Exploring organ donation with families of pediatric patients

Use this evidence-based approach to help grief-stricken families make a critical decision.

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AN END-OF-LIFE discussion with any patient or family can be challenging. It's likely to be even more difficult when the patient is a sick and dying child. Yet this tragic situation can lead to positive outcomes if the family chooses to save other children's lives by donating their child's organs and tissue after death.

Effective education and communication with the families of potential pediatric donors can positively affect the lives of up to 60 patients per donor, exponentially touching hundreds of lives when you factor in family members. (See *Pediatric organ donation: By the numbers.*)

This article offers advice on how to address organ donation with cultural sensitivity, dispel myths about donation, help families consider what their child likely would have wished, and guide families through the decision-making process in a way that can help them.

Nurses' role

Nurses aren't allowed to initiate conversations with families about organ donation, so you're not responsible for providing education on this process. But even though you're not part of the initial discussion and may never be called on to provide input, you need to be aware of how to best help families facing this difficult decision.

Standard policy restricts all direct patient-care team members from initiating an organ donation discussion with the patient and family. Instead, the nurse makes a referral to an organ procurement organization (OPO). An OPO coordinator then approaches the family to discuss the possibility of donation. This policy not only helps shield hospital staff from perceived conflicts of interest, but it also helps protect the family from the false hope of organ donation if the patient isn't eligible. Nurses should, however, be prepared to engage in a discussion at the family's request after the initial OPO approach.

OPO coordinators are educated extensively on all aspects of donation. The OPO coordinator will thoroughly answer all questions and correct misinformation the patient and family might have. However, some patients and families may feel unsure about the information they get from the OPO coordinator because they haven't had a chance to establish a rapport with that person. After observing a nurse providing excellent care for their loved one, they may wish to speak with that nurse before consenting to donation. You can help the family transition to the OPO coordinator's primary role by introducing that person to the family.

What the evidence shows

One study found that families are more likely to consent to organ donation when the healthcare team involved in the child's care is also engaged in the discussion about it. Although these team members can't be a part of the initial donation request, they can aid in this process by expressing support and trust in the OPO coordinator and by remaining engaged in the conversation at the family's request. Despite some healthcare providers' perceptions that they lack adequate communication skills to discuss donation, neither donor nor non-donor parents (those who refuse organ donation) reported being upset by having these conversations with the providers.

Other research suggests that grieving families are more likely to consent to organ donation if the bedside nurse develops a trusting relationship with them, has a positive attitude toward donation, and effectively communicates that something positive can come from their tragedy. Families who receive psychological support from healthcare providers are better able to cope with the reality of their child's death, which makes them more likely to consent to donation. Bedside nurses should strive to provide this emotional support.

Families also were more likely to consent to donation if they perceived the healthcare provider as calm and knowledgeable about organ donation when approached by family members. In general, donor

Pediatric organ donation: By the numbers

According to the U.S. Department of Health and Human Services, as of July 2017 over 117,000 individuals are awaiting life-saving solid organ transplants in this country. Almost 2,000 candidates on the waitlist are under 18 years old.

What a single donor can do

One organ and tissue donor has the opportunity to save up to eight lives, give sight to two people, and improve quality of life for up to 50.

By age

The organs that children tend to need most varies by age:

- Most children younger than age 1 year are waiting for a liver or heart.
- Most children ages 1 to 10 are waiting for a kidney or liver, followed by a heart.
- Most children ages 11 to 17 are waiting for a kidney, followed by a liver.

Giving and receiving

- 1,878 children received transplants in 2016.
- 934 children donated organs. They ranged from newborns to age 17. Most were age 11 to 17, but 135 were younger than 12 months.

When matching organ donors to recipients, body size and the specific organ must be considered. Very small children typically receive donations from other young people; in some cases, older children and adults match. Some children can receive donations of partial organs, such as part of a lung or liver.

Supporting the family considering organ donation

To help support the patient's family during their decision, follow these tips.

- Introduce the organ procurement organization coordinator to the patient's family.
- Ensure the discussion occurs in a quiet, private environment.
- Assess how the family's cultural, religious, and spiritual views might affect their knowledge of and beliefs about organ donation.
- Give accurate information to correct misconceptions.
- Answer questions calmly. If you don't know the answer, say you will find out and get back to the family.
- Provide emotional support by giving the family time to discuss their feelings.
- Contact other resources, such as the hospital chaplain, as needed.

Separating myths from facts

To help promote organ donation, learn about the various myths surrounding this topic. Here are just a few.

Myth Some religions and cultures don't believe in or support organ donation.
Fact The vast majority of religions and cultures endorse organ donation. All monotheistic religions allow donation.

Myth Organ donors can't have an open-casket funeral.
Fact Open-casket funerals are still an option for patients who donate organs.

Myth Medical staff won't be as determined to save the life of a patient who's a designated organ donor.
Fact No patient is considered for organ donation until all attempts at lifesaving measures have failed.

families were more likely than non-donor families to openly interact with and ask questions of healthcare providers.

In a qualitative study of families with chronically ill children, parents reported feeling under-informed during their child's hospital stay. Many felt too intimidated to ask questions when nurses weren't forthcoming with updates or information about their child. This study also found that when families were forced to request information, they commonly interpreted the nurse's attitude as begrudging or hostile.

Caregivers should invest additional education time with families to build a trusting relationship. Be conscious of your tone of voice, attitude, and demeanor when speaking with them. Tailor your communication in a way that matches their religious, spiritual, or cultural expectations. The outcome of their decision to donate hangs in the balance. (See *Supporting the family considering organ donation.*)

Family satisfaction rates

The literature shows that establishing a rapport with family members can significantly influence their decision on organ donation. Caregiver interactions with the family can promote organ donation and shape their lifelong perception of the organ-donation process. Compared to non-donor families, donor families reported higher satisfaction rates and a more positive perception of their relationship with healthcare providers. Satisfaction scores were based on the healthcare provider's ability to provide information sensitively, patiently, and empathetically.

> Research suggests that grieving families are more likely to *consent* to organ donation if the bedside nurse develops a trusting relationship with them.

Cultural and spiritual considerations

Assess the patient's and family's religious, spiritual, and cultural preferences and beliefs around organ donation. Research shows that these preferences and beliefs strongly color one's beliefs and attitudes toward organ donation. Be sure to learn about the viewpoints of various religions and cultures so you can tailor your care to each individual family. In Chinese culture, for example, patients and families may regard healthcare providers as coldhearted and insensitive when discussing critical information. This perception may pose an obstacle in obtaining consent for organ donation.

As appropriate, use such resources as the hospital chaplain or other religious representatives familiar with the family's religious background to help clarify misconceptions about their religion's stance on organ donation. Social workers also can visit grieving families to provide spiritual and cultural support. (See *Separating myths from facts.*)

What would the child have wanted?

Unlike most adults, many children don't have the ability or opportunity to express their wishes about donating their organs. In this case, the family has to make this difficult decision without knowing what their child would have wanted.

You can provide supportive care by encouraging the family to consider the child's attitude of generosity. This can help them determine if their child would have given assent to donation and thus reduce their burden as they consider whether to give legal consent. (Assent holds no legal weight.) While you should never try to sway the family based on your own beliefs or feelings about donation, helping the family consider whether the child would have assented may help bring them closure and healing.

Decoupling technique

In studies, some parents reported uncertainty about consenting to donation because they couldn't accept the finality of their child's death. Decoupling helps by providing a significant time gap between notifying the family of the patient's brain death and requesting consent for organ donation. It not only gives the family more time to process their child's death before being asked to make postmortem deci-

sions, but it also eases caregiver anxiety about discussing organ donation in this emotionally fraught situation.

Saving lives

Public surveys reveal most Americans have favorable attitudes toward organ donation. Yet only about half of families consent to donation during the critical moments after a loved one's death. Pediatric healthcare professionals have the opportunity to help families through the grieving process by discussing organ donation with empathy and using effective communication techniques. Be available to engage in discussion regarding donation at the family's request, providing accurate information or seeking the correct answers. Above all, convey empathy. Your pivotal role can help directly save up to eight lives through the child's organ donation and promote healing for grief-stricken family members. ★

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Selected references

Ashkenazi T, Cohen J. Interactions between health care personnel and parents approached for organ and/or tissue donation: influences on parents' adjustment to loss. *Prog Transplant*. 2015;25(2):124-30.

Bellali T, Papazoglou I, Papadatou D. Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive Crit Care Nurs*. 2007;23:216-25.

Bortz AP, Ashkenazi T, Melnikov S. Spirituality as a predictive factor for signing an organ donor card. *J Nurs Scholarsh*. 2015;47(1):25-33.

Brierley J, Larcher V. Organ donation from children: time for legal, ethical, and cultural change. *Acta Paediatr*. 2011;100(9):1175-9.

Committee on Hospital Care, Section on Surgery, and Section on Critical Care. American Academy of Pediatrics. Policy statement—pediatric organ donation and transplantation. *Pediatrics*. 2010;125(4):822-8.

Donate Life America. Frequently asked questions. 2017. donatelife.net/faq/

Gündüz RC, Şahin Ş, Uysal-Yazıcı M, et al. Brain death and organ donation of children. *Turk J Pediatr*. 2014;56(6):597-603.

McInerny TK, Adam HM, Campbell DE, et al. *American Academy of Pediatrics Textbook of Pediatric Care*. 2nd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2017.

Organ Procurement and Transplantation Network. Department of Health and Human Services. National data. optn.transplant.hrsa.gov/data/view-data-reports/national-data/

Rodrique JR, Cornell DL, Howard RJ. Pediatric organ donation: What factors most influence parents' donation decisions? *Pediatr Crit Care Med*. 2008;9(2):180-5.

Rodriques PF, Amador DD, Silva KL, Reichert AP, Collet N. Interaction between the nursing staff and family from the family's perspective. *Esc Anna Nery*. 2013;17(4):781-7.

Siebelink MJ, Geerts EA, Albers MJ, Roodbol PF, van de Wiel HB. Children's opinions about organ donation: a first step to assent? *Eur J Public Health*. 2012;22(4):529-3