Organ Donation in the Conscious Competent Adult

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Disclosure

• None
Deceased donors in Canada, 2006–2015 (DPMP)

- 42% increase in total number of deceased donors
- 21% DCD
- 29% increase in DDPMP (14.1 to 18.2)
- 31% increase in deceased donor transplants
Background

Recent Developments:

1. Bill C-14 (Canada) and Bill 54 (Quebec) allowing Medical Assistance in Dying (MAID)

2. Increase requests with neuromuscular diseases (ALS)
   - These are patients who are conscious and competent who are able to provide first person consent
   - Clinicians are asking for guidance in order to address organ donation for this patient population
Forum Objectives

1. Understand the medical, ethical, and legal implications of providing organ and tissue donation opportunities to the conscious and competent patient who is able to provide first person consent.

2. Develop leading practice recommendations for patients who have made a decision that will lead to imminent death:
   a. Conscious and competent patients with life-sustaining treatments in place, including invasive or non-invasive forms of mechanical ventilation;
   b. Patients choosing Medical Aid in Dying.
Forum Process

- 38 participants attended the forum representing several medical specialties (Neurology, Palliative Care, Intensive Care, MAiD Providers, legal experts, bioethical experts, and patient partners)

- Participants received a comprehensive pre meeting package

- Participants listened to presentations by experts and then broke into small groups to discuss challenge questions prepared by the planning committee
Background- Forum Preparation

The following information was collected and provided as background information to inform the deliberations:

1. Systematic Review of Neurological diseases – ‘transmissibility’
2. Legal Review
3. Legislative Review
4. Ethical Review
5. Public Opinion Poll
6. Review of transplantation Outcomes
7. Patient and Family Interviews
8. Development of Glossary of Terms and Definitions
Bill C-14/Bill 54 (Quebec)

- Competent adult (> age 18)
- Grievous and irremediable medical condition
  - Serious and incurable illness/disease/disability
  - Advanced state of irreversible decline in capability
  - Enduring physical/psychological suffering, cannot be relieved under conditions they consider acceptable
  - “natural death has become reasonably foreseeable”
# Demographics of MAID

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Netherlands</th>
<th>Belgium</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>79%</td>
<td>80%</td>
<td>80%</td>
<td>57%</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>4%</td>
<td>4%</td>
<td>3%</td>
<td>11%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>16%</td>
<td>5%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td>7%</td>
<td>7%</td>
<td>8%</td>
<td>23%</td>
</tr>
<tr>
<td>“Other”</td>
<td>4%</td>
<td>5%</td>
<td>5%</td>
<td>8%</td>
</tr>
<tr>
<td>Annual Cases</td>
<td>3800</td>
<td>2800</td>
<td>100</td>
<td>970</td>
</tr>
</tbody>
</table>

References:
- Chambaere et al. CMAJ 2010;182:895-901.
Arguments for OD after MAID/WLST

• Increase the number of organs available for donation
  – Organs may be better quality than conventional DCD

• Respect for individual autonomy and self-determination

• Personal benefit to the donor- organ donation giving meaning to death
  – Benefit to family- increased solace or comfort during bereavement

• May increase public acceptance of assisted dying (?)
Overall, 92% of Canadians approve of Organ Donation after death; Support drops for those who choose end-of-life care

Support for the idea that a patient who is conscious and competent should be eligible to donate their organs at the time of their death if they decide to withdraw life-sustaining treatment for their illness.

87%

Support for the idea that a patient who is conscious and competent should be eligible to donate their organs at the time of their death if they receive medical aid in dying.

80%
The majority would accept an organ donation even if the organ was donated by an individual who decided to engage end-of-life measures; a quarter are undecided.

Would you be willing to accept an organ transplant if there was a possibility the organ was donated by an individual who made the decision to withdraw life sustaining treatment or receive medical aid in dying?

More likely to accept
- Those who support organ donation after receiving medical aid in dying (82%)
- Agree the decision to donate organs should be based on evidence (66%)
- Household income of $100+ (80%) and $60K - <$100K (79%), compared to <$40K (64%)

More likely to reject
- Those who oppose organ donation after receiving medical aid in dying (16%)

More likely to be undecided
- Those who oppose organ donation after receiving medical aid in dying (57%)
- Agree the decision to donate organs should be based on recipient concerns (34%)
- Respondents from SK/MB (36%) compared to BC (22%) and Alberta (27%)
- Household income of <$40K (30%), compared to $60K - <$100K (17%) and $100K+ (17%)

9. If you were in need of an organ transplant, would you be willing to accept one if there was a possibility the organ was donated by an individual who made the decision to withdraw life sustaining treatment or receive medical aid in dying?
Base: All Respondents (n=1,006)
## Post-Euthanasia Donors 2005-2015

<table>
<thead>
<tr>
<th></th>
<th>Belgium:</th>
<th>The Netherlands:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>23 donors $\rightarrow$ 92 organs</td>
<td>15 donors $\rightarrow$ 38 organs</td>
</tr>
<tr>
<td></td>
<td>• Kidneys 45</td>
<td>• Kidneys 29</td>
</tr>
<tr>
<td></td>
<td>• Liver 21</td>
<td>• Liver 13</td>
</tr>
<tr>
<td></td>
<td>• Lungs(2) 16</td>
<td>• Lungs(2) 6</td>
</tr>
<tr>
<td></td>
<td>• Islets 10</td>
<td>• Pancreas 13</td>
</tr>
<tr>
<td></td>
<td>$\rightarrow$ All primary function !</td>
<td>+ tissues</td>
</tr>
</tbody>
</table>


Concerns about OD after MAID/WLST

• Does the decision or option to do one thing influence the decision to do another?

• Option may unduly influence patients
  – Person who may not otherwise opt for MAID might choose MAID to donate his or her organs to help others

• May undermine public trust in the organ donation system
  – “physicians would be tempted to be deliberately pessimistic about the patient’s prognosis to enhance the patient change of request for withdrawal of treatment”
Concerns about OD after MAID/WLST

• Potential recipients who oppose MAID may object to receiving an organ from someone who has undergone MAID
  – Should the source of the organ be disclosed?

• Need for hospital death
Conscientious objection considerations

• Lack of consensus around definition and scope
  – ranged from conscientious objection should never be permitted to conscientious objection without limits, scope or follow up obligations

• Lack of clarity concerning the duty to refer
  – objecting providers have an obligation to refer the patient to a non-objecting health care provider without it negatively impacting the patient’s care or provide the patient with information about other non-objecting agencies
Conscientious objection

• Healthcare professionals
  – May object to OD after MAID or WLST, but should strive to accommodate the patients’ desires.
    • Reference to another transplant centre.
    • Reference to another physician.
    • Important to take into account the consequences of no donation (for the patient, for transplant candidates and the society).
Conclusion

• Further empirical research is needed in order to better understand organ donation in the context of MAID and WLST
• Recommendations should be reassessed in the future
• The first reason to procure organs after MAID and WLST is to respect patient’s autonomy (not to solve organ shortage).
Protections for patient/potential donor – avoiding conflict of interest

• Separation of decisions: WLST/MAID and organ donation
  • essential to ensure that the request is not solely motivated by organ donation
• Separation of teams
• Directed donation
  • promotes patient autonomy but concern about undue influence/coercion
• Assessing capacity
  • health care team must ensure that the patient has sufficient capacity
Routine approaches for OD?

**PRO**
- HCP not assume they understand patient values
- HCP should not assume patients are aware of OD; patients may support donation but assume they are ineligible
- Moral/ethical duty to inform about EOL options, including donation
- May be legal requirement to refer to ODO in case of ‘imminent death’ (varies province by province)
- Donation may give meaning to the patient’s death
  - May provide comfort to patient prior to their death
- May assist family in grieving

**CON**
- Risk of pressuring or influencing the patient
  - May feel they have to consent to donate in order to access MAID/WLST
- If patient consents, and deemed ineligible or organs not allocated, may feel regret or loss during final days of life
- Routine requesting in this setting may erode public and professional trust in the donation and/or EOL care system
The majority agree that qualified medical practitioners should be required to discuss organ donation with all adult patients, regardless of illness/condition or end-of-life care decision.

Agreement across all attributes statistically higher among:

- Those who support organ donation after withdrawal of life sustaining treatment
- Those who support organ donation after receiving medical aid in dying
- Those who would accept a transplant if needed from a donor who made end-of-life decision

Q. Do you strongly agree, somewhat agree, somewhat disagree or strongly disagree that physicians or other practitioners should be required to discuss organ donation with... Base: All Respondents (n=1,006)
## Policies and experience with MAID+OD

<table>
<thead>
<tr>
<th>Country or State</th>
<th>Policy on Organ Donation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Switzerland (assisted suicide by non-physician)</td>
<td>Not possible</td>
</tr>
<tr>
<td>Belgium (euthanasia)</td>
<td>Possible at patient’s request; 21 patients (2005-2015)</td>
</tr>
<tr>
<td>Netherlands (euthanasia, assisted suicide)</td>
<td>Possible after euthanasia at patient’s request; working on an official post-euthanasia donation protocol; 15 patients (2012-2015)</td>
</tr>
<tr>
<td>Luxembourg (euthanasia)</td>
<td>Illegal</td>
</tr>
<tr>
<td>Oregon, Washington, Vermont, and Montana (assisted suicide)</td>
<td>Not Possible</td>
</tr>
<tr>
<td>Ontario, Canada</td>
<td>Routine request; ‘imminent’ death</td>
</tr>
<tr>
<td>Quebec, Canada</td>
<td>Patient initiated</td>
</tr>
</tbody>
</table>

adapted from Allard and Fortin, J Med Ethics, 2016
Approach and consent

• Based on ethical principles of autonomy and self-determination, it was broadly agreed that all eligible, medically suitable patients should be approached to donate.
  – Necessity to train and support HCP to face patients’ questions.
  – Decision to donate should be separate from the decision to WLST or MAID.
  – Timing of discussion?
  – Conditions for discussion should be patient-centered.
  – During the discussion, the implications of OD on MAID should be addressed.
  – HCP should be sensitive to any source of coercion or undue pressure.
Also...Donor testing and evaluation

• Importance to minimize burden and inconvenience to patients who chose to pursue MAID.
  – Minimize the interventions and hospital visits.
• Unanticipated finding should also be discussed with the potential organ donor.
• (Consider reimbursing expenses incurred by the patient for testing and evaluation).
ALS - Evidence based answers

1. Is ALS transmissible?
   – Unlikely, but we cannot be certain. If transmission occurs, it will likely take 10 or more years.
   – May be increased risk in genetically vulnerable recipients

2. Does transmissibility risk vary for familial vs sporadic ALS?
   – Uncertain
   – Most animal models of ALS are familial ALS (no reliable sporadic ALS models)

3. Should we transplant organs from ALS patients or patients with other neurodegenerative diseases?
   – ? Yes, with the exception of rapidly progressive “ALS”
<table>
<thead>
<tr>
<th>Question</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is ALS transmissible through organ transplantation?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>0%</td>
</tr>
<tr>
<td>Is ALS transmissibility risk different for sporadic vs hereditary ALS?</td>
<td>12.8%</td>
</tr>
<tr>
<td>Are certain familial ALS mutations more likely to be transmissible?</td>
<td>21%</td>
</tr>
<tr>
<td>Should we transplant organs from ALS patients?</td>
<td>53.9%</td>
</tr>
</tbody>
</table>
Summary Statements

• It cannot be definitively determined if ALS is or is not transmissible.
• It is possible that intracerebral or intraspinal transmission of ALS can occur. The blood brain barrier may protect against ALS transmission from solid organ transplantation.
• If ALS is transmissible through organ transplantation, it will likely take more than ten years to develop.
Current state of ALS Organ Donation

- Toossi, Ann Neurol 2012
  - 12 ALS patients proceeded with DCD in the US prior to 2011.
- Smith, Journal of Palliative Medicine 2012
  - 2 patients with ALS elected to donate organs after DCD
- At least 2 Ontario ALS patients have donated their organs
- Spain- 10 patients
Draft Recommendations

- Caution should be exercised with allocation of organs from donors with undiagnosed end-stage neurodegenerative diseases and rapidly progressing disease.
- The transplant surgeon must balance the benefits of the transplant against any potential for harm of receiving a transplant of an organ from a donor with a neurological illness.
- All cases of ALS or other neurodegenerative diseases that arise in transplant recipients should be centrally reported to determine:
  a. potential associations with donor illness;
  b. the baseline risk of neurodegenerative illness in transplant recipients.
- Active monitoring (i.e. regular visits to a neurologist) is NOT recommended for transplant recipients who have received an organ from a donor with a neurodegenerative disease.
  - This would impose a significant burden on the recipient and present no benefit, particularly since there is currently no benefit to early detection of these illnesses.
- Information resources should be available for transplant candidates and for transplant surgeons to help with the decision regarding whether to accept or refuse an organ for transplant.
Conscious competent donors

- Home or LTC- less available for testing and assessment
- Can choose time/circumstances of death (i.e. not decided by hospital)
- Plans for final period of their lives (i.e. visiting friends, travelling)
- May experience pain, discomfort, or inconvenience associated with assessing eligibility to donate organs
- More sensitive to burden of additional steps or stress required for donation as part of their EOL care process
Clinical Pathway: End of Life Care for Organ and Tissue Donation in the Conscious Competent Patient (OTD CCP)

1. The conscious competent patient
   1.A End stage disease on life sustaining treatment
   1.B Grievous and Irremediable medical condition

2. Decision for WLST or MAID
   2.A Consideration of EOL care
   2.B Consensual decision for WLST
   2.C Patient request for MAID
   2.D MAID eligibility and approval
   2.E First assessment & Second assessment

3. Referral and suitability
   3.A Referral to ODO
   3.B Confirm eligibility for OTD
   4.A Information about organ and tissue donation shared with patient
   4.B First person consent for organ and or tissue donation
   4.C Consider Notification of Coroner Consistent with Provincial Policies

4. Approach and consent
   4.D Donor testing and evaluation
   5.A Admission to hospital
   5.B Pre mortem donor Interventions
   5.C WLST Procedures and comfort care
   5.D MAID procedures

5. Medical procedures
   6.A Cardiocirculatory arrest and determination of death
   6.B Organ and tissue recovery

* The ten day reflection period may be shortened if the patient appears likely to die or lose capacity
Next Steps

The planning committee will oversee the next steps including:

1. Development of a comprehensive meeting report, based on the recommendations resulting from meeting. Participant feedback will be assembled, a provisional report will be drafted by the planning committee and participants will be invited to review prior to finalization.

2. A comprehensive communication strategy will be developed to support the work of the committee and the plans for publication and implementation of the recommendations.

3. A dissemination and implementation plan, including professional education and peer reviewed publication, will be developed.

4. A list of identified research topics will be finalized.

5. Future collaborative opportunities will be developed with current partners and other identified stakeholders.
Questions and Discussion