Pediatric organ donation” Parents facing ethical and moral dilemmas”

Francoise Martens CCRN & Said Hachimi-Idrissi MD, PhD, FCCM
PICU UZ Brussels Belgium
Introduction

- Organ donation is the primary provider of organ supply to overcome the increasing length of the transplantation waiting list. In adult patients, organ retrieval can only be performed after a certified brain death, however organ donation after cardiac death is viewed as one way to partially close the gap between organ supply and demand.

- Despite national and international regulations, organ donation in the ICU setting is still a big concern and only few relatives allow surgical harvesting of organs.

- In children, the situation is even more complicated because of their vulnerability, special safeguards and the greater uncertainty of neurological outcome.
Definitions

- Organs for transplantation come either from living or deceased donors.

- Deceased donors are heart-beating donors who are brain dead, but with adequate end-organ function.

- Non-heart-beating donors (NHBD), referred to as donation after cardiac death (DCD), may be an alternative.

- DCD donors do not meet brain death criteria, but because of irreversible neurological damage or terminal illness, decisions of withholding or withdrawal of therapy can be made.

- Due to organ shortage many transplant centers attempt to increase the donor pool. NHBD seem to be a promising alternative, however data regarding the use of pediatric donation-after-cardiac-death organs remains sparse.
Difficulties

- There is a greater uncertainty in neurological prognosis in children, a greater difficulty in meeting consent requirements and little clinical as well as biological parameters' predicting death with certainty.
- Children’s brains are more resilient than those of adults, so it is very difficult to predict if a child’s neurological state is irreversible or not.
- There is great concern that the desire to donate organs could lead to premature decisions in life support withdraw.
- Little is known however about public understanding and beliefs about the relationship between death and organ retrieval.
- In the majority, health care professionals and the public opinion do accept brain death as a mandatory parameter to withdraw life support and ultimately donate organs.
Influential factors in the decision making

- Demographic characteristics
- Past behaviors
- Characteristics of the hospital
- Previous knowledge and experience
- Characteristics of the request process
- Religion
- Personal response to the request
- Characteristics of the recipient
- Characteristics of the deceased
Parents are facing dilemmas, namely understanding the concept of brain death, accepting the death of the child, making the decision in donating organs, coping with the idea of body mutilation and coping with the rest of the family after their decision in donation or not.

Parents needs include the assurance that the PICU staff will continue to provide adequate care to their child.

They need information about the child's condition.

Parents need time to assimilate the concept of brain death, and time to decide whether to donate organs or not.
- Facilitate the parents' presence at the child's bedside.

- They need to be involved in the discussions about the details of the donation procedure.

- Parents need the opportunity to an extended farewell to their dying child.

- Parents need psychological support during the decision to consent or decline donation.

- The most significant needs for parents are the given information and the ongoing emotional support during the whole process.
Recommendations 1

- Inform the parents about the critical condition of the child
- Support the family in crisis
- Develop a trustful relationship with the family
- Explain the nature of the brain injury
- Provide honest and ongoing information
- Encourage and facilitate bedside presence of parents and family
- Provide information about brain death
- Discuss the results of brain stem testing
- Acknowledge and support the grieving family
- Present the option of organ donation
Recommendations 2

- Support the parents during the decision making process
- Respect the decision to consent or decline organ donation

- Support family who declined organ donation
- Support family during donation procedure

- Provide information about organ retrieval
- Obtain written consent

- Encourage farewell and/or good bye rituals
- Support families after organ retrieval

- Keep ongoing communication
- Assess psychological problems
Conclusions

- Healthcare professionals should be able to identify the challenges that the parents face and the factors that could effect their decision to consent or decline the request of organ donation.

- Adopting a family oriented approach could help them to support families in their decision making.

- On the other hand, the healthcare professionals are the most suitable persons to discuss the option of organ donation or do we need special trained professionals?

- Should healthcare professionals involved in the organ donation procedure follow special training programs addressing the organ donation process?

- Much can still be done to sensitize the countries to the issue of organ donation.

- Public remains considerably unaware or misinformed about the medico-legal issues of brain death. Moreover, the diagnosis brain death is quite different depending on the countries and/or the religions or social and educational status of the family.

- Lack of consent to a request for donation is still the primary cause of the gap between the numbers of potential donors and the number of actual donors.