Navigating Family Resistance to First Person Authorization in Donation After Circulatory Death

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The October Ethics for Lunch centered around a 23 year old, physically active man who experienced severe neurologic evaluation following a motor vehicle accident. He does not meet criteria for death by neurologic criteria, but his neurologic injuries are felt to be irreversible. He remains fully dependent on life-sustaining treatments, including mechanical ventilation, artificial nutrition, and medications. After extensive evaluation, his family decides to withdraw life-sustaining intervention. It is learned that he designated himself as an organ donor on his driver's license. The Family Services Coordinator for the organ procurement organization approaches the family to inform them of the plan to honor his wishes through organ donation following circulatory death. The family is upset about the timing of the donation and whether he is experiencing any suffering.

Learning points:

1. This and similar situations are emotionally challenging. While it is important to respect patient autonomy by honoring the intent to be an organ donor, the discussion of organ donation with family members has to be approached with sensitivity and careful timing and wording.
2. Donations after Circulatory Death (previously referred to as donation after cardiac death or non-heart-beating organ donation) refers to the recovery of organs for transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria (heart and lung function stop).
3. First Person Authorization (also known as donor designation) is a legal process that allows a person to indicate their decision to donate organs and tissue after death. This makes their decision legally binding, and organ procurement organizations (OPOs) must inform the family of the patient's decision instead of seeking their permission.
4. The Revised Uniform Anatomical Gift Act provides individual the autonomous right to donate organs and establishes a means to document their directive to donate organs as a gift. It includes language that bars others from overriding, amending, or revoking the individual's decision to make an anatomical gift.
5. It is rare that family would object to the organ donation based on first person authorization, but sometimes time is needed for them to process the loss of their loved one and be able to ask questions. Heightened emotions may be the result of loss of control in the situation.
6. There is a distinction between disclosure and authorization.
    a. When there is a known First Person Authorization, there is *disclosure* to the next of kin that the organ donation process is underway. Any requests for authorization by the family would be for things outside the OPO's ability to perform the organ procurement (e.g., any tests or medications that might need to be done before death is declared).
    b. When a patient has not previously designated themselves as an organ donor, then the family is approached for *authorization* of organ donation.

7. The only person that can amend a First Person Authorization is the individual themselves. There has to be clear proof that the person no longer wanted to be an organ donor to change the designation. This has to be confirmed by a disinterested party, preferably in writing.
8. When a person designated themselves as an organ donor at the Department of Motor Vehicles, it is unlikely they are aware of all that entails (the testing required, what organs are going to be recovered, the difference between death by circulatory versus neurologic criteria, etc.), but Infinite Legacy does community outreach to educate the public about the process.
9. The priority list of decision makers in the Estates and Trusts article of the law is different than the surrogate decision maker list in the Health Care Decisions Act.
10. It is extremely rare that legal actions/claims are brought for issues related to organ donation.
11. Infinite Legacy has an ethics committee, and the OPO's senior leadership will get involved when they ae challenging situations.
12. Hospital policy requires that there is a decoupling of the decision to withdraw/withhold life-sustaining treatment and the decision to donate organs. It can be hard to answer a family's questions about what the end of life is going to be like when the donor status is not yet known.
13. Once the decision for organ donation is made, the clinical team should make every effort to honor whatever the family needs (e.g., timing and location of organ procurement, who will be present).
14. Minority communities have historically been reluctant to be organ donors, so when a patient from a minority population agrees to be an organ donor, it is important to honor their request because minority patients waiting for a donated organ often have to wait longer than non-minorities due to genetic matching.
15. After organ donation, unused body parts are cremated, but some families may object to cremation based on religious grounds. These have to be handled on a case-by-case basis.
16. The family advocacy program provides an opportunity for a family to voice their concerns and get clarification about any questions they have. Palliative care can also be a supportive resource for the family.

References:

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