Sophie’s Choice: Preserving Patient Autonomy in Organ Donation

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Sophie, a 22-year-old, single female, suddenly collapsed while out boating. When her friends could not arouse her, they called 911 and immediately headed back to shore where emergency service personnel transported Sophie to the nearest hospital. In the emergency room, Sophie remained unresponsive and was placed on a ventilator. Soon after her parents arrived at her bedside, the doctor informed them that their daughter was brain-dead and would not recover consciousness. The father asked for a consultation with the hospital’s organ donation liaison to determine whether or not his daughter was a donor candidate. It was subsequently determined that she indeed was a viable donor. Although initially agreeing to the meeting, the mother became very upset after this consultation because Sophie had previously expressed her strong preference not to donate her organs, stating “I don’t want to be cut up and parceled out.” Sophie’s father acknowledged being aware of his daughter’s wishes but also felt that donating Sophie’s organs would be a way of making something positive come from such a difficult experience. The mother agreed with organ donation in principle, especially after talking with the liaison, but struggled with wanting to honor her daughter’s wishes. Sophie left no living will nor designated a healthcare power of attorney.

Sophie’s parents were distraught and could not agree on an appropriate course of action, beyond the mutual decisions that they did not want to prolong Sophie’s life unnecessarily and would like the ventilator removed. They called Frank, Sophie’s nurse, over to the bedside, saying, “We just don’t know how to handle all this. This decision about whether or not to donate Sophie’s organs is tearing us apart. Please help us. What do we do?!”

The Ethical Dilemma

Although the determination as to whether or not an individual’s organs will be donated ultimately resides with the surrogate decision-makers, the role of healthcare personnel in such
instances cannot be overlooked. Indeed, as the scenario highlights, nurses play a critical role not only in the direct care of patients but also in supporting the patient’s family and significant others. As Ecker (2009) noted, “Nursing is a work of intimacy. Nursing practice requires you to be in contact with clients not only physically but also emotionally, psychologically, and spiritually” (p. 315). With the high degree of personal contact, it is natural for patients and those close to them to turn to the nurse for information. Ethical questions may arise, however, when the desired interaction goes beyond merely gathering information from the nurse and into the realm of seeking advice, particularly if the individual requesting assistance is not even the patient.

In the scenario provided above, Frank must determine what degree of interaction, if any, is appropriate and how any potential interactions should be handled. Such decisions have far-reaching effects, obviously impacting Sophie and her physical state, but also Sophie’s parents, any potential recipients of Sophie’s organs and their families, Frank, and Frank’s relationship with other members of the healthcare team.

Frank’s decision as to his approach must take several ethical principles into consideration. First and foremost is the importance of upholding the patient’s autonomy, the ability “to act independently and make personal choices” (Motta, 2005, p. 100). Sophie is the patient, not her family, and it is her clear and undisputed desire not to be a donor that would be of chief importance for the nurse. That being the case, it is important for Frank to act as her advocate, even in the face of opposition by family members (Ecker, 2009).

Yet, within the nursing field itself, disagreement arises over the application of this principle, particularly in cases of organ donation. As Johnson stated, “Autonomy is an idea based on the respect for persons, and persons have to be alive” (Johnson, 2008, p. 28). From this
perspective, the primary ethical focus should shift from the question of autonomy to that of
beneficence, or the concept of “doing good,” not so much to the patient who is no longer living,
but rather to the living members of society – the potential organ recipients (Johnson, 2008).
Frank needs to be cognizant of the apparent opposition of the two concepts of autonomy and
beneficence in Sophie’s situation. All the while, he must also take into consideration the
family’s need for empathic support in this time of great emotional, spiritual and psychological
distress.

Another factor contributing to this scenario is the sense of immediacy. Sophie’s parents
have chosen to remove her ventilator; therefore, time is of the essence, and a decision regarding
the donation of her organs must take place soon. Frank must settle upon an approach regarding
his response to the parents’ request for help.

**Nursing Actions**

One possible action on the part of the nurse would be to embrace this opportunity to
discuss the value of organ donation and its positive impact on terminally-ill individuals across
the country. Frank could quote statistics and relate anecdotes to support his stance, highlighting
the sense of contribution to society that many organ donors and their families share. From a
purely factual basis, it is clear that there is “a chronic shortage” of donors, with over 90,000
patients awaiting organ transplants in 2006 (Das & Lerner, 2006, p. 71). Yet this heavy-handed
approach is not appropriate, for while Frank encourages beneficence, taking positive actions to
help others (Ecker, 2009), he also crosses the dangerous line of imposing his personal values on
Sophie’s family. Perhaps most egregious of all, Frank ignores the vital issue, and indeed his
ethical obligation, of preserving his patient’s autonomy, as indicated by Sophie’s clearly
articulated desire to remain outside of the donor pool. As the American Nurses Association
Code of Ethics so simply and effectively states, “The nurse’s primary commitment is to the client” – in this case, Sophie (as cited in Ecker, 2009, p. 315). Frank’s choice to interject his own values into the family’s decision-making process is to ignore this fundamental call.

Alternatively, when faced with the uncomfortable and highly emotionally charged situation in which he finds himself, Frank might simply refuse to enter into conversation with Sophie’s parents. He could politely disengage, stating that the decision regarding Sophie’s organ donation is theirs to make, and he cannot ethically participate in the process. As a result, the family may feel further isolation and confusion at an already difficult time. In reality, this response may stem more from Frank’s sense of not knowing how to properly approach the family than from a desire to keep clear of a potential legal and ethical morass. To avoid such a situation, Bosek (2006) recommended, among other things, that nurse managers, especially individuals working on units that routinely face this issue, remain informed about organ donation policies and openly share this information with their nursing staff. Fostering open interchanges among colleagues has the potential to create the type of supportive environment so critical for health care professionals encountering the subtleties surrounding organ donation (Bosek, 2006). Ideally, nurses would feel able to discuss their questions and concerns with professionals who share a common frame of reference, thereby increasing their comfort level with these delicate topics and enabling them to make informed, ethical decisions.

A third, and of the three best, option would be for Frank to recognize the family’s suffering and need for assistance, and to agree to speak with them. The sensitive nurse must realize, however, that entering into such a conversation is difficult and needs to be handled with extreme care because the attitude portrayed by health care professionals regarding both organ and tissue donation has been proven to influence the decisions of family members (Hannah,
2004). For example, it certainly would not be appropriate for Frank to criticize the father’s desire to have Sophie’s organs donated. Indeed, his feelings are understandable, particularly when taking into account the great need for donations. However, it is critical that Frank not forget his role as Sophie’s advocate, and firmly, but respectfully, remind Sophie’s parents that their daughter’s desire was not to participate in the organ donation program.

An action that is within the nurse’s scope of ethical practice is to engage in the therapeutic communication technique of active listening. By Frank truly listening to the parents’ concerns and tangled thoughts, he gives Sophie’s mother and father a forum in which they can verbalize their concerns. In so doing, Frank also provides them with an opportunity to process their emotions, clarify important issues, and identify topics about which they need further information. For example, after talking about the consultation with the organ donor liaison, Sophie’s parents may realize that they now have a different context in which to evaluate the medical status of their daughter. They may desire to speak with the doctor again in order to ensure that they fully understand Sophie’s condition and her prognosis. Frank could, then, assist them in arranging such a discussion in a timely manner, encouraging the parents to ask any specific medical questions they may have at that time. If Sophie’s parents continue to disagree about whether or not to authorize her organs to be donated, however, it is Frank’s responsibility to notify the organ donor liaison of the conflict. Typically, a donor will be rejected if any family member expresses objections to the organ donation (Motta, 2005).

**Outcome**

Sophie’s mother and father will ultimately decide the fate of their daughter’s organs. But the healthcare professionals with whom they come in contact play a vital role in providing them with the materials necessary to make an informed decision that includes the critical piece of
preserving patient autonomy. During this time of confusion, perhaps none will be more influential than the nurse who cared for their daughter at the end of her life. Frank’s responsibilities are great, yet his opportunities to provide appropriate, compassionate care are invaluable. Sensitive topics, such as organ donation and other end-of-life issues, must be discussed openly by all healthcare professionals but especially nurses who have significant contact with terminally-ill patients and their families. The knowledge gained from such interactions will subsequently equip and empower nurses to safeguard their patients’ autonomy and other basic rights while providing patients and their families with the tools and information they need to make the decisions surrounding organ donation with peace and confidence. In this case scenario, Frank is ethically bound to ensure that the parents are aware of the need to remember both their daughter’s desire and the importance of honoring Sophie’s choice.
References


