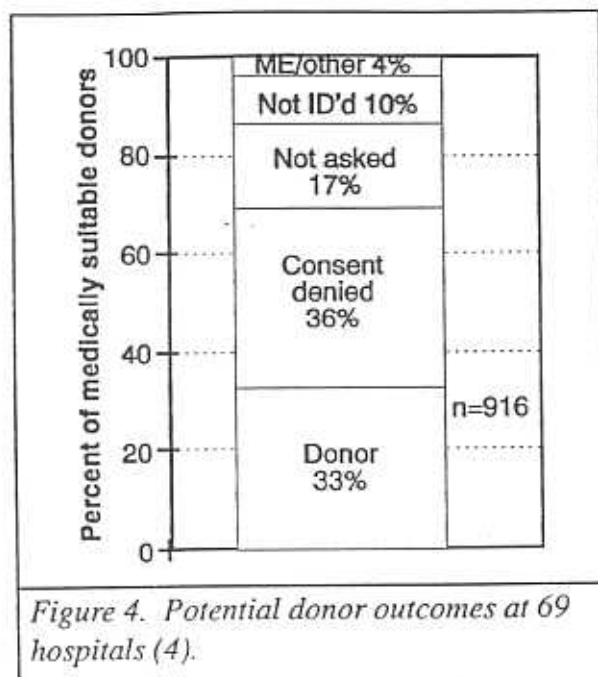


Figure 3. Influencers of donation consent decisions.



These data suggest that an additional 1,800 additional donors per year could be realized if all potential donors were identified and donation were requested of all families, even if consent rates remained flat at about 50%. At the current average of more than 3 organs per donor, the number of transplants could increase by nearly 5,600. In Section 4 of this chapter we detail one successful hospital intervention effort aimed at boosting identification, referral, asking and consent rates in 50 hospitals across 3 regions of the US. In addition to efforts to ensure consistent asking of families, we could boost consent rates by even a few percentage points, thousands more transplants could be performed each year.

What Factors Influence Family Consent Rates?

In their recent review of the available literature on family consent decisions Radecki and Jaccard (7) suggested that the information most consulted by families when confronted with donation was whether or not the deceased relative wanted to become a donor. Unfortunately, only about 29% of the American public report having heard specifics from a family member about their wishes concerning organ donation (8). Thus, most of the families who face the decision about organ donation do so without the benefit of knowing their relative's wishes. When the prior wishes of the deceased are un-

known, hospital-based situational factors (e.g. perceived emotional support of the medical staff) may become important determinants of consent decisions (Fig. 3).

We have long believed that it is crucial to understand the experiences of families in order to better address their needs when facing organ or tissue donation. In order to understand both donor and non-donor families' experiences with organ donation in the hospital setting we interviewed 164 families who had been faced with the donation option in the 6 months prior to the interview (9,10). This study showed that consent was more likely when families understood brain death and were satisfied with both the quality of care their relative received and the donation request itself.

The interview protocol included several questions about quality of care at the hospital, how and when the donation request was made, who was involved in the family's decision and about how and when brain death was explained relative to when the subject of organ donation was first presented.²

Quality of care. While practitioners have long believed that family consent to donation was strongly related to the family's overall assessment of the care they received at the hospital, our study documented this relationship. We asked families to indicate their level of agreement with 8 statements, including "The medical staff took the time to answer questions about how [name] was doing," and "I was kept updated on how [name] was doing." Based on the 8 statements, we constructed a "quality of care received" scale (range = 0-8; Cronbach's alpha = .66; Table 1). While 82% of donor family respondents had a score of 6 or higher on this scale, only 48% of non-donor family respondents had scores of 6 or higher ($p < .00004$).

Inspection of Table 1 reveals that the items which most differentiated donor from non-donor family respondents were those having to do with provision of information to the family. When families are not given the information they need, their trust of hospital staff may be un-

² Three OPOs (Delaware Valley Transplant Program, New Jersey Organ and Tissue Sharing Network, New York Organ Donor Network) 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. Faculty from the Harvard School of Public Health assisted with the study design and analysis. Contact with families was coordinated through the Harvard School of Public Health.

Table 1. Beliefs and attitudes about the quality of care reported by donor and non-donor respondents (9).

Survey item	Percentage of respondents indicating agreement		
	Donor	Non-donor	Chi-square
[NAME] received the best possible care before [s/he] died.	92	70	13.36 (df=1), p<.0003
Everything that needed to be done to try to save [NAME's] life was done.	91	69	13.37 (df=1), p<.0003
The medical staff showed they cared about me and my family and what we were going through.	94	82	5.62 (df=1), p<.02
I was kept updated on how [NAME] was doing.	90	74	7.25 (df=1), p<.008
I was told that [NAME] might not survive long before [s/he] died.	80	69	2.68 (df=1), NS
The medical staff took time to answer my questions about how [NAME] was doing.	95	77	11.38 (df=1), p<.0008
My family and I were able to spend the time we needed with [NAME] when [s/he] was near death.	92	92	<1 (df=1), NS
My family and I were able to spend the time we needed with [NAME] after [s/he] died.	85	76	1.81 (df=1), NS

Note: Respondents were asked to indicate whether they strongly agreed, agreed, disagreed, or strongly disagreed with each statement. "Don't know" responses were grouped with the disagree responses. df, degrees of freedom; NS, not significant.

determined. Only 69% of non-donor family respondents endorsed the statement: "Everything that needed to be done to try to save [name's] life was done."

The findings concerning general satisfaction underline the importance of involving hospitals actively in improving donation practices. When families are dissatisfied with the care provided in the hospital, there is little that an OPO coordinator can do to remedy this after the fact. Yet, if hospitals were more attentive to the needs of families of critically ill patients, especially their desire for communication, families' satisfaction with the overall quality of care throughout the institution would probably improve.

Explanation of brain death. The data suggest that families' comprehension of brain death is one of the most potent determinants of familial consent decisions. Non-donor family respondents were significantly *less* likely to report that they had received any explanation of brain death, were *less* likely to understand an explanation they did receive and were *more* likely to be asked for donation in the same conversation where they received the brain death explanation.

When asked, for example, "Thinking back to the time when all of this happened, was the meaning of 'brain death' ever explained to you?", only 54% of non-donor and 64% of donor respondents answered positively. Only

14% of the respondents said visual aids such as pictures or charts were used to help explain the concept to them. Eighty-three percent of donor and 56% of non-donor family respondents said that they were given enough time to understand that their relative was dead before medical staff brought up organ donation ($p<.0004$).

When asked a series of questions to investigate their understanding in more detail, it became clear that brain death was confusing to many, particularly the non-donor family respondents. Respondents were asked whether someone who is brain dead is in a coma or dead; whether someone who is brain dead is dead even though their heart is beating, and whether it is possible for someone who is brain dead to recover. For each of these questions, non-donor families were much more likely to answer incorrectly. For example, when asked if they agreed that people cannot recover when they are brain dead, 80% of donor family respondents correctly agreed with this statement, while only 48% of the non-donor family group did so ($p<.0002$).

We created an index from the 3 brain death items, giving one point for each correct answer (Cronbach's $\alpha=.54$). Among donor families, about 80% answered 2 or 3 of the questions correctly; only 52% of non-donor families scored that high ($p<0.00008$).

Table 2. Beliefs and attitudes about the donation request process reported by donor and non-donor respondents (9).

Survey item	Percentage of respondents indicating agreement		
	Donor	Non-donor	Chi-square
The person who asked for my consent to donate made the request in a way that was sensitive to my needs.	97	59	37.77 (df=1), p<.000001
The person who approached me with the consent form handled the situation in a way that was sensitive to my needs.	97	62	31.43 (df=1), p<.000001
I felt comfortable talking with the medical staff about organ donation.	92	52	32.85 (df=1), p<.000001
I felt the medical staff would be supportive of my decision no matter what I decided.	94	80	7.47 (df=1), p<.007
After we had reached a decision about organ donation, the medical staff supported our choice.	98	80	15.18 (df=1), p<.0002
My family and I were given enough information to make an informed decision about organ donation.	95	67	22.23 (df=1), p<.000001
At the hospital, organ donation was discussed in language I could understand.	99	75	23.32 (df=1), p<.000001
People at the hospital were able to answer all of my questions about donation.	97	67	24.52 (df=1), p<.000001
My family and I were given the privacy we needed to make our donation decision.	95	73	15.24 (df=1), p<.00001
My family and I were given enough time to talk about donation and to make sure we were making the right decision.	96	73	17.20 (df=1), p<.00004

Note: Respondents were asked to indicate whether they strongly agreed, agreed, disagreed, or strongly disagreed with each statement. "Don't know" responses were grouped with the disagree responses. df, degrees of freedom; NS, not significant.

Thus, it appears that many families—especially those who refuse donation—never fully grasp that brain death is death and enter the donation request phase of the process with lingering beliefs that their relative may, in fact, be alive. It is no wonder that many families find it difficult to assent to donation.

The request itself. Donor families expressed greater satisfaction with the way the request was handled than non-donor families suggesting that careful, sensitive requests are strongly associated with consent. We asked the respondents to indicate their level of agreement with 10 statements addressing the following issues (Table 2). For each of the 10 statements, donor families expressed significantly higher levels of satisfaction than non-donor families. In order to assess overall satisfaction with the donation request we calculated an index (range 0-10; Cronbach's alpha = .90) which summed responses to all items addressing satisfaction with the request. Virtually all (94%) donor families had a score of

8 or above on this scale, while fewer than half (47%) of the non-donor families had a score that high (p<.000001).

In summary, whatever knowledge or attitudes families bring with them to the donation situation, they are less likely to consent to donation when their situational needs, i.e. their needs at the hospital for information, time and privacy, are not respected. These quality-of-care, process-related factors are powerful predictors of the family's likelihood to donate.

Implications for OPOs and Hospitals

Since the quality of the request process itself has a major influence on consent rates for the majority of families — those who do not know the donation wishes of their deceased relative — OPOs and hospitals can improve their donation effectiveness by ensuring that the request process proceeds consistently, incorporating the process factors that best meet families' needs and are

associated with higher consent rates. One key element in standardizing request practices is training critical care staff in relevant request skills. In a survey study conducted in 1991 (11), we examined the effects of training on donation rates by comparing staff training levels and capabilities at "high-performing" hospitals to staff training levels and capabilities at "low-performing" hospitals and found that training in donation skills was strongly predictive of donation effectiveness.

High-performing hospitals were hospitals with donation rates at least one standard deviation above the aggregate mean, and low-performing hospitals were hospitals with donation rates that were at least one standard deviation below the aggregate mean. The aggregate mean donation rate was 36%, $sd=14.4\%$.

We surveyed 1,061 critical care nurses and physicians who had been involved in a potential donor case recently.³ The survey was carried out in 1991-1992 in large bed-size hospitals only (mean size was 456 beds). Response rates to the survey averaged 52% across all hospitals surveyed with a range of 30-92%. Unfortunately we collected no data on non-respondents so we cannot claim that our respondents are representative of all staff in critical care settings. Nevertheless, we did survey from a relatively large region of the US.

Compared to respondents at low performance hospitals, respondents at high performance hospitals were significantly more likely to report having received training in: a) how to request donation; b) how to explain brain death to the family, c) family grief counseling, and d) how to decouple the explanation of brain death from the request for donation (Fig. 5). Clearly, training in donation, particularly in the areas of family care and the request process itself, positively impacts on familial consent decisions. Unfortunately, only 33% (346/1061) of respondents across all hospitals had received any training at all in "how to request organ donation" and only about a quarter received training in explaining brain death or in family grief counseling—this despite virtually unanimous agreement among staff that training should be provided for those involved in organ donation (Fig. 6).

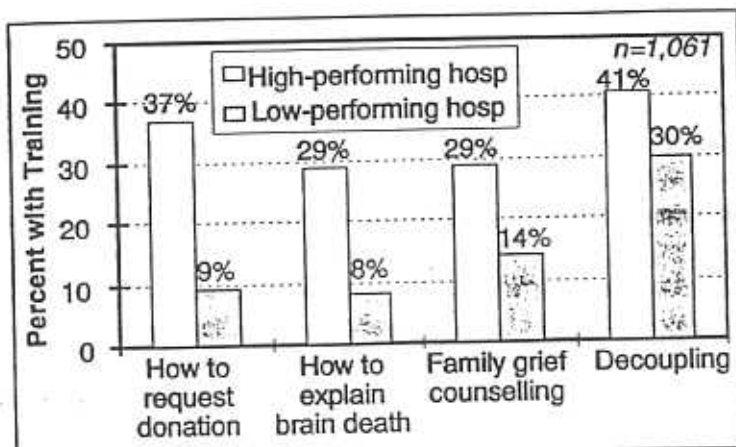


Figure 5. Hospital staff readiness and hospital performance, training comparison (11).

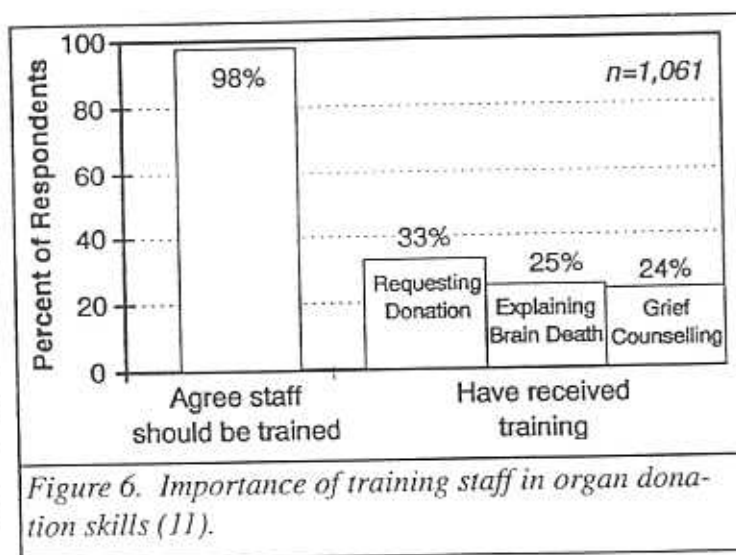


Figure 6. Importance of training staff in organ donation skills (11).

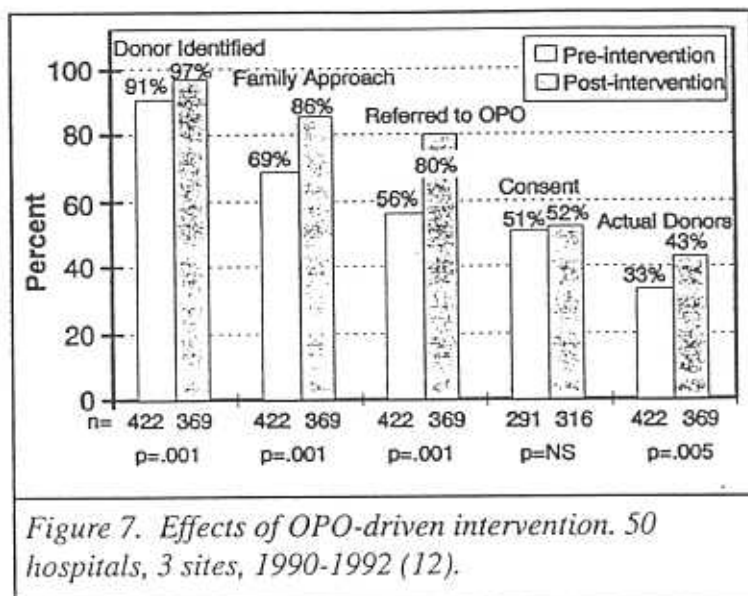
When providing training for staff likely to be involved in requests for organ donation the focus should be on strengthening staff capabilities at those points where the donation process is most likely to break down; i.e. in identification of brain-dead patients, in explanation of brain death to the family, coordination of efforts with the OPO

³ This non-random sample of hospitals included 16 that were trauma-certified, 7 that were both trauma certified and a transplant center and 5 that were neither trauma-certified nor a transplant center. The participating hospitals were divided among 4 Organ Procurement Organization (OPO) regions as follows: Washington Regional Transplant Consortium: 10 hospitals; LifeSource Upper Midwest OPO: 6 hospitals; California Transplant Donor Network: 8 hospitals; and Kentucky Organ Donor Affiliates: 4 hospitals.

when approaching families for donation and in making the request itself. We demonstrated that staff can be successfully trained in donation-relevant skills in a study conducted in 1991-92 (12) (Fig. 7). Training was provided to staff in 50 hospitals in the service areas of 3 OPOs.⁴

We collected baseline data on donation performance for calendar year 1990 in all hospitals for use in comparing rates of donor identification, rates of donor referral to the OPO, rates of donation request, and rates of consent to donation. Similar data were collected throughout the intervention. Hospital interventions began in early 1991 and continued for 18 months. We compared donation performance for the third and fourth quarters of 1990 (pre-intervention) with that of the third and fourth quarters of 1992 (post-intervention). There were no data available on the request process variables discussed above (privacy, decoupling, and OPO participation) prior to the start of the study, so we were unable to detect changes in the management of the donation process prior to and after the study. We did, however, track process variables prospectively throughout the intervention. This allowed us to test the hypothesis that the 3 request process factors would be positively related to consent rates and could be taught to critical care staff. We designed organ donation protocols for each hospital that included the following elements: identification of all potential donors and notifying the OPO before asking each family about organ donation; ensuring a decoupled request; asking families about organ donation in a quiet, private setting; and actively including the OPO coordinator in the donation request.

We observed significant improvements (relative to baseline) in the rates of donor identification, referrals to the OPO, asking families to donate, and donation. Identification rates increased by 6.5 percentage points, referrals by 24.7 percentage points, requests to families by 16.6 percentage points and donation by 9.6 percentage points. We did not observe any change in the rate of family consent to donation suggesting that the observed changes in donation were a function of better identification of potential donors and more requesting of donation from families, rather than a change in the quality of the request process.



The data confirmed the association of higher consent rates with the 3 factors previously mentioned—privacy, decoupling, and a collaborative request involving hospital and OPO staff. However, we did not observe an improvement in actual consent rates. This anomaly was attributable to the fact that the decoupling rate across all hospitals remained at about 49% throughout the project.

This study underlined the vital importance of harnessing hospital systems to ensure consistent practices around the donation request. Relying on hospital staff to comply with the recommended request practices voluntarily is not sufficient. There are many barriers to implementing quality improvement initiatives around organ donation requests. Because donation is such an infrequent event, most staff do not have frequent opportunities to improve their skills. Staff who do become involved are often self-appointed with little or no oversight from any other body in the hospital. Therefore there is no accountability or negative consequences when untrained but well-intentioned staff members perform poorly. The lack of formal donation protocols and associated training opportunities for staff perpetuate poor family care around donation.

⁴ The participating hospitals were divided among the 3 OPOs as follows: CTDN: 24 hospitals; LifeSource: 14 hospitals; WRTC: 12 hospitals. One hospital in California was originally served by another OPO and later added to the study in 1991.

CONCLUSIONS

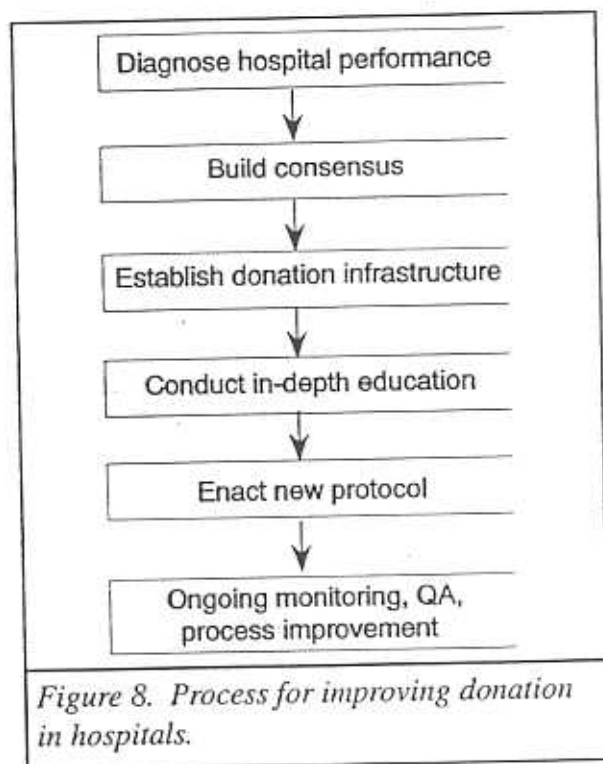
What then are the factors which influence familial consent decisions at the hospital and what can be done to improve donation effectiveness? Data from a number of studies using a range of converging study methodologies (retrospective MRR, prospective donor tracking tools, staff surveys, family interviews etc.) suggest that the care the family receives at the hospital strongly influences consent decisions. Clear and consistent information about the status of the patient, clear explanations of brain death, sensitive, informative and decoupled request procedures which take place in private settings and so forth, all have an enormous impact on the decision-making processes of families of brain-dead patients. However, we have observed that these basic practices are followed only infrequently in actual potential donor situations, even though the concepts have become quite familiar to hospital and OPO staff. Even where one might predict better adoption of these practices, i.e. in large hospitals with transplant programs, we find donation rates that are no better than those found in centers without transplant programs (13). Now the challenge for the transplant and donation communities is to shift from rhetoric to actual practice by harnessing key hospital systems to ensure quality and consistency in requesting donation. Although difficult, these factors can be taught to staff who normally care for families of brain-dead patients. They appear to be necessary in order to fulfill the obligation to allow the family to make an informed decision about organ donation.⁵

Hospital development efforts should include the following key elements (Fig. 8):

- 1) Set an accurate baseline of hospital performance around organ donation. This means conducting a medical records review of donor potential and outcomes, to identify points where potential is being lost (14). If staff are not identifying suitable candidates for organ donation then training should focus on brain death identification procedures and referral to the OPO. If, on the other hand, consent rates are low, the institution will need to address the need for a better designed process for requesting donation and the associated needs for staff training and quality assurance.
- 2) In most large hospitals, formal donation protocols will need to be introduced. This requires consensus among critical care staff and other interested

parties that these new protocols are needed and appropriate.

- 3) Once consensus has been attained, a donation infrastructure will need to be established. This infrastructure should include an oversight committee responsible for tracking institutional donation performance, a point person or small team from within the hospital to provide support to families of potential donors and ensure that communication is well-coordinated as well as interfacing with the OPO staff.
- 4) OPO staff and the in-hospital donation committee should then set up a series of training opportunities for relevant critical care staff which focuses on donation protocols and the best demonstrated request



⁵ The Partnership for Organ Donation is currently collaborating with a group of large hospitals and OPOs across the US to establish formal protocols for organ donation, incorporating what we now understand about "best practices." The intervention model also includes designating an in-hospital team to ensure quality and consistency in family communication related to organ donation, and to guarantee smooth coordination with, and active involvement of the OPO. The design also encompasses intensive education, as well as long-term monitoring and quality assurance procedures to ensure that the protocol becomes the practice norm. It is too soon to know the outcome of this work; by late 1998 there will be sufficient data to share the outcome of this work with the donation and transplantation communities.

- practices. The goal for the in-hospital donation specialists is to attain a high level of competency and comfort in coordinating a complex process and in interacting with grieving families. For the rest of the critical care staff, the key messages revolve around their role in the protocol, and how and when to access expert resources on donation to assist in the communication and management of the case.
- 5) The protocol then needs to be enacted with the appropriate clinical trigger. Choosing an objective clinical trigger to activate the protocol simplifies the process by minimizing the degree of subjective judgment involved. It is also helpful to enact the new protocol at a particular point in time, so that staff can be adequately prepared for the change.
 - 6) With each protocol activation, data should be collected and then used to provide feedback to involved parties to ensure continuous quality improvement across the entire process. This feedback mechanism requires installation of a performance measurement and monitoring system for ongoing quality control.

What we have demonstrated in the studies reviewed above is that when quality family care occurs in the hospital we can expect a corresponding response from the families. The challenge ahead is to transform these findings into standard, accepted practice in hospitals across the country so that families faced with terrible loss receive appropriate support, allowing them to say yes to donation.

APPENDIX ON METHODS

Any investigation of family decision making around organ donation faces several significant logistical and design problems. Organ donation is a rare event at even the largest of hospitals and data collection therefore tends to be time consuming, expensive, and episodic. In addition, assessment of actual family decision making as events unfold in the hospital has to be indirect as direct interviews would constitute an intrusion on family privacy. Direct observers may also influence the very decision-making processes we want to study thus creating validity problems for the study. Instead, we have relied on unobtrusive or observational data collection techniques which utilize hospital and OPO staff as data collectors. In order to corroborate data collected by these involved parties we supplement direct observational data with

retrospective data from reviews of medical records." In addition we often survey large numbers of hospital staff in order to derive a profile of current staff knowledge and practices around donation and, finally, we have developed techniques to follow-up with families themselves via structured phone interviews 6 months after the hospitalization of their relative. We turn now to a summary of strengths and limitations of each of these data collection techniques.

Data Collection Tools

1. Medical record review methodology (MRR)

MRR is used to measure a hospital's donor potential and to identify what happens to that potential. It is therefore an ideal technique for measurement of a hospital's performance vis-a-vis families of brain-dead patients (14). Each case of brain death is identified and its outcome is recorded. Charts are examined individually to confirm the absence of medical contraindications to donation and to determine whether patients met the clinical criteria for brain death. A "potential donor" is classified as a patient who has conditions consistent with brain death and who shows no sign of medical unsuitability based on the ICD-9-CM codes and chart review. An organ *donor* is defined as a medically suitable case that results in organ recovery intended for transplant.

MRR "outcomes": Measures of hospital donation performance include: *request rate* (number of requests / potential number of donations), *family consent rate* (number of consents / (number of donation requests) and *donation rate* (number of successful donations/potential number of donations, as revealed by MRR). "*Not asked*" rate indicates the percentage of suitable cases whose families were not approached for donation. The "*not identified*" rate indicates the percentage of suitable brain death cases that were not identified as brain dead. Reliability analyses for these MRR coding procedures have been reported elsewhere (4) and indicate very high agreement among independent coders. Copies of data collection instruments are available upon request.

Limitations of MRR: Although MRR provides an objective source of information about potential donor candidates, results may be affected due to non-documentation of certain key elements. Missing documentation would have an impact on estimates of the number of patients who were not identified, the number of families not asked about donation, and ultimately, the number of

families who denied consent. One way to deal with these problems of non-documentation is to supplement the retrospective MRR-driven data collection effort with prospective data collection tools.

2. Donor Tracking Tool (DTT) The primary prospective data collection instrument we use is the DTT. The tool is designed to track information on how a family of a brain dead patient is approached for donation. What is the quality of the request a family receives from staff who care for that family? We assume that quality family care involves clear, consistent and sensitive delivery of information concerning the status of the patient. The option of donation is not presented until the family has had time to absorb the meaning of the brain death diagnosis (a "decoupled request"). Communication with the family is respectful of its privacy and needs for information and so on. The DTT is usually completed by in-hospital (organ) donation coordinators employed by the hospital or by the local OPO coordinator. Coordinators collect the data either first hand after witnessing or taking part in the request or by gathering the relevant information from the personnel who were involved in the request.

Limitations of DTT. As mentioned above, a potential limitation of use of the DTT to track the quality of donation requests is the reliance on hospital or OPO staff who might be considered biased observers, as data collectors. The reasons for reliance on these individuals as data collectors were mentioned above. To check for biased reporting we analyzed outcomes as reported by OPO staff as a function of OPO involvement and found that over 70% of donation requests in which they themselves participated did not include "favorable" outcomes. It seems unlikely, therefore, that data collection/reporting with the DTT carries a major risk of systematic bias.

3. Hospital Survey Instrument. Quality family care around organ donation requires a knowledgeable and supportive critical care staff. In order to assess the readiness of critical care staff to effectively handle interactions with the families of brain dead patients we survey relevant staff on their knowledge, training and comfort levels with brain death, working with grieving families, requests for donation and so forth. The survey instru-

ment is composed of 16 key questions and takes roughly 10-15 minutes to complete. It contains items in multiple formats including several in Likert Scale format, true/false forced choice items and open-ended questions.

Limitations of surveys. The most serious limitation of survey-derived data is low response rates. In our studies we generally achieved reasonable response rates although we were not always able to collect information on non-respondents. Logistical problems in carrying out the survey in so many hospitals across a variety of critical care units are formidable but not impossible to deal with.

4. Structured Interviews. A crucial source of information concerning care of families of brain dead patients and family consent decisions is of course the family itself. Since interviews with the family at the hospital (at the time of their relative's death) might be experienced as an added burden by the family we elected to interview families 6 months after the death of their relative. We used a structured interview technique with trained interviewers. Interviews are conducted over the phone and last about an hour. A range of issues are covered: 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 their knowledge and attitudes about organ donation and transplantation. Key to the success of this type of data collection, especially among non-donor families, is rigorously screening the survey instrument and all communications with families for "pro-donation" bias.

Limitations of structured interviews with the families. As with surveys of hospital staff, the most serious methodological limitation with interviews is the sampling problem: are respondents representative of those who did not respond. A second limitation is that these interviews are based on subject's recollections and thus are accurate only to the extent that subject's memories of these events are accurate. It is also particularly important to use trained interviewers when dealing with families who might still be grieving the loss of a relative 6 months after the death.

SUMMARY

More than half of the nation's donor potential is lost due either to failure to identify medically suitable potential donors, or to family refusal to donate. While family consent rates typically average around 50% we show that these rates can be substantially improved by incorporating a few simple request process ele-

ments that are designed to meet the needs of grieving families. If relevant critical care and OPO staff are trained and empowered to carry out high-quality request procedures, consent rates, and donation overall can increase substantially.

REFERENCES

1. 1995 Annual Report of the US Scientific Registry for Transplant Recipients and the Organ Procurement and Transplantation Network – Transplant Data: 1988-1994. UNOS, Richmond, VA, and the Division of Organ Transplantation, Bureau of Health Resources Development, Health Resources and Services Administration, US Department of Health and Human Services, Rockville, MD.
2. Nathan HM, Jarrell BE, Broznik B, et. al. Estimation and characterization of the potential renal organ donor pool in Pennsylvania: Report of the Pennsylvania Statewide Donor Study. *Transplantation* 1991; 51:142.
3. Evans RW, Orians CE, Ascher, NL. The potential supply of organ donors: An assessment of the efficiency of organ procurement efforts in the United States. *Journal of the American Medical Association* 1992; 267:239.
4. Gortmaker SL, Beasley CL, Grenvik A, et. al. Organ donor potential and performance: Size and nature of the organ donor shortfall. *Critical Care Medicine* 1996; 24:432.
5. Christiansen CL, Gortmaker SL, Williams JM, et. al. A method for estimating solid organ donor potential by organ procurement region. Manuscript submitted for publication.
6. Siminoff LA, Arnold RM, Caplan AL, et. al. Public policy governing organ and tissue procurement in the United States. *Annals of Internal Medicine* 1995; 123:10.
7. Radecki CM, Jacard J. Psychological aspects of organ donation: A critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychology* 1996; 16:183.
8. Gallup Organization, Inc. The American Public's Attitudes Towards Organ Donation and Transplantation. Conducted for the Partnership for Organ Donation, Boston MA, 1993.
9. DeJong W, Franz HG, Wolfe SM, et. al. Requesting organ donation: An interview study of donor and non-donor families. *American Journal of Critical Care*. In press.
10. Franz HG, DeJong W, Wolfe SM, et. al. Explaining brain death: a critical feature of the donation process. *Journal of Transplant Coordination* 1997; 7:14.
11. Evanisko MJ, Beasley CL, Brigham LE, et. al. Readiness of critical care physicians and nurses to handle requests for organ donation. *American Journal of Critical Care*. In press.
12. Beasley CL, Capossela CL, Brigham LE, et. al. The impact of a comprehensive, hospital focused intervention to increase organ donation. *Journal of Transplant Coordination* 1997; 7:6.
13. Sheehy E, Porotsky, A, Gortmaker S, et. al. Relationship of hospital characteristics to organ donation performance. *Transplant Proc* 1996; 28:139.
14. McNamara P, Franz HG, Fowler RA, et. al. Medical record review as a measure of the effectiveness of organ procurement practices in the hospital. *The Joint Commission Journal on Quality Improvement*. 1997; 23:321.