Increasing Organ Donation: A Successful New Concept

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ABSTRACT

Background: Organ donation rates nationally have changed little in the last 15 years, despite a growing waiting list. About 6000 patients die each year for lack of a donated organ. South Carolina’s organ procurement organization, LifePoint, recently restructured itself in an effort to increase donation and transplantation rates. The main change was division of the procurement coordinator position into five new positions. A unique innovation was the creation of a bereavement counseling and education service to provide families of potential donors emotional support as well as education regarding brain death and the value of transplantation.

Methods: Retrospective review of Association of Organ Procurement Organizations data and LifePoint’s in-house databases, covering the period from 1997 to 2001.

Results: From 1997 to 2001, donation rate within LifePoint’s service area increased from 18.2 to 33.6 donors per million of population (85%) and transplantation rate increased from 54.8 to 108.6 transplants per million of population (98%), while the national rates were virtually unchanged (p<0.01).

Conclusions: Division of procurement function into several separate positions, including family bereavement counseling and education, can substantially increase donation and transplantation rates. If these innovations could be effectively adapted by other organ procurement organizations, the number of patients nationally who die on waiting lists could be substantially reduced.
INTRODUCTION

The gap between the number of patients with end-stage organ failure on transplant waiting lists in this country and the number of organs available for transplantation has continued to grow at an alarming rate. Over the last 10 years, the need for organs has grown nearly 5 times faster than the number of cadaveric donors. The annually compounded rate (1990-2000) of increase in number of patients on waiting lists has averaged 14.1% a year, while the rate of increase of donors has averaged 2.9% a year. Donation rates have remained relatively stable in recent years, despite intensive educational efforts aimed at the general public and the passage of several laws intended to increase donation rates. The number of patients dying each year while awaiting a donated organ has recently been around 6,000. The puzzle of how to increase donation rates has stubbornly resisted virtually all solutions.

South Carolina has a population of 3.6 million and is served by a single organ procurement organization (OPO), LifePoint. The state is small and mostly rural, with a generally low national standing in measures of educational level, and therefore is an unlikely candidate for high organ donation rates. Since 1999, however, LifePoint has instituted changes that have dramatically increased donation rates and organs available for transplantation. It has accomplished this by altering the guiding vision of the organization, changing its mission and goals, and restructuring to reach these new goals. The most critical new concept was to provide intensive emotional support and education of families of potential donors at the time of their sudden and unexpected loss. This is accomplished with a

*Formerly known as South Carolina Organ Procurement Agency (SCOPA)
Family Support Service that is unique among OPOs.

In this communication, we describe the DOVES (Donation Opportunity after Valuable Education and Support) program that has led to markedly improved donation rates. We also speculate on why DOVES has worked well and on implications for organ donation nationally.

MATERIALS AND METHODS

Early structure and function

Like all OPOs, LifePoint is responsible for many aspects of the donation process: responding to initial referral of potential donors, securing consent from families, managing donors from declaration of death to removal of organs in the operating room, distributing organs to transplant centers, and handling follow-up contacts with donor families. Before 1999, one of 8 procurement coordinators handled all these responsibilities for each donor. The 8 procurement coordinators also were on-call for offers of organs from outside the service area, for flying to distant locations to procure organs, and for all hospital staff education. There was little division of labor throughout the donation process. Public education and administrative tasks were handled by 6 other employees.

Throughout the period from 1984, when LifePoint was founded, to 1998, the donation rate (donors per million of population) in its service area was consistently below the median of national OPO rankings. These persistently low donation rates in our state led us to thoroughly evaluate LifePoint’s structure and function. There was little sense of an organization-wide approach to organ donation, and this fragmentation led to wide variations in the way coordinators related to families of potential donors, to hospital staff, and to other coordinators. Each procurement coordinator was responsible for all aspects of donor
services, though each performed some specific services well and others less well. The entire donation process, from receiving the referral telephone call to completing the paperwork after distribution of organs, was lengthy, lasting from 12 to 36 hours.

The combination of highly complex tasks and long time periods needed for completion of each donation made it difficult for coordinators to handle several donors in succession, and led to early burnout. Responsiveness to referrals and enthusiasm for starting new donors were adversely affected by the intense workload, resulting in a relatively low consent rate.

Factors external to the organization also worked against donation. Nationally, the general population has a poor understanding of brain death, as do many health care professionals, including physicians and nurses. Hospital staffs are short-handed and hard-pressed to provide the expected high level of patient care, so insufficient time is available for them to support adequately the acutely grieving family and explain the need for transplantation, the process of dying, and the meaning of brain death. Consent rates are substantially lower when initial mention of donation to the family is made by a physician or hospital staff member rather than a trained requestor. Refusal to donate by families is the single most important factor in low donation rates. Moreover, South Carolina’s population has a generally low level of education and the state is largely rural; both factors may militate against high donation rates.

Development and implementation of new program

In response to this set of adverse factors, a pilot program was carried out in 1998 at a single hospital, the Medical University of South Carolina (MUSC), in cooperation with the Department of Neurosurgery at that institution. Specially trained coordinators were assigned to provide bereavement support services and education regarding brain death and
transplantation to families of potential donors. These coordinators spent substantially more
time with families, on the order of 6 to 12 hours for each family, than was possible for
hospital staff. Within a year after the pilot program began at MUSC, the consent rate at that
center doubled from 30% to 60%.

Stimulated in part by that experience, reorganization of LifePoint was initiated. To
improve donation rates, we identified strategies used by other OPOs or recommended in
evidence-based literature, and chose for implementation those most likely to be effective in
our environment. We developed a strategic plan that included a vision statement describing
the future shape of the organization, a concise mission statement, and a set of goals,
objectives, and strategies, each with specific measurable outcomes and specific time frames
in which they would be completed.

The fundamental change was in conceptualization of the organization’s purpose.
LifePoint continued to hold the OPO contract with the Department of Health and Human
Services’ Centers for Medicare and Medicaid Services (CMS, formerly the Health Care
Financing Administration) to provide procurement services in South Carolina. The OPO’s
mission included maximizing the number and quality of donated organs, as well as providing
public and professional education regarding donation. A separate mission was conceived,
however, for the new and unique Family Support Service, which aimed not to increase
consent rate, but to assure that families of dying patients referred to LifePoint made well-
formed decisions about donation and had timely bereavement counseling and follow-up.
The basic structural change was division of the procurement coordinator’s functions into five
distinct positions, briefly summarized in the Table. Each of the coordinator positions was
filled with an experienced professional who had a background appropriate for the tasks, as
noted in the Table. The total number of field staff increased from 8 to 21. An important functional change was to increase administrative oversight by directing all referral calls to an administrator-on-call, who was also responsible for most decisions regarding management of the donation and procurement processes. This allowed for consistent response to the critically important referral call, for efficient assignment of personnel, and for improved consistency and accuracy of donor and process management. The number of administrators (four) remained unchanged throughout the transition. A new medical director became actively involved in managing organizational change and the procurement process.

Each component of DOVES’ goals had targeted objectives. For example, to increase the total number of potential donors, Clinical Services Liaisons worked with hospital staffs to achieve timely referral of all potential donors. To optimize the consent process, hospital staffs were encouraged to “decouple” the donation request from notifying the family of brain death, and to assure that a Family Support Counselor was present when donation was first mentioned to the family. To increase the number of available organs, LifePoint developed treatment protocols in collaboration with transplant center physicians, aiming to keep organs in as physiologically sound condition as possible.

Data Collection and Analysis

The donation rate is number of donors per million of service area population and the transplantation rate is number of organs supplied to the transplantation system per million of service area population. The time period we investigated was from 1997 (when no changes had taken place), through 1998 (the year of the pilot study at MUSC) and 1999 (the transition year), concluding in 2001, when DOVES had been fully functional for two years and the latest year for which data are complete. To evaluate the effect of the new program on
donation, we used two sources of data: the national database of the Association of Organ Procurement Organizations (AOPO)\(^8\) and LifePoint’s in-house database. From the AOPO database, we extracted, for each year, donors per million of service area population and number of organs supplied to the transplantation system per million of service area population, for LifePoint and for all OPOs.

We defined the consent rate as the number of donors per referral of medically suitable potential donors. A potential donor was defined as a neurologically compromised patient who had deteriorated to a Glasgow Coma Score of 3 and had no absolute contraindications to donation. From LifePoint’s database, we extracted the number of referrals of medically suitable potential donors, total number of consents, and number of consents when the initial contact with a family regarding donation included a LifePoint coordinator. (These data were available only since 1997.) Using these raw numbers, we calculated total consent rate (consents per referral of medically suitable potential donors), as well as LifePoint consent rate (consents when the initial mention of donation to a family regarding donation was made by a LifePoint coordinator).

To determine the costs associated with implementation of DOVES, we used LifePoint’s database to gather information on expenditures during the period of the study. To measure the effect of DOVES on expenses of the organization, we calculated the rate of growth in LifePoint's expenses per organ transplanted, and compared it to the rate of growth of the national consumer price index for medical care\(^9\) over the same period. We calculated separately the rate of growth of administrative and general expenses (including personnel costs) and of direct expenses (those related to procurement of organs).
Statistical Methods

Trends and comparisons of donor rates and transplantation rates were evaluated using Poisson regression. Linear regression was used to compare the expense per organ transplanted with the consumer price index for medical care. Changes in both total and LifePoint consent rates were analyzed using the test for linear trends in proportions. P values less than 0.05 were considered to indicate statistical significance. All analyses included data for each of the five years from 1997 to 2001.

RESULTS

Donation rate increased by 85% from 1997 to 2001, from 18.2 to 33.6 donors per million of population. (Figure 1) Transplantation rate increased by 98%, from 54.8 to 108.6 per million of population. (Figure 2) Both donor rate (p<0.01) and transplantation rate (p<0.001) increased significantly when compared with national rates.

The number of referrals of medically suitable potential donors rose from 200 in 1997 to 298 in 2000 (49%), while the number of consents rose from 61 to 175 (187%). The total consent rate increased by 97%, from 61/200 (31%) in 1997 to 175/298 (61%) in 2001 (p<0.0001). LifePoint consent rate rose by 137%, from 39/113 (35%) in 1997 to 139/167 (83%) in 2001 (p<0.0001). The proportion of referrals in which initial contact with the family regarding donation included a LifePoint coordinator was essentially the same in 1997, 113/200 (57%), as in 2001, 167/298 (56%).

LifePoint’s total expenses rose from $2.94 million in 1997 to $7.91 million in 2001 (169%; p<0.05). The majority of the increase was related to direct expenses, which rose from $1.25 million to $4.89 million (291%); a smaller share of the cost increase was related
to administrative and general expenses, which rose from $1.69 to $3.02 million (79%). The cost per organ transplanted increased from $16,799 in 1997 to $19,870 in 2001, an increase of $3,071 (18%), while the consumer price index for medical care in the United State rose by 16% (p=NS). (Figure 3)

DISCUSSION

Implications of the DOVES model

This experience demonstrates two important points: 1) Donations and organs available for transplantation can be increased substantially by organizational changes emphasizing division of labor and emotional support and education of families. 2) Implementing a program like DOVES can be expensive, but need not significantly increase cost per organ transplanted.

Implementation of DOVES was associated with an increase in donation rate of 85% from 1997 to 2001, and an increase in transplantation rate of 98%, while national rates were virtually unchanged over the same period. The two main factors that determine donation rate are number of referrals of medically suitable donors, influenced mainly by Clinical Services Liaisons, and the rate of consent to donate, influenced mainly by Family Support Counselors. Both increased after implementation of DOVES, but the largest change from 1997 to 2001 was in the total and LifePoint consent rates, which increased by 97% and 137%, respectively. These findings confirm a recent retrospective study that suggested that more family contact with OPO staff and an optimal request process were likely to increase donation rates. Most of the increase in donation rate came from referrals in which the initial contact with a family regarding donation included a LifePoint coordinator. Little further growth can be expected in the consent rate achieved by Family Support Counselors (83%), because it is
already close to the proportion of the population that expresses support for organ donation, about 85% in several surveys. Hospital development that aims to encourage hospital staffs to involve LifePoint in initial family contact has potential to produce considerable growth in donation rates, because 44% of referrals still involve initial mention of donation by someone other than a LifePoint coordinator.

The results of the DOVES program may have national implications. In 2001, there were 69.7 transplants per million of population nationally, compared with LifePoint’s 108.6, a difference of 55.8%. If all OPOs had achieved the same transplant rate as LifePoint’s, the number of transplants in this country would have increased from about 20,000 transplants to over 31,000. More than 11,000 additional lives would therefore have been saved or improved. This would likely have substantially reduced deaths on the waiting list, which have recently been on the order of 6,000 deaths annually.

The organizational changes we have implemented have proven to be expensive. Since 1997, the total expenses of LifePoint have increased by 169%, due more to increased procurement activity than to higher personnel costs. Yet, because of increases in the number of organs transplanted annually, the cost per organ transplanted increased by only 18%, not significantly different from the rate of inflation for medical care costs, 16%.

**Ethical implications of the Family Support Service**

The terminal illness of a potential donor is usually unexpected and of sudden onset: for example, motor vehicle accident, accidental drowning, or stroke. Therefore, the family’s emotional state at the time of such a death reflects great personal loss, emotional pain, and grief, often against a background of denial that their loved one is actually gone. Moreover, the concept of brain death is widely misunderstood; it is believed to be something less than
‘real’ death. The natural tendency to deny that death has occurred is reinforced by the belief that brain death is not really death, that there is hope even when death has been pronounced. This emotional constellation creates a barrier for most families to consider organ donation, and makes refusal far easier than consent. Refusal of donation by families is the leading factor in the shortage of organs available for transplantation.

We believe that the intractability of the problem of increasing donation rates nationally is related in part to general lack of understanding of the effectiveness of transplantation and the meaning of brain death. It is also our impression that public education efforts, the mainstay of campaigns to increase organ donation rates, have failed to achieve their goals because most people do not want to think about their own mortality or the eventual and inevitable death of their loved ones. The success of DOVES is related to the changes made in all aspects of the donation process. We attribute the lion’s share of the success, however, to the addition of the Family Support Service. This service has been responsible for most of the increase in consent rate we have observed. Its implementation has presented many advantages, but at the same time has posed ethical challenges deserving of special comment.

Families of patients dying with acute neurological damage need intensive emotional support and clear explanation of the implications of donation, procurement and transplantation. Most hospitals are not prepared to provide the required lengthy support and education. Therefore, most of the time, the decision to consent or to refuse donation is not well informed. The DOVES model presupposes that a better-informed decision will most often be in favor of donation. We therefore focus on providing the many hours of emotional support and education of families of potential donors to assure that their decision is as informed as possible. We have offered to train hospital personnel in the specialized
knowledge and techniques needed to be “designated requestors” (the terminology used in federal regulations regarding OPOs), but few have accepted. Thus, it has fallen to LifePoint to provide this critically important service.

Family support cannot be successful if it remains part of the procurement function of the organization. The Family Support Counselors must serve only the interests of the potential donor and the family, because a truly informed consent or refusal requires that the information disclosed to the family be unbiased. Even the perception of bias subverts this requirement, because the emotional support needed by families would be seriously weakened were they to suspect they were being manipulated by an agency committed only to procuring organs.

A potential conflict of interest exists between LifePoint’s role in organ procurement and its role in supporting families. This potential conflict requires that the Family Support Service be isolated as a separate function of the organization, with a separate mission. Our coordinators do not attempt to obtain consent for donation. Instead, they provide unbiased information, and when the family has arrived at an appropriate level of understanding, they describe options to them. Their options include consent to donate, refusal of donation with consequent discontinuation of pharmacological and mechanical support, and, rarely, when permitted by hospital policy, continuation of support until cardiopulmonary arrest occurs. Irrespective of the choice made by the family, bereavement support continues throughout and after the hospitalization. The Family Support Service and the aftercare program are not linked in any way to consent for donation.

We believe that the family support LifePoint provides is not only ethically acceptable, it is ethically necessary. Informed consent critically depends upon accurate, unbiased
information provided without deception or ulterior motives. Hospital caregivers who are known and trusted by families would be the best source of such information, but they are often overwhelmed by demands for patient care, especially in critical care units. They cannot provide the many hours of careful and repetitive explanation required for optimal understanding, nor do they have the knowledge of the donation process to answer accurately questions related to donation, procurement, and transplantation. We created the role of Family Support Counselor to provide this sorely needed service.

**Inferences and Conclusions**

The DOVES program has divided the donation process into several distinct parts, each assigned to a coordinator with specific expertise in that area. The single most effective and important alteration has been the addition of the Family Support Service. It addresses the central causes of the current low donation rate nationally: acute grief of the family in the wake of a sudden and unexpected death, the power of denial in the face of that death, and the general misunderstanding of brain death and of the value of transplantation. Sensitive, caring bereavement support and unbiased education by Family Support Counselors enable families to make as informed a decision about donation as is possible under the circumstances. Our data support our presupposition that a secondary consequence of such support is increased likelihood of consent to donate.

The inadequate numbers of cadaveric donations nationally has contributed to the deaths of thousands of patients with end-stage organ failure each year. Numerous voluntary and legislative efforts to elevate the slope of donation rate have had little impact. Many of the organizational innovations we report have been recommended in the past, but have not been implemented in the comprehensive manner that DOVES has achieved. A unique component
is the Family Support Service that functions independently of the procurement process. We have shown that such a program may increase donation rates substantially in a mostly rural state with a generally low education level.

We cannot be confident that our observations and experience with organizational changes are generalizable, because there are wide variations in the cultures of OPOs and the demographics of their service areas. Nevertheless, our experience has been so salutary that we feel justified in suggesting that other OPOs should examine the possibility of making similar changes in their organizations, and should consider adopting parts of the DOVES model that may be relevant to their own situations. There is little to lose and perhaps thousands of lives to save.
ACKNOWLEDGEMENTS:

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LEGENDS

Table: Specialization within the procurement process

This table describes how the DOVES program divided the single position of Procurement Coordinator into five distinct positions, including their functions and goals, and the professional backgrounds of those who filled the new positions.

Figure 1. The number of donors per million of the OPO’s service area population for the four year period starting immediately before implementation of the DOVES program (1997) to the most recent year of complete data (2001).

Figure 2. The number of transplants emanating from the OPO per million of the OPO’s service area population for the four year period starting immediately before implementation of the DOVES program (1997) to the most recent year of complete data (2001).

Figure 3. The annual change from base year 1997 in cost per organ transplanted and in the consumer price index for medical care.
<table>
<thead>
<tr>
<th>Function</th>
<th>Goals</th>
<th>Background</th>
</tr>
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<tbody>
<tr>
<td>Clinical Services</td>
<td>educates medical and hospital staffs in OPO’s service area regarding donation process, reviews hospital records for appropriateness of referrals</td>
<td>to assure staffs’ understanding of brain death, need for organ donors, legal obligations, and procedures of LifePoint</td>
</tr>
<tr>
<td>Liaison</td>
<td>to assure staffs’ understanding of brain death, need for organ donors, legal obligations, and procedures of LifePoint</td>
<td>educators or sales and marketing executives</td>
</tr>
<tr>
<td>Family Support</td>
<td>cares for families, offers donation option; no other role</td>
<td>bereavement counselors or social workers, some from minority groups</td>
</tr>
<tr>
<td>Counselor</td>
<td>to assure that family makes well informed decision, to provide emotional support, whether or not consent granted</td>
<td></td>
</tr>
<tr>
<td>Donor Clinician</td>
<td>provides intensive management of donor in intensive care unit after death is pronounced, identifies recipient transplant centers</td>
<td>to optimize donor’s physiology prior to organ procurement, to place organs with transplant centers</td>
</tr>
<tr>
<td></td>
<td>to optimize donor’s physiology prior to organ procurement, to place organs with transplant centers</td>
<td>intensive care nurses</td>
</tr>
<tr>
<td>Recovery Coordinator</td>
<td>supports transplant surgical teams in operating room (local and remote), prepares organs for transport to transplant centers</td>
<td>to assure efficient surgical procurement of organs, to preserve and distribute organs</td>
</tr>
<tr>
<td></td>
<td>to assure efficient surgical procurement of organs, to preserve and distribute organs</td>
<td>operating room nurses or technicians</td>
</tr>
<tr>
<td>Aftercare Coordinator</td>
<td>follow-up contacts with family, manage support groups, provides (or refers) bereavement counseling, carries out satisfaction surveys</td>
<td>to provide post-donation support to families, to assimilate donor families as part of donation system</td>
</tr>
<tr>
<td></td>
<td>to provide post-donation support to families, to assimilate donor families as part of donation system</td>
<td>experienced psychological counselors</td>
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REFERENCES


8 American Association of Organ Procurement Organizations. Falls Church, Virginia.


