Session 102: Pediatric Donation After Circulatory Determination Of Death: The Provider’s Role
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Disclosures
• I have no conflicts of interests to disclose
• I have no relevant financial relationships
• I do participate in organ donation and donation after circulatory determination of death
• I am not an ethicist

Learning Objectives
• Identify the ethical challenges of pediatric donation after circulatory determination of death (DCDD)
• Describe the role of the provider through the DCDD process from consent to recovery including tools for difficult conversations
• Utilizing a case study, highlight program successes, areas for improvement, and family perceptions in the pediatric DCDD process

Abbreviations
• DCDD: Donation after Circulatory Determination of Death
• NDD: Neurologic Determination of Death
• WLST: Withdrawal of Life Sustaining Therapy/Treatment
• UDDA: Uniform Determination of Death Act
• OPOs: Organ Procurement Organizations
• OPTN: Organ Procurement and Transplant Network
• UNOS: United Network for Organ Sharing
• NEOB: New England Organ Bank

History of Organ Donation
• Hindu texts from 3000 BCE to 2500 BCE provide descriptions of skin grafting of noses
• In the early 20th century Alexis Carrel performed many experiments transplanting kidneys in cats

• The first human recipient of a human donor kidney was performed in 1936 by Russian surgeon Dr. Yu Yu Voronoy
• The first successful living donor kidney transplant occurred in 1954 by Dr. Joseph Murray at the Peter Bent Brigham Hospital in Boston
Brief History of Donation after Circulatory Determination of Death (DCDD)

- First performed donation after circulatory determination of death completed in 1951
- No long-term survival
- DCDD decreased due to criteria for neurologic determination of death (NDD)
- Unfilled organ demand and less patients meeting NDD criteria prompted centers to reexplore DCDD

<table>
<thead>
<tr>
<th>Age of Recipient</th>
<th>Transplants</th>
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<tbody>
<tr>
<td>&lt; 1 Year</td>
<td>203</td>
</tr>
<tr>
<td>1-5 Years</td>
<td>543</td>
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<tr>
<td>6-10 Years</td>
<td>302</td>
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<td>11-17 Years</td>
<td>743</td>
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<td>18-34 Years</td>
<td>3,736</td>
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<td>65+</td>
<td>6,231</td>
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<td>Total</td>
<td>33,056</td>
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Pediatric (0-17) Transplants By Age of Recipient - 2016

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Pediatric (0-17) Transplant by Age of Recipient - 2016.

Transplants By Organ Type - 2016

<table>
<thead>
<tr>
<th>Organ</th>
<th>Transplants</th>
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<tbody>
<tr>
<td>Kidney</td>
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<tr>
<td>Liver</td>
<td>7,341</td>
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<tr>
<td>Pancreas</td>
<td>215</td>
</tr>
<tr>
<td>Kidney / Pancreas</td>
<td>787</td>
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<tr>
<td>Heart</td>
<td>2,351</td>
</tr>
<tr>
<td>Lung</td>
<td>2,927</td>
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<tr>
<td>Heart / Lung</td>
<td>16</td>
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<tr>
<td>Intestine</td>
<td>147</td>
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<tr>
<td>Total</td>
<td>33,090</td>
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Transplants By Organ Type - 2016.

Organ Donation in the United States by Donor Status, 2000-2013. Data are from the Scientific Registry of Transplant Recipients.

Transplant Donor Type - All Organs

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<tr>
<th>Year</th>
<th>Decreased Donor Transplants</th>
<th>Living Donor Transplants</th>
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<tr>
<td>2012</td>
<td>22,167</td>
<td>5,899</td>
</tr>
<tr>
<td>2013</td>
<td>23,307</td>
<td>5,897</td>
</tr>
<tr>
<td>2014</td>
<td>23,716</td>
<td>5,845</td>
</tr>
<tr>
<td>2015</td>
<td>24,980</td>
<td>5,905</td>
</tr>
<tr>
<td>2016</td>
<td>27,821</td>
<td>5,975</td>
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<tr>
<td>Total</td>
<td>121,470</td>
<td>29,035</td>
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Transplant Donor Type - All Organs.
• Vital organs should be taken only from dead patients,

  and

• Patients should be declared dead before organ procurement, rather than dying as a result of organ donation.

  If not

• Violation of these ethical norms would violate state laws, and therefore have legal consequences.
Does DCDD Conflict with the Dead Donor Rule?

- Direct conflict with the dead donor rule if you are declaring a patient dead under this term and then harvesting the HEART and having a SUCCESSFUL transplant
- Was the patient really dead?

How do we define death?

- Uniform Determination of Death Act (UDDA) in 1981
- An individual who has sustained:
  1. Irreversible cessation of circulatory and respiratory functions, OR
  2. Irreversible cessation of all functions of the entire brain including the brain stem, is dead.
- A determination of death must be made in accordance with accepted medical standards.

Autoresuscitation

- The phenomenon of the heart being able to restart spontaneously and generate anterograde circulation and not just electrical activity as is seen in pulseless electrical activity (PEA)
- Also referred to as the Lazarus Phenomenon
- 2012 survey of Critical Care physicians, 37% say they had witnessed autoresuscitation

Lazarus Phenomenon

- Auto resuscitation has been reported from a few seconds up to 33min after asystole
- “if one holds that the DDR is an inviolate principle of organ donation, then the difference between “dying” and “dead” becomes crucial. Even a very slim chance of a false positive makes a difference. If the patient is, in fact, not dead or not known to be dead at the time of the declaration of death, then the DDR has been violated” (Troug, 2010)

Case report autoresuscitation

<table>
<thead>
<tr>
<th>Author</th>
<th>Age (yr)</th>
<th>Diagnosis</th>
<th>Rhythm</th>
<th>Max</th>
<th>Outcome</th>
<th>EKG</th>
<th>HR</th>
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<tr>
<td>Lee et al.</td>
<td>16</td>
<td>Sudden</td>
<td>asystole</td>
<td>7</td>
<td>death at 3 d</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Miralles et al.</td>
<td>15</td>
<td>CHF</td>
<td>asystole</td>
<td>0</td>
<td>death at 10h</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Kottelat et al.</td>
<td>64</td>
<td>CVA</td>
<td>asystole</td>
<td>5</td>
<td>not noted</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Sankar et al.</td>
<td>67</td>
<td>MI</td>
<td>asystole</td>
<td>2</td>
<td>normal at 57</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>Castellanos-Carballo et al.</td>
<td>94</td>
<td>SAH</td>
<td>asystole</td>
<td>3</td>
<td>death at 18 h</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Malik et al.</td>
<td>80</td>
<td>Sepsis</td>
<td>asystole</td>
<td>1</td>
<td>death at 12</td>
<td>-</td>
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<td>Dhillon et al.</td>
<td>70</td>
<td>Hepatorenal</td>
<td>asystole</td>
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<td>Ben-David et al.</td>
<td>66</td>
<td>Sudden</td>
<td>asystole</td>
<td>19</td>
<td>normal</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Monteiro et al.</td>
<td>72</td>
<td>MI</td>
<td>asystole</td>
<td>2</td>
<td>death at 15 h</td>
<td>-</td>
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</table>

- University of Maryland Medical Center
- Level 1 Trauma Center
- 8 Pediatric Patients included (all adolescents)
- Patients consented for DCDD
- Objective to observe any events of autoresuscitation
• All patients had an arterial catheter
• Five minute waiting period after the presence of asystole
• Criteria for death included
  • Absence of pulse pressure by arterial catheter
  • Absence of heart sounds by direct auscultation
  • Apnea
  • Unresponsiveness
• There were no episodes of autoresuscitation during the 5 minute waiting period, including the first 2 minutes after asystole
• Recommending more consistency and transparency in DCDD protocols to a waiting period of 2 min which would lead to less warm ischemic time

Findings

• Only 4 of 41 patients had return of arterial blood pressure following cessation
• The longest period of cessation of arterial blood pressure before resumption was 89 seconds
• The duration of resumed activity ranged from 1 to 172 seconds
• Of the 4 pediatric patients there was no resumption of arterial blood pressure

Case reports

• 3 pediatric case reports of autoresuscitation all preceded by CPR
• Mechanism-unknown however hypothesis is that it is related to hyperventilation and a degree of auto- positive end expiratory pressure

Defining Death by Cardiovascular Standards-
Circulatory Determination of Death

• Accepts that the heart alone may not be “dead” but the entire CV system is not functioning to the extent that the entire “organism” can survive
• No consistency nationally
• Asystole alone, some add lack of pulsatile flow
• Waiting period varies from 2-10 minutes— Longer wait times less chance of auto resuscitation
• But have longer warm ischemic time
• 2010: Multidisciplinary task force to determine the definition of death states death should be "declared by establishing the permanent cessation of circulation and respiration in the donor patient using accepted standards of assessment."

Understanding and Defining Death

• Bernat et al in Critical Care Medicine 2010
  – “We conclude that (DCDD) respects the DDR because it fully satisfies the requirements of the UDDA by reflecting “accepted medical standards.” The manner in which permanent cessation of circulation and respiration is used to determine death in DCDD is completely consistent with physician’s use of this standard in all other contexts in which circulation and respiration are measured. Whereas we recognize that proving the moment of permanence usually is not consequential in non-donor patients, DCDD creates an exceptional circumstance in which it is essential for physicians to determine the exact timing and methods to determine permanence.”
Timing of Death

- Varies by institution however most facilities are 2 minutes up to 10 minutes
- Why the variation?
  Still no consistency amongst national organizations

Is the Brain Dead in Brain Death?

- Not dissimilar to cardiac death or cardiovascular death
- Accepted legally and ethically as criteria for the determination of death
  - Acknowledges that the brain can no longer function to maintain the entire organism
  - However, the brain can still take up glucose on PET scanning
  - Brain cells from brain dead patients can be grown in culture
- So why is it not OK to accept that cardiac death is as hard to define as brain death, or death at all
  - When organ donation is an option we need to recognize the potential for significant conflicts of interest

Other Concerns with DCDD

- Some procedures or medications are given prior to withdrawal of support
  - Medication examples: Heparin, thyroid hormone
  - Some hospitals or circumstances require bypass cannulation prior to being declared “dead”
- Highly monitored process of death and patient must expire within a certain time frame “warm ischemic time”

Potential Conflicts of Interest and Challenges

- Caregiver being responsible for donor and recipient
- Desire to help those on waiting list will create institutional bias towards WLST and donation
- Concern that this bias greater in brain injured children
- Concern that conflicts of interest can be subtle

Consent Process

- Deceased donation is governed by Anatomical Gift Legislation in the United States
- In DCDD, aspects of the donation process occur before the determination of death
- Question as to whether one can give valid consent for something that may cause harm to the donor yet benefit the organ recipient
Proposed Components of Consent

- Precise method of determining death
- Logistics of the process
- What organs may be available for donation
- Explanation that donation may not be possible
- What palliative care would look like if donation is not possible
- The ability to withdraw consent

The Task of Breaking Bad News

“If we do it badly, the patients or family members may never forgive us; if we do it well, they may never forget us.” (Buckman, 1992)

Communication

“Words are, in my not-so-humble opinion, our most inexhaustible source of magic; capable of both inflicting injury, and remedying it.”

- Albus Dumbledore Harry Potter and the Deathly Hallows, Part 8

Self Awareness

- Self awareness can help providers be more attentive to the presence of stress
- Increased mindfulness is correlated with reduced burnout and total mood disturbance in physicians
- Patient centered qualities are correlated with increased mindfulness (Krasner 2009)
SPIKES

- Set-up
- Perceive
- Invite
- Share Knowledge
- Empathize
- Summarize

Set-Up and Staging

- Arrange for privacy
- Manage interruptions (pager, phone)
- Review the chart
- Involve others
- Sit down
- Introduce everyone

Perception

- Get information before you give information
- What have you been told already?
- What are you aware of already?

Invite

- Ask how they like to receive information
- Ask whether anyone else should be there
- Inform them that unfortunately you are about to share information that may be hard to share

Knowledge

- Give information in small pieces
- Avoid euphemisms
- Check their knowledge frequently

Empathize

- Stop talking and observe
- Identify the Emotion
Summarize

- Check overall understanding
- Recap the goals
- Discuss the plan
- Probe the questions
- Document the discussion

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NURSE

<table>
<thead>
<tr>
<th>N</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>U</td>
<td>Understand</td>
</tr>
<tr>
<td>R</td>
<td>Respect</td>
</tr>
<tr>
<td>S</td>
<td>Support</td>
</tr>
<tr>
<td>E</td>
<td>Explore</td>
</tr>
</tbody>
</table>

- I wonder if you are feeling upset.
- I see that you are frustrated.
- It is hard to imagine what you are going through. This is a lot to be dealing with.
- I see how strongly you have been advocating for her. You are amazingly strong and loving parents.
- I want you to know that I am here for you. We are available as questions come up.
- Tell me more about what you are thinking. How are you doing today?

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Ask-Tell-Ask

- Ask
- Tell
- Ask
- Tell Me More

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Resources on Difficult Conversations

- Courageous Parents Network
  - [https://courageousparentsnetwork.org](https://courageousparentsnetwork.org)
- American Academy of Pediatrics Section of Palliative Care
  - [http://www2.aap.org/sections/palliative/ResilienceCurriculum.html](http://www2.aap.org/sections/palliative/ResilienceCurriculum.html)

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Why is this important?

- To relate to individuals with emotional skill, the practitioner, “needs to sense the sharing of suffering, ... be willing to be fully present, ...(and move) fluidly between a position as expert and as curious and respectful fellow human being. Self-awareness and reflective practice are central to compassionate communication” (Browning, 2002)
The Provider’s Role

• Families’ hospital experiences affect their decision to donate organs
• DeJong (1998) completed a qualitative study examining the differences between donor and nondonor families
  – 83% of donors vs 46% of nondonors said the donation discussion occurred at the right time
  – Nondonor respondents felt as though the organ donation process was not discussed in language they could understand and lacked privacy (52% of nondonors were asked to sign consent in the hallway or waiting room)

Our Process: Potential Organ Donor Phase

• Critical Care Team-Confirms CMO and DNR orders are obtained and documented
• NEOB screening
• Contact Medical examiner

Organ Donor Preparation Phase

• Obtains consent from family/legal representation for heparin
• Heparin dose is determined by NEOB
• Consent obtained for any additional procedures that are necessary to support the organs
• Critical care team, NEOB, OR, and FAMILY develop a plan

Process

• Extubation of patient
• Circulatory death
  – Apnea and
  – Five minutes of zero pulse pressure as determined by monitoring or electrical asystole
• Lack of circulatory death
  – Continues to breath or has a pulse for more than 2 hours the donation process is stopped
Connor’s Story continued

- Request for face transplant however not eligible
- Able to transplant both kidneys and corneas

Discussion

- Benefit of OR staff
- Overwhelming list of organs and tissues to donate
- Prayer request
- Lack of understanding on the withdrawal process
- Nurse continuity and value of the night shift
- Follow-up

Take Home Points

- There are significant ethical challenges providers will face with DCDD and we must be aware of our personal opinions and beliefs
- One of the best gifts we can give a patient and their loved ones is effective communication and a better understanding of how to compassionately deliver difficult news

- Every patient and every family is unique
- Developing a well thought out plan is one of the most important steps in the DCDD process
- Presence is vital and follow-up critical
Questions and Thanks