Consent, capacity, and substitute decision-making

What you need to know.

Regional Ethics Rounds
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Joshua T. Landry M.Sc., CCE, HEC-C
Director and Ethicist
Central East Regional Ethics Network
CORE Network Member, Joint Centre for Bioethics
University of Toronto

Central East
Regional Ethics Network

Objectives

- Explore the informed consent process
- Discuss decision-making capacity
  - What is it? Who is it determined by?
- Examine the role and obligation of the substitute decision-maker

Case 1

Mrs. Green, is a 75-year-old patient with renal failure, currently on dialysis, who also has COPD, moderate dementia, diabetes and a new diagnosis of stage one breast cancer. There is also a past history of depression according to the family. She has been admitted to the ICU after falling down her stairs at home and is in critical condition with multiple fractures to her hip, ribs, wrists and neck. Mrs. Green does not have the capacity to make her own medical decisions and has recently started to refuse eating.

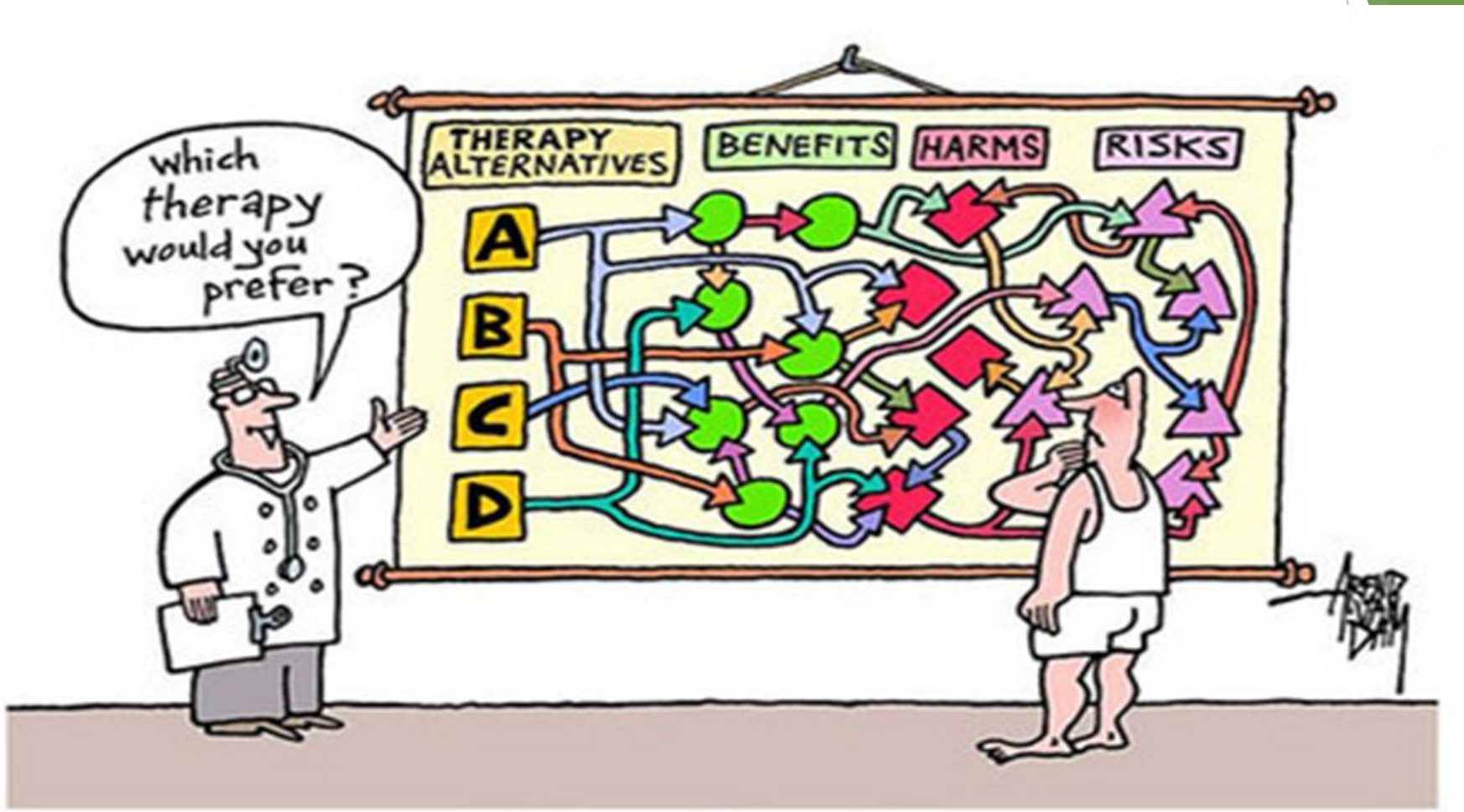
Upon discussion with GI Specialists, the team agrees that the patient is not an appropriate candidate for a PEG (feeding) tube. The patient's daughter, who is her POA, insists that the you proceed with the placement of the PEG, stating that if the tube is not placed she will contact her lawyer and proceed with legal action against the physician and hospital. Because of this, the attending physician agrees, and orders the PEG to be placed. To make matters worse, Mrs. Green begins attempts to pull the PEG and other tubes out shortly after they are placed. Since the team is experiencing human-resource shortages, and are unable to provide sufficient monitoring to prevent Mrs. Green's actions, restraints have been regularly used.

What should you do?

Case 2

Mrs. Potter is a 93-year-old resident of your long-term care home who once traveled the world as a culinary expert, sharing her love of food with many. She now has end-stage Alzheimer's. In the last year it has worsened to the point that she is no longer capable of making her own medical decisions, and she has begun to experience difficulty swallowing solid foods. Three months ago a daughter of Mrs. Potter, her Power of Attorney, consented to have her mother be provided a pureed diet in order to reduce the risk of choking. At present time, however, this daughter believes that the pureed diet is affecting the quality of her mother's life (even though Mrs. Potter has not expressed this herself). After being completely informed of the risks and benefits, she requests that her mother be given solid foods. The staff feel uncomfortable with the daughter's request due to the real possibility that Mrs. Potter will choke on solid foods, and are unsure of what to do.

What are some of the ethical issues in this case?



informed consent

Informed consent

- What is it?

- Why do we need informed consent?
  - Ethically: Respect for persons and their informed choices as far as is reasonable.
  - Legally: To have a clear process in place to protect the rights of individuals. (e.g. Health Care Consent Act [HCCA])

- What type of choices must we respect?
  - Can patients (or SDMs) demand treatments? +/-

Informed consent

- Legal process: In Ontario the Health Care Consent Act (HCCA).
- Consent must be obtained before treatment begins, possible exception in emergency case.
- Consent may be refused or withdrawn by a capable patient at any time.

Informed consent

- Differing models; HCCA views consent to require:
  - Decision-making capacity
  - Disclosure of relevant information (Informed)
  - Voluntariness
  - Consent

What does it mean to have decision-making capacity?

Capacity

- **Capacity – two parts:**

UNDERSTAND **&** APPRECIATE

- The facts around the decision about treatment
- What the different options are
- The risks/benefits
- The expected outcomes
- The consequences - What happens with or without the treatment?

- How their life and health will be affected by the different treatment options
- How the side effects, risks and benefits may change their life or function

- **Capacity** is also:
  - Presumed
  - Task specific, and
  - Varies over time
  - Age?

When is consent informed?

Consent is **informed** when:

- The patient received the information…that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
- The person received responses to his or her requests for additional information about those matters.

HCCA 1996, c. 2, Sched. A, s. 11 (2).

When is consent informed?

For consent to be **informed** the following information must be communicated:

- The nature of the treatment or intervention being proposed
- Expected **benefits** of the treatment or intervention
- Possible **risks**
- Potential **side effects**
- **Alternative** courses of action
- Likely consequences of not having the treatment or intervention

HCCA 1996, c. 2, Sched. A, s.11 (3)

Voluntariness

- Protection for patients
- Free from coercion, and undue influence
- Positive or negative influences are possible
- After the above elements are met, one can provide (or refuse to provide) consent!

Patient lacking capacity

- If the patient lacks the capacity to make particular health care decisions, a substitute decision-maker (SDM) shall be designated to do so on their behalf.

- Hierarchical list in HCCA:
  - Guardian of the incapable person
  - POA for personal care
  - A representative as appointed by the CCB
  - The spouse or partner of the incapable person
  - A child or parent of the incapable person
  - A parent with only right of access
  - A brother or sister of the incapable person
  - Any other relative of the incapable person

SDM Requirements

- Must be capable
- Must be 16 years old*
- Must not be prohibited by court order
- Must be willing and able to give or refuse consent

- Must act in accordance with previously expressed wishes. If not known or not applicable, best interests to guide decision making.
  - More than one eligible? Disagreement?

Best Interests

- "... a person who gives or refuses consent on an incapable person's behalf shall do so in accordance with their best interests." (HCCA, 1996) Taking into consideration:

1. The values and beliefs that the Substitute Decision Maker knows the incapable person held when capable, and believes he or she would still act on if capable.
2. As well we must assess whether the treatment is likely to:
   - Improve the incapable person's condition or well-being,
   - Prevent the incapable person's condition or well-being from deteriorating, or
   - Reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

Best Interests (cont.)

3. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her. And finally,

3. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

Can be very subjective!

Disagreement – Code status

- Disagreements with code status can be particularly challenging, and may be facilitated by better understanding substitute decision-maker responsibilities.
- Questions to first ask include: What code status are you willing to offer or pursue? Is this patient a candidate for resuscitation?

- The CMA *Statement on Life-Saving and -Sustaining Interventions*** states that

> "CPR is not clinically indicated in all cases and hence cannot always be considered a standard intervention."

And that,

> "After several decades of experience and review, it appears that there are people who benefit from life-saving and -sustaining interventions, and others for whom there is no benefit and potentially significant harm. In this situation, "benefit" can mean both the likelihood of being able to make a recovery from a reversible illness, as well as the likelihood of regaining a state of meaningful interaction with one's environment where the illness is not reversible and the person cannot survive without life-sustaining interventions."

Canadian Medical Association (2013). *Statement on life-saving and -sustaining Interventions*. CMA. Ottawa, Canada.
**Policy no longer active, though the excerpt remains relevant.

Disagreement – Code status (2)

- Disagreements about code status can be particularly challenging when caring for patients, especially when substitute decision-makers are involved.
- Such disagreements may be facilitated by better understanding substitute decision-maker responsibilities.
- Questions to ask when disagreements arise, include:
  - What code status are you willing to offer or pursue?
  - Is this patient a candidate for resuscitation?

Disagreement – Code status (3)

Consider:

- The College of Physicians and Surgeons of Ontario (CPSO)'s position, in the *Planning for and Providing Quality End-of-Life Care* policy:

- "15. Physicians **must not** unilaterally make a decision regarding a no-CPR order.
  a. Before writing a no-CPR order in the patient's record, physicians **must** inform the patient and/or substitute decision-maker that the order will be written and the reasons why.[13]
  b. If the patient or substitute decision-maker disagrees and insists that CPR be provided, physicians **must** engage in the conflict resolution process as outlined in this policy and **must not** write the no-CPR order while conflict resolution is underway.
  c. If the patient experiences cardiac or respiratory arrest while conflict resolution is underway regarding the writing of a no-CPR order, physicians **must** provide all resuscitative efforts required by the standard of care, which may include CPR."

**See *Wawrzyniak v. Livingstone, 2019 ONSC 4900* for more.

College of Physicians and Surgeons of Ontario (2019). Planning for and Providing Quality End-of-Life Care Toronto, Canada. Retrieved from: [*https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Planning-for-and-Providing-Quality-End-of-Life-Car*].

Disagreement – Code status (4)

Wawrzyniak v. Livingstone, 2019 ONSC 4900 explored the requirement to obtain consent for No-CPR / DNR Orders, among other things. The Court found that:

- Writing a No-CPR / DNR order does not constitute treatment within the meaning of a 'treatment' under the Health Care Consent Act.
- Since writing a No-CPR / DNR order is not a 'treatment', withholding CPR does not require consent, even if a prior agreement exists that the patient be 'full code'.
- The withholding of a CPR (or other treatment) is, legally, different from the withdrawal of a treatment that is currently being provided. The latter requires consent as found in ***Cuthbertson v. Rasouli, 2013 SCC 53***.

Wawrzyniak v. Livingstone, 2019 ONSC 4900 (CanLII). Available at: [https://www.canlii.org/en/on/onsc/doc/2019/2019onsc4900/2019onsc4900.html]. Accessed: 10 Nov. 2021.

IDEA decision-making tool

Step 1: Identify the Facts	**Step 2: Determine Ethical Principles in Conflict**
Identify what is known versus what is not known. · Medical Indications · Client Preferences · Quality of Life, and · Contextual Features, Users of the framework should take into account all of the relevant considerations and stakeholders; this often includes facts that may not be known initially.	Identifying the ethical principles in conflict will not provide solutions; however, this step will assist in further clarifying and articulating the issues. Common ethical principles to consider might include, but are not limited to: · Autonomy · Beneficence (or doing good) · Non-maleficence (or doing no harm) or · Justice
Step 3: Explore Options	**Step 4: Act and Evaluate**
The intent of this section is to brainstorm different alternatives and to consider the potential outcomes and impacts of each one (e.g., evaluate the potential positive and negative considerations of each option). Do the options fit with the patient's preferences? Do the options comply with corporate policy, regulations, and the law?	Develop and document the action plan in the patient's chart and obtain consent. Evaluate the plan. Were the intended results obtained, or is additional follow-up and/ or action required? Ongoing documentation and communication of the evaluation is necessary. Self-evaluate your decision. What have you learned?

The IDEA framework tool is comprised of four steps to work through clinical ethical issues. The first letter of each step in this framework forms the acronym "**IDEA**."

Case 1

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What should you do?

Case 1

- What are some of the ethical issues in this case?
- Can the substitute decision-maker demand treatment in this case?
  - Is the team obligated to comply with the demands for PEG placement?
- Do we know what the patient would want, if she could tell us?
- What is in the patient's Best Interests, as defined in the Health Care Consent Act?

Case 2

Mrs. Potter is a 93-year-old resident of your long-term care home who once traveled the world as a culinary expert, sharing her love of food with many. She now has end-stage Alzheimer's. In the last year it has worsened to the point that she is no longer capable of making her own medical decisions, and she has begun to experience difficulty swallowing solid foods.

Three months ago a daughter of Mrs. Potter, her Power of Attorney, consented to have her mother be provided a pureed diet in order to reduce the risk of choking. At present time, however, this daughter believes that the pureed diet is affecting the quality of her mother's life (even though Mrs. Potter has not expressed this herself). After being completely informed of the risks and benefits, she requests that her mother be given solid foods. The staff feel uncomfortable with the daughter's request due to the real possibility that Mrs. Potter will choke on solid foods, and are unsure of what to do.

Case 2

- What are some of the ethical issues in this case?
- Does a resident have the right to live at risk?
- Does a substitute decision-maker (SDM) have the right to consent to their loved one living at risk? Does it matter if this is what their loved one would have wanted?
- What mechanisms can be implemented to address the potential moral distress of staff?

Questions?

Next Rounds:

When: 18th May, 2022

Where: MS Teams via link

Topic: Privacy and Confidentiality

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