A Study of the Presumptive Approach to Consent for Organ Donation

A New Solution to an Old Problem

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For more than 10 years, organ procurement organizations (OPOs) have publicly lamented the fact that organ donation rates have consistently remained stagnant. The past few years have witnessed a significant increase in the number of deceased donors; however, the number of organs recovered from deceased donors is not enough to meet the increasing demand. The disparity between the number of organs available for transplantation and the number of patients in need continues to grow. Refusal by families of potential donors to give consent for donation continues to be a major obstacle in organ donation.

Many solutions have been proposed to increase consent rates, including mandated choice, presumed consent, and financial incentives for donation. The OPO community has always concerned itself more with the actual decision than with the motivation behind the decision. Little is known about why some individuals decline to donate, and even less is known about the motivations of those who do decide to donate. The Study of the Presumptive Approach to Consent for Organ Donation is one of the first systematic national studies conducted to (1) determine whether the manner in which a patient’s family members are approached for organ donation influences the family’s decision to donate and (2) measure the impact of a new approach on organ donation rates. In this article, we discuss in detail the philosophical perspective behind the shift from the standard approach to the presumptive approach and discuss specific, measurable aspects of presumptivity.

The Presumptive Approach

The presumptive approach is based on 2 philosophical assumptions: (1) that most persons in the United States, when given the opportunity to save a life, will do so and (2) that organ donation is the right thing to do. The Study of the Presumptive Approach to Consent for Organ Donation is one of the first systematic national studies conducted to (1) determine whether the manner in which a patient’s family members are approached for organ donation influences the family’s decision to donate and (2) measure the impact of a new approach on organ donation rates. In this article, we discuss in detail the philosophical perspective behind the shift from the standard approach to the presumptive approach and discuss specific, measurable aspects of presumptivity.

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History of Organ Donation and the Standard Approach

The presumptive approach can be described as a shift in the language used by a requestor when approaching the family of a potential...
organ donor. Historically, requestors have used what has been referred to in the transplant community as a value-neutral approach, or one in which donation is described in an unbiased manner. The hallmark of this approach is that the requestors offer donation as one option for a patient’s family after the patient has been declared brain dead. The focus is on obtaining permission by anticipating and systematically overcoming the family’s objections. The requestor’s primary role is as a grief counselor and liaison between the family of the potential donor and the medical staff. The requestor focuses more on helping the family through the grieving process than on the decision about organ donation. For many years, this philosophy was appropriate and necessary because of the culture of organ donation.

In the early years of transplantation, before the establishment of independent OPOs, the United Network for Organ Sharing, and the Organ Procurement and Transplantation Network, little regulation existed about the way in which patients’ families were approached for donation. This lack of regulation led to an overall sentiment of great skepticism and ethical concern at a time when organ donation was new. As a result, a system of third-party neutral requestors, OPOs, was instituted to discuss the option of donation with patients’ families. OPOs were given defined jurisdiction over specific hospitals in geographic areas to prevent competition for organs. Requestors were to be neutral parties, without a vested interest in either the decision to donate or the outcome for the transplant recipient.

In the past decade, a remarkable change has occurred in the culture of organ donation and transplantation. Organ transplantation, once considered an unusually extreme measure to prolong life, is now considered commonplace, and a much more established aspect of culture. Transplantation is featured in entertainment television, news programs, movies, and many other media. Donation is no longer foreign to most people in the United States. In fact, surveys indicate an overwhelming support for organ donation.

Unfortunately, consent rates in the United States do not seem to reflect this sentiment about donation. One possible explanation for this disparity is the request process. The public is regularly exposed to the need and benefits of donation, yet when the time comes to discuss donation, requestors continue to resort to the traditional approach. The presumptive intervention is an attempt to shift the philosophy used by requestors when discussing organ donation with patients’ families to one that more accurately reflects contemporary values and culture (Table 1).

### Table 1: Comparison of standard and presumptive philosophical approaches in requests for organ donation

<table>
<thead>
<tr>
<th>Standard</th>
<th>Presumptive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requestors act as grief counselors</td>
<td>Requestors are part of the medical team that specializes in donation</td>
</tr>
<tr>
<td>Requestors view themselves as advocates of the families of potential donors</td>
<td>Requestors view themselves as advocates for both donors and recipients</td>
</tr>
<tr>
<td>Requestors use value-neutral language: I’m here to provide you with information about organ donation</td>
<td>Requestors use value-positive language: I’m here to provide you with the opportunity to donate your loved one’s organs</td>
</tr>
<tr>
<td>The approach is passive: Did you ever discuss organ donation with your loved one?</td>
<td>The approach is active: The overwhelming majority of people in the United States support organ donation and transplantation</td>
</tr>
<tr>
<td>Requestors raise the possibility of donation: We will support you in whatever choice you make</td>
<td>Requestors are affirmative about donation: Most people, if given the chance to save a life, will do it</td>
</tr>
<tr>
<td>The request for consent is nonpresumptive: If you decide to donate …</td>
<td>The request for consent is presumptive: When you decide to donate …</td>
</tr>
</tbody>
</table>

**Method and Focus of the Presumptive Approach**

Currently, OPOs and donation requestors are charged by the federal government to obtain consent and recover transplantable organs. Fulfilling this obligation to recover organs requires the support of critical care nurses and intensive care unit teams. The presumptive approach is one method to increase the number of organs available for transplantation, and it is important for critical care personnel to understand the philosophy behind the method.

Presumptivity is based on the assumption that persons who consent to organ donation do so because of the desire to help others and the potential to save lives. Information that focuses on this motivation is presented as a key element of the conversation in which donation is requested. When using the standard (current) approach, the requestor approaches a patient’s family with
the mind-set that the requestor must overcome the family’s objections to donation. As a result, the requestor is limited to providing the information necessary to overcome the objections that he or she presupposes the family will have.

The presumptive approach re-directs the conversation about consent from one that historically has been process driven to one centered on the benefits of donation and the opportunity to save lives. In the past, designated requestors for organ donation often approached patients’ families with the assumption that the families had little knowledge of donation, and requestors were trained to discuss the clinical process of donation in such a way as to address families’ discomfort and objections in order to obtain informed consent from families. Conversations of this nature emphasized the clinical aspects of donation that elicit a visceral response to the donation process. This approach may have provided negative reinforcement about the donation process and made obtaining consent more difficult. The information provided as a result of this strategy focuses the discussion on the less palatable aspects of donation and creates unnecessary obstacles for both the patient’s family and the requestor.

With the presumptive approach, the requestor assumes that patients’ families consent to donation not because a particular type of incision will be used or because an open-casket funeral is possible, but because donation is the right thing to do. Although each family should be made aware of such facts, the purpose of the initial conversation should be to provide information relevant to the family’s decision. Donation requestors should focus on the reasons that compel people to donate. The family needs to know that the donation will save the lives of up to 8 patients who would otherwise die. Organ donation is an opportunity for the family’s loved one to leave a legacy and become a “hero” to all of those who benefit from the donation. When presented in this manner, organ donation is no longer a difficult decision; rather it is an obvious one. By focusing on the benefits of donation, the requestor shifts the tone of the conversation from discomfort and doubt to compassion and possibility. This shift enables the family to understand donation as an incredible opportunity and to concentrate on the family’s ability to turn a terrible situation into something positive and hopeful.

Donation requestors who use the presumptive approach are taught to avoid closed-ended questions. Closed-ended questions, especially those that elicit negative responses, can derail or halt a consent conversation. Once a family has a negative response to any question, it may be difficult for the requestor to resume the conversation and focus on the benefits of donation. With the presumptive approach, the donation requestor uses open-ended questions to promote discussion, understand the family’s grief process, assess the family’s understanding of brain death, and move toward donation with deliberate and positive information.

### Key Elements of the Presumptive Approach

Table 2 summarizes the 6 key elements in the presumptive approach. These specific elements provide donation requestors a framework in which to understand presumptivity, and requestors are encouraged to adapt the elements to their current practice in ways that are comfortable. As a result of this strategy, presumptivity is constantly evolving in the field and in training sessions.

#### Intention to Be Presumptive

A donation requestor should intend to use the presumptive approach with the family of any potential organ donor unless the family has previously expressed a strong and definite opposition to donation. If a family is opposed to donation, the requestor should still approach the family with presumptive statements, but the assumption that the family wants to donate may be inappropriate.

Donation requestors are, and should be, advocates of donation. The intent to be presumptive begins with an acknowledgment of this role.
and the recognition that donation is a good thing. It is the responsibility of the requestor to affirm this belief to the family of any potential organ donor. In this sense, presumptivity provides donation requestors not only with the confidence of knowing that what they are doing is right but also with the permission and tools to act on their natural inclination.

Furthermore, the requestors’ intention to be presumptive involves envisioning themselves as part of the medical team and identifying with organ recipients as much as, or perhaps more than, with the grieving families of potential organ donors. The intent to be presumptive begins before a requestor enters the room and is maintained throughout his or her interactions with a patient’s family.

Hospital staff may begin to recognize small changes in the language used by donation requestors. The conversation about giving consent may take a different form, but donation requestors will continue to be supportive of the families of potential donors regardless of the outcome of the conversation and will maintain a strong commitment to assisting the families while intending to use presumptivity and work toward donation.

### Introduction as an Expert

Donation requestors are donation experts. They are highly trained in the profession and are the most competent individuals available to manage organ donation and recovery. The presumptive framework emphasizes this expertise. Requestors should view themselves as experts and should also be viewed as experts by the hospital staff and by the families of potential donors. Therefore, the donation requestor is introduced to a patient’s family as a member of the medical team or as an end-of-life or donation expert. Critical care nurses can be instrumental in helping requestors be introduced and perceived in this light.

The reasoning behind this type of introduction is 2-fold. First, this type of introduction validates or reinforces the requestor as an expert who is trained in acquiring consent from patients’ families and in facilitating the process of donation. Second, the portrayal of the requestor as an expert, a specialist, or a member of the medical team helps build a relationship of trust between a patient’s family and the requestor. This trust will allow the family to feel confident in the information and support the requestor provides. As the requestor portrays organ donation as a positive opportunity, this trust will enable the family to understand donation as such, thereby easing the decision to donate and alleviating some of the pressure of making difficult end-of-life decisions.

### Use of a Presumptive Transition

The transition from a discussion that was previously focused on brain death to one that is focused on organ donation is the third key element of a presumptive conversation. A presumptive transition is based on an understanding that the families of both the potential donors and the potential recipients are struggling with similar tragedies. Helping the family of a potential organ donor make this connection elicits empathy for the potential recipients and enables the family members to concentrate on the possibility that something positive can come out of the donor family’s tragedy. As in the standard decoupled approach, the transition to the discussion of donation should occur after the donation requestor is confident a patient’s family members understand and accept their loved one’s grave prognosis. The key to the transition is the family’s acknowledgment that despite every effort by the medical team, the family’s loved one will not recover. The requestor should connect the grief of the donor family with the grief of the families of potential recipients and should convey the donor family’s ability to prevent further grief by donating their loved one’s organs and thereby saving lives. The donation requestor should help the donor family pair loss with gain, death with life, tragedy with heroism. This transition will set the tone for the discussion of donation; therefore, the conversation should open on a positive note, focusing on the benefits of organ donation.

### Reference to the Recipients

The fourth key element of a presumptive conversation is the use of explicit references to the recipient or recipients during the discussion of donation. The presumptive approach shifts the role of the donation requestor to one in which the requestor identifies with the potential recipients as much as, if not more than, with the potential donor. Donation requestors often find themselves taking on myriad roles, from counseling the donor family to donor management. Shifting to the role of a dual advocate does not diminish the support for the donor family; in fact, in many circumstances, the presumptive conversation is
more compassionate because it enables the members of the donor family to take pride in their decision and empathize with others whose lives will be saved by that decision. The donation requestor is the voice of all those patients on the waiting list for transplantation who do not have the power to advocate for themselves and who will die without a transplant. Referencing the recipients is a major element of presumptivity, because it enables the families of potential donors to conceptualize the need and importance of donation. Critical care nurses can share their experience in medical care and tell potential donor families stories of past donors and recipients and help the families find comfort in the benefits of organ donation.

Families’ desire to donate is a reflection of their humanistic desire to help others. In contrast to the situation in the historical approach, donation requestors who use the presumptive approach appeal to this desire instead of de-emphasizing it. By advocating for recipients, requestors who use presumptivity provide the families of potential donors with specific examples of patients who are on the waiting list or who have recently received transplants.

Storytelling can be a powerful tool, because it allows the families of potential donors to develop a sense of connection with potential recipients. In addition, referencing recipients shifts the conversation from one focused on hopelessness to one focused on feelings of empowerment in the ability to save many other lives. By evoking empathy through the mention of potential recipients, this element will serve 2 distinct purposes. First, it will increase consent rates, because people are more likely to donate if they can identify with the potential recipients. Second, it will help ease the suffering of the family members of a potential donor, enabling them to focus on the hope they might bring to another person’s tragic situation and the legacy their loved one will leave behind. Donation requestors who have begun to reference recipients in their conversation have generally encountered positive reactions from the families of potential donors and positive results.

Use of Presumptive Statements

The use of presumptive statements throughout the consent conversation is the fifth element of presumptivity. By affirming and emphasizing the benefits of donation, presumptive statements empower a family to make
the decision to donate. In the past, donation has been conveyed as a difficult decision; in a presumptive approach, donation is considered the obvious choice. This change does not mean that the decision to donate no longer requires strength and compassion, but the decision to donate is the one that most people in the United States already support. If given the opportunity to save a life, most people will do so; donation is an opportunity for a potential donor and his or her family to save a life.

The concept of heroism is another powerful and presumptive description of a potential donor. In today’s culture, people are fascinated with heroes; although the term immediately conjures up images of firefighters and purple hearts, organ donors are truly heroes. The donation requestor should help the family members of a potential donor understand their loved one’s opportunity to be remembered as a hero, both by the organ recipients who will be saved and by the donor’s family.

Many donation requestors discuss a potential donor’s personality and try to link that personality to the decision to donate. Presumptivity takes this approach a step further by having the requestor discuss the type of legacy a potential organ donor will leave behind. A legacy of kindness and generosity and the ability for their loved one to continue giving and helping others as he or she did in life resonate with many families and are compelling arguments for donation. The key to presumptive statements is that most families do find comfort in organ donation, and it is the responsibility of the donation requestor to present donation in such a way that it enables a particular family to understand the importance of the family’s decision and the comfort the decision can bring.

### Presumptive Ask

Once the family of a potential donor has been provided with the appropriate and necessary information to make their decision, it is time to use a “presumptive ask,” the sixth and final element of presumptivity. The ask should be consistent with the presumptive framework; it should be open ended and geared to moving the conversation forward, with the ultimate goal of providing a lifesaving transplant. If the approach has been presumptive and successful, then the family has already begun consenting to donation in a series of small affirmations throughout the conversation. Therefore, the ask is

| Table 3 | Comparison of standard and presumptive language in a request for organ donation |
| --- | --- | --- |
| **Element** | **Standard** | **Presumptive** |
| Introduction | This is Mary. She works with families like yours who have lost a loved one. Would it be possible for her to speak with you for a moment? | Mary is a member of our team who is a specialist in working with families facing end-of-life decisions. She is going to speak with you and will answer any questions you might have. |
| Transition | I am very sorry about the loss of your husband. You now have the option of organ donation. Have you ever had a discussion about organ donation? | Up to this moment you’ve looked to us to save Sam’s life. Unfortunately, despite all of our efforts and technology, we could not save Sam. I am very sorry. Mr. Jones, what you have now is the ability to offer to another family what you have wanted more than anything, but were unable to have: hope that your loved one can live on. It is a decision that requires a great deal of compassion and strength to do what is right, to give away what you yourself want most but cannot have. … |
| Reference to recipient | If you decide to donate, I can provide you with a letter that will tell you about the people who receive your son’s organs. | Close to 90,000 people in our country are awaiting a lifesaving transplant. In our area alone, there are as many as 200 families waiting at their loved one’s side, praying for news of an available organ. More than 17 patients die each day while waiting for a transplant. By donating your son’s organs, you have the ability to save up to 8 people tonight. |
| Presumptive phrases | Some families choose the option of donating their loved one’s organs. I am here to help you make the decision that is best for you and your family. | You and your husband now have the opportunity to make your son a hero through the gift of organ donation. |
| The presumptive ask | Would you like me to give you some time before you make your final decision? | If you do not have any more questions, I will now guide you through this process. |
the time to ask the family members if they have any additional questions before moving forward.

In some ways, the presumptive ask can be considered the transition from the discussion of donation to the signing of the consent form. The ask provides benefits to both the requestor and the family members of a potential donor, because it is often difficult for families to be placed in a direct decision-making role during what are often the early stages of their grieving process. The presumptive ask alleviates this pressure on potential donor families by eliminating the forcefulness and finality of the traditional request for donation. Instead, donation requestors ask to move ahead with the donation process after the legal next of kin has agreed throughout the conversation that donation is the right thing to do. The additional pressure of a traditional request for donation not only is unnecessary but also may lead to a negative decision about donation by families who cannot handle making another decision at an already highly stressful moment. The presumptive ask should also help increase consent rates by preventing requestors from asking a close-ended question; such questions may make it difficult to reopen the conversation if a family is not yet ready to donate.

Table 3 provides a linguistic comparison between the standard approach and the presumptive approach; the examples are based on the 6 key elements of the presumptive approach.

**Summary and Conclusions**

This era is a new one in transplantation. Medical advances now enable transplantation in patients who would not have been considered candidates for transplants in the past. Most laypersons no longer fear organ donation but embrace it. Despite this change, however, the number of patients waiting for a transplant nationwide continues to grow and the need for organs is profound. Despite many proposed solutions, the discrepancy between the number of organs needed and the number of organs available for transplantation continues to exist. The introduction of the presumptive approach to consent is an attempt to help reduce the organ shortage crisis by increasing the national consent rate.

Healthcare providers are essential to organ donation and transplantation; those in the critical care setting are often the medical professionals...
that patients’ families trust and ask for advice. Critical care nurses are most often the vital link between a grieving and confused family and a donation requestor. Like other transplant professionals today, critical care nurses are encouraged to openly support organ donation when asked. A value-neutral position is no longer expected. Nursing staff can encourage and support a patient’s family through all of the family’s medical and end-of-life decisions, including organ donation. By being positive about donation and using many of the elements of presumptivity, nurses, other clinicians, and donation requestors not only will empower a family to donate but also will save the lives of sick and desperate patients on the waiting list for transplantation.

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