Trust & Integrity of the Deceased Donation System

Sam D. Shemie

Critical Care Canada Forum, Deceased Donation Symposium
Nov 8th 2018

McGill University Health Centre, Montreal Children’s Hospital, MUHC Research Institute
Division of Critical Care

McGill University
Professor of Pediatrics

Canadian Blood Services
Medical Director, Deceased Donation
**TUESDAY, OCTOBER 3, 2017**

<table>
<thead>
<tr>
<th>TIME</th>
<th>SESSION</th>
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<tr>
<td>12:00 - 12:45</td>
<td><strong>MID-DAY PLENARY</strong>&lt;br&gt;Moderators: Sonny Dhanani, Andrew Baker&lt;br&gt;&lt;br&gt;<em>Death of the Dead Donor Rule? Pro-con Debate</em>&lt;br&gt;Robert Truog - Sam Shemie (10mins each presentation, 5mins rebuttal and 15mins for discussion)</td>
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What are the Principle Goals of a Deceased Donation System?

1. Provide the opportunity to donate without compromising the duty of care to the dying patient

2. Serve the wishes of potential donors & their families

3. Do so in an ethical, legal, safe and equitable manner

4. Serve the needs of potential transplant candidates
Historically in Canada, the organ donor was an orphan in health care.
Results

Illustrative ICU Quotes

• “Why are you wasting a precious resource like blood on a dead person?” 1998
• “Letting them rot on the vine so you can steal their organs” 2003
• “For ICU staff doctors, organ donation is really just big hassle” 2005

• “ITS NOT OUR FUCKING PROBLEM”
  Pro-Con debate, Fisher vs Shemie

“Should ICU’s be responsible for organ donation’
Toronto Critical Care Symposium 2000
The need for re-design was recognized, but little improvement seen: 1994-2008

Source: CORR 2007 Annual Report and E-Statistics
Canada: Deceased donation rate by donor type, 2006 – 2017 (dpmp)

Results reported may be subject to change pending final validation

DCD = 25% of deceased donors

Results reported may be subject to change pending final validation
The Journey from “It’s not our fucking problem” to “It’s our job”
Collaborative Effort in Canada

Population: 35.5 million Canadians
Size: 9.7 million square kilometers

- Canadian Blood Services
- 10 Provincial Organ Donation Organisations
- 80 Transplant Programs
- 286 Intensive Care Units/Emergency Departments

2016 Statistics
- 758 deceased donors
- 545 living donors
- 2903 transplants
- 4541 waiting list
  - 260 deaths
Provincial Organ Donation Organizations
Deceased Donation: Canadian Strategies

1. ICU engagement and ownership
   - Partnership with Canadian Critical Care Society, Canadian Association of Critical Care Nurses
   - Communities of Practice

2. Professionalization of donation services
   - Nurse coordinators, ICU donation physicians

3. Research to inform health policy & practices
   - CBS, Canadian Critical Care Trials Group, Canadian National Transplant Research Network, independent

4. *National* leading practice/guidelines for each step of donor process
   - best available evidence
   - consensus process
   - embedded knowledge translation
   - peer reviewed publication
Leading Practices

Deceased Donation Leading Practices 2003-2018

n = 18

- Hospitalization
- Identification and Referral to ODO
- Family Consent
- Organ Recovery

- Declaration of Death (NDD)
- Declaration of Death (DCD)

- Donor Management (2004)
- Controlled DCD (2005)
- Donation Physician Specialists (2011, 2015)
- System OTDT Ethics (2011)
- End-of-life Family Conversations/ Consent (2014)

- Pediatric DCD (2014-16)
- Death Audits/Medical Record Review (2015-17)
- Donor ID&R System Accountability (2015-17)
- ECMO-CPR-organ donation (2016-18)
- OD Conscious Competent Patient (2016-18)
- DCD Quality Assurance (2016-18)
- Donor Management CPG update (2016-18)
- DCD Heart Donation and Transplantation (2018)
Building a Community of Experts
Enhanced Focus on ‘Donation Medicine’

ORGAN AND TISSUE DONATION AND TRANSPLANTATION

Report on the Consultation
“Donation Physicians in a Coordinated OTDT System”

February 21 - 22, 2011
Whistler, British Columbia

Improving the process of deceased organ and tissue donation: a role for donation physicians as specialists

Sam D. Shermie MDCM, Shavaun MacDonald MD, on behalf of the Canadian Blood Services — Canadian Critical Care Society Expert Consultation Group*

The disparity between the demand for transplants and organ availability has been identified as a worldwide public health concern. In Canada, donation rates and access to transplantation differ between provinces, and deceased donation rates have remained stagnant and rank well below other countries with advanced transplantation services. At the end of 2011, there were 4541 Canadians on transplant waiting lists. In 2010, 16% of transplant candidates waiting for a kidney, pancreas or both died while on the wait list; this figure was 19% for lung transplant candidates, 22% for liver transplant candidates and 24% of intensivists, is available at all times to provide direct donor care in all intensive care units. In coordination with the local organ-procurement organization, their role includes evaluation and diagnosis of brain death, donor management and communication with the transplant team.

In contrast, in the UK, donation physician specialists (referred to as clinical leads for organ donation*) promote donation through the provision of knowledge, leadership, education and administrative guidance. They do not attend to every donor, but they work closely with the nurse donor coordinators who provide direct donor care.

Competing interests: None declared.

*For the list of members see Appendix 1: www.ccmj.ca/content/185/10/1500

Correspondence to:
Sam Shermie, sam.shermie@mcgill.ca
Implementation of Donation Physicians in Canada
(n=103)

Note: Current as of Jan. 2018
Resistance to Organ Donation

- Ethical
- Philosophical
- Religious
- Cultural
- ICU culture

Provides obstacles and challenges but..
Serves to check and balance the system

Resistance to Supportive
It used to be Transplant pushing a resistant ICU
Now it’s a motivated ICU pushing Transplant
Your sensitivity to ethical boundaries will be naturally influenced by your professional experience in medicine.
Mortality Toll and Culture of ICU Death

1. Pediatric ICU
   - 1-2\% \textit{mortality}, 1000 admissions/year
   - = 10-20 deaths per year – 1-2 deaths/month

2. Adult ICU
   - 20\% \textit{mortality}, 1000 admissions/year
   - = 200 deaths per year – 18 deaths/month = 4-5 deaths/week
Qualitative Use of Life Support in the ICU
Canadian Critical Care Trials Group

Although life-support technologies are traditionally deployed to treat morbidity and delay mortality in ICU patients, they are also used to orchestrate dying.

Advanced life support can be withheld or withdrawn to help determine prognosis. The tempo of withdrawal influences the method and timing of death.
Respirologist Dr. Nancy Morrison gave Paul Mills, a terminally ill cancer patient, a massive dose of nitroglycerin and potassium chloride to hasten his death in 1996.

Morrison was charged with first-degree murder, but a provincial judge ruled the charge out, saying no jury would convict her.
Ontario judge refuses family's plea to keep brain dead woman on life-support

Taquisha McKitty's father disappointed in decision, saying 'she's never stopped being alive'

John Riot · CBC News · Posted: Jun 26, 2018 12:44 PM ET | Last Updated: June 26

Taquisha McKitty was declared brain dead in September 2017, and has been on life-support since. Now, an Ontario judge has ruled she can be taken off the mechanical ventilator. (Instagram)
<table>
<thead>
<tr>
<th>Ethical Tensions</th>
<th>VS</th>
<th>Ethical Tensions</th>
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<tbody>
<tr>
<td>The decision to withdraw life sustaining treatment</td>
<td><strong>VS</strong></td>
<td>The decision to donate organs</td>
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<tr>
<td>Optimizing the quality of the dying process</td>
<td><strong>VS</strong></td>
<td>Optimizing the quality and quantity of the donated organs</td>
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<tr>
<td>Obligations to provide balanced informed consent</td>
<td><strong>VS</strong></td>
<td>Belief that we should promote organ donation</td>
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<tr>
<td>Belief that we need to follow the “dead donor rule”</td>
<td><strong>VS</strong></td>
<td>Protecting and fully respecting the donor’s wishes</td>
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Truog, CCCF 2017
Selection Bias

Families that:

1. Consent to withdrawal of life sustaining measures
2. Consent to donation
Canada Conjoining Euthanasia/Organ Donation

By WESLEY J. SMITH | January 5, 2018 7:04 PM

In my first anti-euthanasia column, published in Newsweek in 1993, I warned that eventually medicalized killing/suicide would be conjoined with organ harvesting “as a plum to society.”

Organ and Tissue Donation in the Conscious Competent Patient

Workshop Agenda for Monday May 15, 2017 (Day 1)
Sheraton Gateway Hotel (Terminal 3, 3000 Toronto Pearson International Airport) – Alpine Room
MAID vs. DCD

If you are a MAID provider:

a. It is permissible to give an intravenous cocktail to end the life of a patient
b. Based on sustained first person consent

If you are a DCD provider:

a. Give pre-mortem heparin
b. Withdrawal life support
c. Manage EOL care & palliation
   • Based on surrogate consent
d. You may not intentionally expedite death
DCD Donors & DCD Did Not Die Within Acceptable Time by Donor Hospital 
2016 Calendar Year

- **DCD Attempts**
- **Transplanted**
- **Did not die**

34% do not proceed
A gift ungiven: The anguish of losing a loved one can be compounded when their wish to be an organ donor can't be fulfilled

ELIZABETH PAYNE

Published on: March 26, 2018 | Last Updated: March 26, 2018 12:46 PM EDT
Motivated by Good but Doing Bad?

Have you felt, or acted upon, the internal or external pressure to "make DCD donation happen" for families?

“Donation Palliation”
Evolving EOL Care Culture in Canada

10 years ago, MAID may have had moral merit, but was illegal.

Today, donation palliation may have moral merits, but is illegal.
DCD Donors & DCD Did Not Die Within Acceptable Time by Donor Hospital 2016 Calendar Year

Overall 34% do not proceed

With thanks, Andrew Healey
## Interview Characteristics

<table>
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<tr>
<th></th>
<th>Recontact Consent</th>
<th>Consent to Interview</th>
<th>Refused Interview</th>
<th>Lost to follow up</th>
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<tr>
<td>DePPaRT</td>
<td>48</td>
<td>28 (58%)</td>
<td>5 (10%)</td>
<td>15 (31%)</td>
</tr>
<tr>
<td>TGLN</td>
<td>14</td>
<td>8 (57%)</td>
<td>0</td>
<td>6 (43%)</td>
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<tr>
<td>TOTAL</td>
<td>62</td>
<td>36 (58%)</td>
<td>5 (8%)</td>
<td>21 (34%)</td>
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### Type of case

<table>
<thead>
<tr>
<th>Type of case</th>
<th>Number</th>
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<tbody>
<tr>
<td>DCD consent (successful attempt)</td>
<td>14</td>
</tr>
<tr>
<td>DCD consent (failed attempt)</td>
<td>14</td>
</tr>
<tr>
<td>DCD Refusal</td>
<td>4</td>
</tr>
<tr>
<td>Found to be DCD ineligible</td>
<td>3</td>
</tr>
<tr>
<td>Found to be NDD</td>
<td>1</td>
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Preliminary observations -

• Impact of time
  – Delaying WLST in order to donate
    • Sometimes welcomed: “gave us more time with him”
    • Sometimes not: “I’m questioning my registration, whether I’d put my kids through that again”
  – Difficulty of the “window”
    • Multiple families found it hard to be “hoping” for death in order to be able to donate. One called it “torture.”
    • Multiple families wanted something done to “speed it up”
Preliminary observations

• Handling unsuccessful DCD attempts
  – Preparing family
  – Continuing care for px and family after failed attempt
  – Celebrating all attempts as valuable

• Conflict of interest and trust
  – *Occasional suspicion death was hastened*

• Important quality improvement
  – Asking for monetary donation in letter thanking family for donating tissue
Ethics Guide? What and Why

ETHICS FOR IDIOTS

RIGHT = GOOD
WRONG = BAD

WOAH...
German Deceased Donation Trends

Donor PMP

INDEPENDENT

News › World › Europe

Doctor in court over organ donor fraud scandal as transplant centres across Germany placed under criminal investigation

Prosecutors charged that he had changed data on the files of at least 25 patients to push them up the transplant list

Tony Paterson | Monday 19 August 2013 17:44 BST | 0 comments

Eurotransplant
Risk of Ethical Misconduct in the Canadian ODT System
What Would be Considered Catastrophic?

1. Falsifying data for waiting list patients to get priority access
2. Accepting money for priority access on the list
3. Accepting money to create more donors
4. Taking organs from someone who is not dead
5. Intentionally hastening the death of a donor
6. Killing a patient for organs
Ethics Guide for Donation Physicians

Recommendations developed through a national collaboration among Canadian deceased donation experts and bioethicists, and endorsed by the Canadian Medical Association

Released November 2015

Abstract: Donation physicians are specialists with expertise in organ and tissue donation and have been recognized internationally as a key contributor to improving organ and tissue donation services. Subsequent to a 2011 Canadian Critical Care Society-Canadian Blood Services consultation, the donation physician role has been gradually implemented in Canada. These professionals are generally intensive care unit physicians with an enhanced focus and expertise in organ/tissue donation. They must manage the dual obligation of caring for dying patients and their families while providing and improving organ donation services.

In anticipation of actual, potential or perceived ethical challenges with the role, Canadian Blood Services in partnership with the Canadian Medical Association organized the development of an evidence-informed consensus process of donation experts and bioethicists to produce an ethics guide. This guide includes overarching principles and benefits of the DP role, and recommendations in regard to communication with families, role disclosure, consent discussions, interprofessional conflicts, conscientious objection, death determination, donation specific clinical practices in neurological determination of death and donation after circulatory death, end-of-life care, performance metrics, resources and remuneration. Although this report is intended to inform donation physician practices, it is recognized that the recommendations may have applicability to other professionals (eg, physicians in intensive care, emergency medicine, neurology, neurosurgery, pulmonology) who may also participate in the end-of-life care of potential donors in various clinical settings. It is hoped that this guideline will assist practitioners and their sponsoring organizations in preserving their duty of care, protecting the interests of dying patients, and fulfilling best practices for organ and tissue donation.

(Transplantation 2017;101: S41-S47)
8.3 Guidelines:……Managing the dying process follows existing ICU/critical care practice and is not influenced by donation potential.

11.2 For potential DCD donors, after the donor's family has consented to donation and prior to the withdrawal of life-sustaining therapy, the donation team only uses interventions that do not harm the potential donor or hasten death.
1. Be aware of overt and covert pressure from family and/or staff
2. Acknowledge these pressures
3. Advocate adherence to recommended practices
4. Should not engage or condone:
   • Withholding appropriate analgesia/sedation for fear of perceptions about expediting death
   • Providing analgesia/sedation that may expedite death as its primary aim
   • Providing analgesia/sedation intended to hasten death in order to ensure the patient’s/family’s wishes for donation are realized.
In 2012, the CBS Deceased Donation Medical Advisory Committee (DDAC) requested that the Canadian Critical Care Society develop national recommendations for the procedures and actions regarding WLST.

Guidelines for the withdrawal of life-sustaining measures

James Downar¹, Jesse W. Delaney², Laura Hawryluck², and Lisa Kenny⁴

Abstract

Background: Withdrawal of life-sustaining measures is a common event in the intensive care unit yet it involves a complex balance of medical, legal and ethical considerations. Very few healthcare providers have been specifically trained to withdraw life-sustaining measures, and no comprehensive guidelines exist to help ensure clinicians deliver the highest quality of care to patients and families. Hence, we sought to develop guidelines for the process of withdrawing life-sustaining measures in the clinical setting.

Methods: We convened an interdisciplinary group of ICU care providers from the Canadian Critical Care Society and the Canadian Association of Critical Care Nurses, and used a modified Delphi process to answer key clinical and ethical questions identified in the literature.

Results: A total of 39 experienced clinicians completed the initial workshop, and 36 were involved in the subsequent Delphi rounds. The group developed a series of guidelines to address (1) preparing for withdrawal of life-sustaining measures; (2) assessment of distress; (3) pharmaceutical management of distress; and (4) discontinuation of life-sustaining measures and monitoring. The group achieved consensus on all aspects of the guidelines after the third Delphi round.

Conclusion: We present these guidelines to help physicians provide high-quality end of life (EOL) care in the ICU. Future studies should address their effectiveness from both critical care team and family perspectives.

Keywords: Consensus, Delphi technique, Standards, Critical care, Terminal care, Palliative care, Life support care.
GUIDELINE IMPLEMENTATION AND QUALITY ASSURANCE DEVELOPMENT FOR WITHDRAWAL OF LIFE SUSTAINING MEASURES (WLSM) IN HOSPITALS SUPPORTING DONATION AFTER CIRCULATORY DEATH (DCD)

1. Implementation tools
   a) documentation tool
   b) family information package
   c) system audit tool
   d) case audit tool

2. Quality assurance tools
   a) order set
   b) checklist

3. WLSM organizational policy template
‘Organ and tissue donation is an essential component of high quality EOL care and it is essential that EOL care be of high quality in organ and tissue donation’.

WLSM DCD QA, Mike Hartwick, with thanks
Realities of Intensive Care Practice
Independent of Organ Donation

• Ethical tensions are a routine challenge
  – EOL care
    • Prognostication
    • Withdrawal/withholding of life sustaining treatments
    • Palliation and comfort
  – ICU capacity- triage, admission, discharge decisions
  – Technological advances, cost and ‘futility’
    • can do vs. should do
Reflective Questions for Donation Medicine

Is it Defensible?

• The ability to explain and account for one’s decisions and actions in light

How to manage Moral Uncertainty

• Refers to situations where one is not sure whether something is “right” and/or what values or principles may apply to a particular situation.
Editorial

Moral distance and distributive justice: how the increase in organ donation is helping us make better ethical decisions
Donation Physicians as Leaders in Ethics of EOL care

1. Often working/thinking/reading/researching at the intersection of dying, death and donation

2. Support the development & *implementation* of community-derived leading practices

3. Awareness & management of tensions and risks of erosion of ethics
   a. Dead donor rule
   b. WLSM consistent with national guidelines titrated to objective & documented criteria
   c. Resist/educate re unbridled motivation for organ donation
   d. Providing optimal processes for patient care 1st, donation care 2nd but always.
Lookout for the Warning Signs

The End