PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #79
DISCUSSING ORGAN DONATION WITH FAMILIES
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Background Organ transplantation is one of critical care medicine's modern success stories. Unfortunately, the success of organ transplantation has not been matched by organ procurement. One reason may be that health care providers are often ill-prepared to deal with and discuss the procurement process. The purpose of this *Fast Fact* is to review issues surrounding organ donation and best practices for discussing organ donation with families. See *Fast Fact* # 115 for more information on brain death.

Who is eligible? Organ donation relies on the "dead donor rule" which states that vital organs should only be taken from the deceased (with the exception of living donors for pancreas, single kidney, partial liver, or partial bowel). To avoid mistakes in identification, Federal legislation requires that health care professionals notify Organ Procurement Organizations (OPO) of all impending deaths. It is important that this happen early and prior to medical decisions that might result in not being able to use the organs.

Who should talk to the family? Federal law mandates that only clinicians who completed certified training approach the family about organ donation. Physicians approaching families independently are associated with the lowest rate of consent. Hence, it is best practice for OPO staff to approach families together with the health care team. There are some data that requestor race/ethnicity congruence is important to donor families.

When should the issue of organ donation be discussed? Temporal separation (decoupling) between the notification of death (either brain death or cardiovascular death) and the request for donation is supported by the literature. Actual timing as well as perceived timing from the decision-maker perspective is important. Ample time should be allowed for both the discussion and deliberation in the decision-making process if possible. Discussions should be held in private and in person.

What is the role of organ donation cards? Organ donor cards (e.g. back of a driver's license) are legally binding. Thus, if the patient filled out an organ donor card, the family should not be asked about donation, but told that their loved one wanted to donate.

Who agrees to donate? The most important determinant of consent is the family's knowledge regarding the patient's pre-morbid views about donation. Families who have a positive perception of the health care provided at the time of donation are also more likely to agree to donation. Minority populations are less likely to donate, though regional variation does exist. More disturbingly, data suggest that health care providers are less likely to talk to African Americans about organ donation and use different language compared with potential white donors. Age, socio-economic status and education also seem correlated with consent rates. Most religious groups support the act of donation.

What communication processes correlate with donation? Three things seem important:

(a) Discussion of specifics and logistics. Common misconceptions relate to the effect of donation on open caskets and cost.
(b) Provide the donor family adequate time with the OPO staff. In a large study, families' main feedback was to spend more time with OPO staff and to have the OPO staff involved early in the decision-making.
(c) Psychosocial support for the grieving family from chaplaincy and social workers.

What efforts are being made to close the "donation gap"? Public awareness campaigns have been led by national organ procurement organizations. A quality improvement tool (RAPiD survey) has been developed to better identify facilitators and barriers in local donation processes. Most recently OPOs are considering compensating families for expenses associated with the donation process – travel, hotel, etc.

Expansion of the eligibility criteria to include donors after cardiac death has also improved procurement numbers. The majority of these donors have experienced controlled cardiac death (cDCD), usually after

planned withdrawal of life support in the hospital setting. A second population, donors with uncontrolled cardiac death (uDCD), is the focus of recent debate. Though the IOM recommends further development of uDCD procurement protocols, and other countries have demonstrated its success, there is controversy whether perfusion procedures violate the dead donor rule. Studies are ongoing to evaluate the feasibility and acceptance of uDCD processes in the United States.

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