An Unlikely Partnership: How a Palliative Care Team and an Organ Donation Organization Collaborate to Support Families on the ICU

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DISCLOSURE

We have no actual or potential conflict of interest in relation to this program/presentation.
Goals for Today

- Discuss how uncertainty impacts ICU care and family decisions regarding organ donation, and how palliative care can help

- Explain how the palliative care team interfaces with the organ donation organization and the ethical and practical foundation for this collaboration

- Demonstrate how coordinated communication and support can mitigate families’ risk for ICU-related post-trauma and complicated grief
Temple University Hospital (TUH) Palliative Care

- 721-bed non-profit acute care hospital in North Philadelphia, PA (99 ICU beds)

- Palliative Care Team
  - 3 Physicians (2 part-time)
  - 1 Nurse Practitioner
  - 3 Social Workers (1 part-time)
  - 1 Chaplain
  - (Residents, Fellows, medical students, social work interns)
Our Community

- Our primary population service area includes more than 630,000 residents
- 79% of the population is African American, Latino, or another minority
- More than 2/3 have a household income of under $20,000
- Highest volume of patients covered by Medicaid in Pennsylvania among full-service hospitals
- Poverty, trauma, and family estrangement are prevalent
The ICU: Perfect Storm for Palliative Care
Uncertainty in the ICU Setting

- 20% of patient deaths in the U.S. occur in an ICU
- 10-20% of ICU patients die either in the ICU or prior to hospital discharge
- Fewer than 5% of ICU patients have the capacity to make decisions regarding their own medical care
- In the U.S., as many as 90% of deaths in an ICU involve a decision to withhold or withdraw life support

Uncertainty in the ICU Setting at TUH

- More than half of TUH Palliative Care Patients are seen in ICUs, and many of those will die in the hospital.
- Scant supportive resources available in the community.
- Population at high risk for complicated grief.
- Families who experience time in the ICU as traumatic are at higher risk for complicated grief. (Tyrie & Mosenthal, 2012)
And now you want to talk about organ donation…?
Why should palliative care be involved?

- We are skilled communicators, particularly in delivering difficult information
- We have expertise in end of life care issues
- We practice patient and family-centered care
- We know how to manage symptoms
- We provide anticipatory grief and bereavement support, including emphasis on meaning-making
NASW Code of Ethics

Ethical Principles
- Service
- Social justice
- Dignity and worth of the person
- Importance of human relationships

Ethical Responsibilities
- Informed Consent
- Conflicts of interest
- Interdisciplinary Collaboration

Ethical Principles utilized in donation

Respect for persons:
Considers individual autonomy, including the right to refuse to donate an organ; emphasizes transparency of processes

Justice:
Equal respect and concern are given to each individual

Utility:
Takes into account possible goods and harms and makes decisions that overall benefit the affected groups
Definitions

- **OPO** – Organ Procurement Organization (a non-profit organization that is responsible for the evaluation and procurement of deceased-donor organs for organ transplantation)

- **DCD** – donation after circulatory death (life support is withdrawn; if the potential donor dies within a certain time, organs are recovered)

- **Brain death** - irreversible brain damage causing the end of independent respiration, regarded as indicative of death
Six Scenarios That Trigger A Donation Discussion

- Family Mentions Donation
- Brain Death Pronounced; Explained to the Family / Family understands
- Donation Mentioned Independent of Gift of Life
- Decision To Limit, Decelerate or Withdraw LST
- Pulmonary or Hemodynamic Instability (On the Verge of Coding)
- Family Understands Death / Non-Survivable Nature of Injury (Prior to Formal BD Pronouncement or discussion of removing LST)
Case Study: Mr. Brown

Poor communication impacts families
Case Study: Mr. Brown

**HISTORY**

- 29 y/o, African American male
- No major problems in medical history (some asthma)
- Transferred to TUH from OSH after experiencing flu-like symptoms for previous week, followed by SOB and hypoxia

- **Day 2 at TUH**: Develops ARDS requiring VVECMO; + legionella in urine
- **Day 3 at TUH**: Possible lymphoma is discussed and ruled out
Case Study: Mr. Brown

DAY 11: 0800-1625

- **0800** Patient appears brain dead; head CT shows large bleed
- **0900** Resident calls Mom and explains her son is brain dead; she is a teacher and is teaching a class at the time
- **1000** Referred to Gift of Life by bedside RN
- **1100** Palliative Care is consulted; chaplain meets with Mr. Brown’s aunt as mother not at bedside
- **1440** Cerebral Blood Flow study consistent with brain death
- **1530** 1st exam consistent with brain death
- **1625** Brain death is declared
Case Study: Mr. Brown

**DAY 11**

1645

ICU Physician and Gift of Life meet with family *(Palliative Care not called to participate in meeting or to meet mother)*

Physician discusses pronouncement - family is in shock

After believing that family is understanding brain death, Gift of Life offers donation opportunity

Family asks for more time, and ICU team gives family until the next day to decide
ICU Physician and Gift of Life again speak with family—they are still struggling with understanding brain death.

Palliative Care Chaplain present and offers support, but family already angry.

Physician again explains hospital course and confirms brain death.

Family decide they do not want to speak w/Gift of Life anymore—concerned ICU team only declaring death for donation purposes.

Gift of Life does not re-approach.
Case Study: Mr. Brown

- **DAY 13**: Ethics consult, including Neurologist and Palliative Care Chaplain - committee speaks with family
  - All parties agree to remove ventilatory support the following day
- **DAY 14**: Meeting with ICU Physician, patient’s Mom, mom’s lawyer, TUH Legal Counsel, and TUH Risk Management
  - Physician again explains brain death pronouncement; all decide to give family a couple more hours before turning off the ventilator and ECMO
  - By the end of the day all life-sustaining therapies are removed
Helping Families Manage Uncertainty

- Improve Communication
- Educate Patient/Family
- Allow Time to Absorb Information
Palliative Care in the ICU

- Communication interventions such as early family meetings about goals of care have been clearly shown to improve end of life care in the ICU.

- More than 95% of family disputes are resolved in meetings between treating physician(s) and patient’s surrogate(s).

Pope, 2010; Curtis, Patrick, & Shannon, 2001
Palliative Care in the ICU

- Families require assistance in understanding the information provided
- Families require support during the decision-making process
- Families need assistance with alleviating guilt

Lautrette, 2006
## Palliative Care & Donation

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<thead>
<tr>
<th>Patients without Opportunities for Organ Donation</th>
<th>Patients with Potential for Organ Donation</th>
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<tbody>
<tr>
<td>Discuss difficult end-of-life issues such as:</td>
<td>Palliative Care education about end-of-life care may shift.</td>
</tr>
<tr>
<td>• Treatment options</td>
<td>If patient likely to fulfill brain death criteria, recommend supporting the patient/family through brain death protocol versus recommending withdrawal of life-sustaining measures</td>
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<td>• Advance directives</td>
<td></td>
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<td>• Levels of care, including Do Not Resuscitate (DNR) orders</td>
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<td>Assist patients and their families to set informed goals of care and treatment.</td>
<td>Consider how those goals might impact the families’ ability to donate. Some decisions may need to be adapted to the donation process.</td>
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<tr>
<td>Coordinate communication between families and medical providers.</td>
<td>In addition to usual communication, important to keep OPO up to date. <strong>Palliative care might introduce OPO, but NEVER introduces donation.</strong></td>
</tr>
<tr>
<td>Patients without Opportunities for Organ Donation</td>
<td>Patients with Potential for Organ Donation</td>
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<td>Management of pain and other symptoms.</td>
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<td>Psychosocial and spiritual support and intervention.</td>
<td>In addition to usual intervention, communication between the OPO and Palliative Care vital in order to reduce family confusion and risk of family later developing complicated grief.</td>
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Discussing existing family dynamics with OPO helps everyone to be “on the same page.”
Mitigating the Risks of ICU Post-trauma

Palliative Care Offers Assistance for Grieving Families
Anticipatory Grief

• Experienced when a loss is perceived as inevitable
• Risk Factors:
  – Patient aged <35
  – Patient with young children
  – Rapid decline
  – Multiple losses
• Early intervention can help people cope more effectively, which leads to more adaptive forms of grief expression
• Those who receive support prior to death of loved one tend to cope better when assessed at 13 months post-death (Worden, 2009)
• Debriefing is key in preparing families both before and after discussions of organ donation
Complicated Grief

• Grief that is extended, repressed, or manifests in maladaptive behaviors
• Estimated to affect 10% of bereaved people (Waller, et al, 2015)
• Risk Factors:
  – Sudden, unanticipated death
  – Violence, mutilation, destruction
  – Preventability and/or randomness
  – Multiple deaths
  – Mourner’s personal encounter with death

• REMINDER: Families who experience death in the ICU as traumatic are at greater risk for complicated grief
Case Study: Mr. Thomas

Good communication makes a difference
Case Study: Mr. Thomas

HISTORY

• 33 y/o, African American male
• **Past Medical Hx**: polysubstance abuse
• Admitted to TUH after girlfriend found him unresponsive
• Intubated in field w/return of spontaneous circulation
• **Tox Screen**: + benzos, marijuana, and oxycodone
Case Study: Mr. Thomas

DAY 1: Referred to Gift of Life by bedside RN

- Patient appears brain dead
- Plan for exams to begin 24 hours after admission
- Palliative Care consulted in the morning for family support; Social Worker meets with patient’s significant other and extended family

Day 2: Cerebral Blood Flow Study shows no flow

- Patient breathes when vent dialed down; family praying for a miracle
- ICU Physician agrees to support patient through brain death versus discussing withdrawal of life sustaining measures
- Palliative Care Social Worker supports patient’s significant other and 3-year-old daughter during visit with Mr. Thomas
Case Study: Mr. Thomas

**DAY 3: After apnea test, brain death declared**
- Palliative Care meets family to coordinate patient’s daughter coming to say good-bye
- Palliative Care gives significant other info on how to talk to daughter about death
- Family authorizes donation and wants to explore directed donation; potential recipient is a perfect match but can’t be transplanted d/t foot infection

**DAY 5: Donation occurs**
- Patient donates his heart to a man in his 50s, liver to a woman in her 50s, right kidney to a woman in her 40s (listed since 2009), and left kidney to a woman in her 50s
- Ongoing: Mr. Thomas’ significant other receives follow-up bereavement call and card from Palliative Care and is invited to grief support group; Mr. Thomas’s significant other and mother receives follow-up call from GLDP family support services offering support groups and counseling services, will follow-up again at 6 months
Questions?
Comments?
Thanks to Liz Lowry and the GIFT of LIFE DONOR PROGRAM.
Thank You!

Temple Palliative Care Team
Temple Medical/Respiratory ICU Staff
Our Gift of Life Colleagues
References


McCullough, L.B. (2013). The professional medical ethics model of decision making under conditions of clinical uncertainty. *Medical Care Research and Review Supplement to 70*(1), 141S-158S.


