

# Speaking up for organ donors

**Consider the ethical issues raised by organ donation, such as how to define death. Then examine your own opinions.**



By Ellen Bridget Linde, RN, BSN

AS NURSES, WE FACE TOUGH ethical dilemmas as we provide end-of-life care, especially when our patients are candidates for organ donation. In this article, I'll explore two basic issues: how death is defined and who makes decisions for potential organ donors who haven't made their wishes known. First, let's look at some basic ethical principles.

## Examining your values

Nurses must consider respect for life and bodily integrity in light of the procedure for recovering organs. Nursing is primarily grounded in beneficence (doing good) and nonmaleficence (not doing harm). But nurses interpret these guiding principles in various ways. Some, believing that removing vital organs is what kills the patient, view organ donation performed under current criteria for pronouncing death as an act of killing.<sup>1</sup> Others suggest that organ donation is a "moral duty, an obligation," considering society's lack of alternative health-care resources.<sup>2</sup> But not all nurses are comfortable with a value system driven primarily by the needs of transplant recipients rather than by the needs of the potential donor.

To get to the bottom of these issues, let's explore how death is defined and how this affects organ donation.

## Death and the dead donor rule

Whether the mechanically ventilated, brain-dead body still functions as a *living person*—a whole, integrated organism—is a matter of ongoing mystery and debate.<sup>3</sup> Moreover, once death has occurred, relinquishing the body and mourning the person are no longer the only concerns. The irreversibly dead body now has a novel *potential* as a source of much-

needed tissues and organs for patients who need them.<sup>4</sup> In the United States, over 90,000 patients are on waiting lists for organ transplants.<sup>5</sup>

The so-called dead donor rule is the legal and ethical standard that requires patients to be declared dead before the removal of life-sustaining organs for transplantation. But what is death and when does it occur? These are complex and controversial questions.


Definitions of death fall into one of two main categories: cessation of brain function, and

absence of respirations and pulse. As we look at each more closely, you'll see how these definitions can overlap and conflict.

Death needs to be determined before organs can be harvested, according to the dead donor rule, and the Uniform Determination of Death Act gives guidance to the definition of death.

**Brain death.** The Uniform Determination of Death Act provided the legal articulation of the whole-brain criterion of death: "irreversible cessation of all functions of the brain, including the brainstem."<sup>6</sup>

A determination of death must be made in accordance with accepted medical standards. According to the American Academy of Neurology, the clinical diagnosis of brain death is the absence of clinical brain function when the cause is known and irreversible. "The three cardinal findings in brain death are coma or unresponsiveness, absence of brainstem reflexes, and apnea."<sup>3</sup> A clinical evaluation and a repeat evaluation 6 hours later are rec-

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ommended. Sometimes confirmatory testing, such as cerebral angiography, is recommended.

A variation of this view, called **higher-brain death**, defines death as the irreversible loss of function of the neocortex—the part of the brain responsible for consciousness, memory, personality, and perception.<sup>7</sup> This higher-brain criterion, which doesn't require loss of function in the entire brain, is ethically problematic because it could clear the way for retrieval of organs from patients in a permanent vegetative state. It would be difficult to find nurses willing to participate in procurement under such circumstances because the Code of Ethics for Nurses explicitly stresses patient advocacy, respect for inherent dignity, safety, and rights of the patient.<sup>8</sup>

**Non-heart-beating donation.** This defines death as the irreversible cessation of cardiopulmonary function and provides the rationale for retrieving organs from patients who aren't brain-dead.<sup>9</sup> An example would be a victim of cardiac arrest who's suffered severe and irreversible brain damage and is being sustained by mechanical ventilation. If he doesn't meet the diagnostic criteria for brain death, he's not considered brain-dead. Under a typical organ donation protocol, however, he's a candidate for organ donation if cardiopulmonary function ceases after life support is withdrawn. A waiting period of several minutes is required to make sure cardiopulmonary function doesn't resume spontaneously. Organs are then retrieved as quickly as possible to preserve their viability.

Providing optimal perfusion and oxygenation prior to brain death may increase the number of organs recovered, with more patients receiving lifesaving organ transplants.<sup>10</sup>

The idea of using organs from non-heart-beating donors for transplantation was first tested in the 1950s and 1960s when clinical organ transplantation became a reality. Unfortunately, the outcomes were suboptimal. With the development of both the ICU and legal definitions of brain death, cadaveric organ donation from brain-dead patients became the most common and preferred source of organs for transplantation.<sup>11</sup> However, some ethicists and others object to it because they believe that organs may sometimes be retrieved from patients who aren't legally dead. They also note that technical advances in preservation solutions and procedures have facilitated shortened warm ischemic times and improved quality of organs retrieved from donors.<sup>9</sup> *Warm ischemic time* is the interval between extubation (that is, withdrawal of treatment) until the initiation of cold perfusion (for preservation).<sup>12</sup>

## Issues surrounding brain death

But defining death as brain death also presents ethical quandaries. Robert D. Truog, MD, director of clinical ethics at Harvard Medical School in Boston, Mass., writes that using brain death as the standard legitimizes organ removal from bodies that continue to have circulation and respiration (usually sustained by mechanical ventilation), and this “fails to correspond to any coherent biological or philosophical understanding of death.”<sup>13</sup>

Chiong describes a 1998 study by Shewmon, who reported on 175 cases in which the bodies of patients reliably diagnosed as fulfilling the whole-brain death criterion (in general, they didn't have brain waves) were maintained for varying periods, in some cases years, with little aggressive intensive care besides mechanical ventilation. The argument revealed that these patients exhibited a “litany of non-brain-mediated somatically integrative functions.”<sup>7</sup> Amazingly, among these were wound healing, successful gestation of a fetus in 13 women, sexual maturation and growth, and, most disturbing of all, cardiovascular and hormonal stress responses to incision for organ retrieval.<sup>14</sup>

Fitzgerald and colleagues studied 11 brain-dead organ donors during organ procurement surgery. In 6 of the 11 patients, BP increased after skin incision, remained high at sternotomy, then decreased toward the end of the observation period 45 minutes later. Although these patients were declared clinically brain-dead, I believe they continued to respond to pain despite their lack of brain activity. I think the brain may not necessarily be the only active component in the experience of pain.<sup>15</sup>

Now let's look at one case, which I observed as a nursing student, that illustrates some tough ethical dilemmas.

## A sudden event

Marion, 45, an administrative assistant with no known health problems, suddenly became unresponsive at work. In the ED, it was determined that a ruptured intracranial aneurysm had caused an acute subarachnoid hemorrhage. She was endotracheally intubated, placed on mechanical ventilation, and transferred to the ICU. Marion was classified as a brain-dead donor even though her heart continued to beat. Mechanical ventilation was continued to ensure heart and lung perfusion and to preserve organ integrity for possible transplant.

Her husband Bob and her parents, clearly shocked, were soon by her side. I'll never forget their sadness and utter confusion as nurses, residents, and finally their family physician attempted to explain Marion's condition. Her parents

seemed unable to accept the fact that their only child was brain-dead. After all, they could plainly see her chest rise and fall with each ventilator breath. Looking for a glimmer of hope, they asked each person who entered the room, “Can she hear us? Does she know we’re here? Does she feel pain?”

The staff was instructed *not* to mention organ donation to the family. Instead, in compliance with Pennsylvania law, the resident on call notified the Gift of Life (GOL) donor program, a nonprofit agency responsible for recovering and distributing organs and tissues for transplants throughout eastern Pennsylvania, southern New Jersey, and Delaware.<sup>5</sup> When the GOL coordinator arrived, he immediately took charge of the situation. Marion’s care was now focused on preserving organ perfusion to facilitate successful transplant to a qualified recipient on the waiting list, should her husband decide to donate her organs.

Marion didn’t have a living will or other advance directive, and no one seemed to know her wishes. Under these circumstances, would organ retrieval proceed? (See *How the Uniform Anatomical Gift Act addresses legal issues.*)

Research has shown that a significant number of Americans *don’t* want their organs used for transplant.<sup>16</sup> When given the option, families refuse consent between 40% and 50% of the time. In the past, they’ve had the power to refuse consent, even overriding the patient’s previously expressed wish to be a donor, although this is no longer true.<sup>17</sup>

In Marion’s case, the GOL coordinator approached Bob for consent. Bob didn’t know Marion’s preference, or even if she had one. As the surrogate decision maker, Bob’s duty was to protect Marion’s life goals by acting as her advocate.<sup>18</sup> Current legal and ethical norms specify that clinical care surrogates should base their decisions on the *substituted judgment standard*.<sup>19</sup> According to this standard, as the person closest to her, Bob was in the best position to speculate what Marion’s choice would be, based on her values.

His next step would be to use the *best interest standard*. Factors that should be considered when weighing the harm and benefits of various treatment options include the pain and suffering associated with continuing treatment to keep her alive, the degree of and potential for benefit, and any impairment that may result from continuing treatment. The social worth and benefit of the potential organ recipient or society in general shouldn’t be a consideration. Although it wasn’t an issue in this case, caring for a loved one at the end of life can be a tremendous

## How the Uniform Anatomical Gift Act addresses legal issues

The growing need for organ and tissue transplants led to several revisions of the Uniform Anatomical Gift Act (written in 1968 and last revised in 2006) in many states.<sup>25</sup> According to this act, a donor’s declared intent to be an organ donor is legally binding. When a person documents on her driver’s license that she’s an organ donor, this is sufficient evidence of consent for the removal of organs. The procurement team doesn’t need the consent of her spouse or her family in addition to the wishes documented on her driver’s license. These steps ensure that the proposed donor’s wishes will be honored, regardless of family objections.<sup>26</sup>

The act also requires that hospital and medical personnel ask patients on admission if they would consider being organ donors. This practice is commonly called “routine inquiry.” When a person who dies didn’t officially declare her interest or lack of interest in donating her organs upon death, hospital or medical personnel are required to discuss with that person’s relatives or surrogates whether they’d be interested in donating the person’s organs. This practice is commonly referred to as “required request.”

Finally, the act permits medical personnel to remove organs without receiving explicit consent from a potential donor or a relative of the donor as long as the appropriate medical personnel or authorities have made a reasonable effort to discover any objection by the donor or her family.<sup>26</sup>

burden. Surrogates’ decisions may be affected, even unconsciously, by financial and other considerations.<sup>19</sup>

One way to ensure that a decision isn’t inappropriately influenced by the surrogate’s own interests or values is to determine the course of treatment that most reasonable persons would choose for themselves in similar circumstances.<sup>20</sup> But the data available on this aren’t clear. Despite public opinion polls reporting that more than 75% of the American public is willing to donate their organs, in most hospitals, far fewer actually donate.<sup>21</sup> In my experience, people agree with organ donation in theory, but in practice they find it difficult to have organs removed from their loved ones at their death. Were Bob to rely on statistical public opinion for decision making, the best interest standard would dictate that he not donate Marion’s organs.

Nurses help patients to exercise their right to self-

determination when making healthcare decisions.<sup>22</sup> The uncertainty of Marion's wishes about organ donation made her nurse's role as her advocate especially difficult. Her nurses also had to set aside their own agendas and personal values to affirm the decisions and choices that the patient and family made according to their own values, goals, and priorities.<sup>22</sup>

In the end, Bob donated Marion's organs and tissues to the GOL. Only Bob knows how he reached his decision. Two young men each received one of her kidneys and will no longer depend on dialysis. Marion's liver was given to a man in his 40s, and her heart valves went to another patient.

### Personal viewpoints

Studies indicate that although nurses generally report positive attitudes toward the idea of donation, their unwillingness to donate their own organs or the organs of their family members suggests either some uncertainty or other barriers to donation.<sup>23</sup> Perioperative nurses involved in organ procurement experience a variety of feelings as they participate in the removal of organs from a body that physically appears the same as that of any other surgical patient. Perioperative nurses have described their participation in organ procurement as disrespectful, traumatic, and emotionally draining.<sup>24</sup>

Where do I stand on organ donation? When I started researching this article, I was an avid, outspoken advocate for organ donation, but I've since had a change of heart. Shewmon's study of 175 patients who met the full criteria for whole-brain death led me to conclude that it's ethically wrong to recover organs from a person who's still breathing—regardless of whether or not breathing is achieved through mechanical ventilation. Although I'm no longer a potential organ donor, I'm an avid and outspoken supporter of stem cell research because I believe it's a realistic alternative to organ procurement. ✧

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