HEALTH JUSTICE PROGRAM

Health Justice Tuesdays

"Health and Capacity, Decision-Making and Advance Care Planning

September 10, 2019

Mercedes Perez and Dr. William Sullivan

Health Justice Tuesdays – *Supported* by:

Legal Aid Ontario (Program Funding)
St. Michael's Family Health Team and Hospital (In Kind Support)
AFHTO Bright Lights Award
Nasmith Award (DFCM)

Organized by Education Subcommittee:
Gary Bloch, Emily Hill, J. Stone, R. Shoucri

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Gaa kina gwii waabamaa debwewin
All those who seek the truth
Aboriginal Legal Services of Toronto

ARCH Disability Law Centre

HALCO
HIV & AIDS Legal Clinic Ontario

NLS

St. Michael's
Inspired Care.
Inspiring Science.

Academic Family Health Team

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Presenter Disclosure

Faculty: William Sullivan

Relationships with commercial interests:

- **Grants/Research Support:**
  Dev. Disabilities Primary Care Program
  IACB
- **Speakers Bureau/Honoraria:**
  None
- **Consulting Fees:** None
- **Other:** Staff physician at St. Michael's Hospital Academic Family Health Team & Surrey Place

Faculty: Mercedes Perez

Relationships with commercial interests:

- **Grants/Research Support:**
  None
- **Speakers Bureau/Honoraria:**
  None
- **Consulting Fees:** None
- **Other:** None

Disclosing Commercial Support

This program has not received financial support nor in-kind support from any commercial interests

Potential for conflict(s) of interest:

- ***None***

Mitigating Potential Bias

- *Not applicable*

Objectives – by the end of this session, you will be able to …

1. Describe the how consent, capacity, and advance directives work and apply them to typical patients

2. Define “ableism” and appreciate how the above approaches to decision making can foster ableism when applied to people with vulnerabilities

3. Elaborate three ways to counter ableism in promoting health care decision making among people with vulnerabilities

Agenda

1. Why is consent to treatment necessary?
2. What is capacity to consent to treatment?
3. Who determines if a person is capable of consenting to treatment?
4. If a person is found incapable of making a treatment decision, who provides consent?
5. What is a power of attorney for personal care?
6. Is a power of attorney for personal care necessary?
7. What is an advance care directive?
8. Are advance care directives only legally valid if written down?
9. “Ableism” in health care decision making when applied to people with vulnerabilities
10. Countering ableism through: (a) a capabilities approach; (b) accommodating needs; and (c) supported decision making
11. Discussion

Case A

- *Mrs. Murphy is 84 years old. She attends at a doctor's office for a follow up appointment. She is accompanied by one of her daughters. The physician informs Mrs. Murphy that recent exploratory tests revealed bladder cancer. In general, with a palliative approach, there is a 2 year prognosis. With surgery, radiation and chemotherapy, there are generally various risks and uncertainties but also a > 50% chance of cure. However, Mrs. Murphy's age and general health condition increases the risk of serious injury or death from one or more of the proposed treatments.*
- *Mrs. Murphy's daughter asks many questions and then advises that they are deciding on a palliative approach.*
- *Mrs. Murphy doesn't say much but following her daughter's decision, she simply states "where there is life there is hope". It appears that she wants to say more but her daughter advises her to remain calm and relax.*

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1. Consent, Capacity, Decision-Making and Advance Care Directives in Ontario Law

Why is consent to treatment necessary?

- With limited exceptions, no one may be treated medically without his or her consent (one exception is the emergency context)
- The right to choose what to do with one's body is essential to liberty, autonomy, and bodily security
- The right of self-determination includes the right to refuse physician recommended treatment, even if the refusal entails serious risks, including death

Continued …

- Any non-consensual touching that is harmful or offensive to a person's reasonable sense of dignity is actionable (ie. in law this is battery and/or assault)

- Capable patients are the decision-makers in the doctor-patient relationship

- Doctrine of informed consent protects a patients' right to control his or her own medical treatment. Consent must be informed and voluntary.

- No medical procedure can be undertaken without a patient's consent obtained after the patient has been provided with sufficient information to evaluate the risk, benefits, alternative courses of action, and likely consequences of refusing the proposed treatment

What is capacity to consent to treatment?

- Presumption of capacity (even persons under the age of 16 may be capable of making their own treatment decisions)
- Capacity to consent to treatment: this is a legal test codified in statute (*Health Care Consent Act, 1996*)
- Requires the ability to understand information relevant to making a treatment decision and the ability to appreciate the reasonably foreseeable consequences of a treatment decision
- Capacity is issue specific and time specific

Who determines if a person is capable of consenting to treatment?

- Any “health practitioner” proposing a “treatment”

- “Health practitioner”: A member of a College under the *Regulated Health Professions Act, 1991* (ie. physicians, nurses, midwives, occupational therapists, dentists, dieticians, etc)

- “Treatment” is broadly defined as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose” (excludes admissions to hospital, capacity assessments, etc)

If a person is found incapable of making treatment decisions, who provides consent?

- Court-appointed guardian for personal care
- Attorney for personal care
- Representative appointed by Consent and Capacity Board
- Spouse or partner
- Child or parent (the child must be at least 16 years old)
- Sibling
- Any other relative
- Public Guardian and Trustee

What is a power of attorney for personal care?

- Legal document which gives the appointed individual the right to make "personal care" decisions for you if you become incapable of "personal care" decision-making
- "personal care": covers health care (including treatment), nutrition, shelter, clothing, hygiene and/or safety
- A person may be incapable of one or more personal care decisions yet capable of other personal care decisions
- A person who is incapable of making a treatment decision may be capable of giving a power of attorney for personal care (lower threshold of capacity for giving a power of attorney)

Continued …

- The grantor must be over the age of 16
- The attorney must be over the age of 16
- Must be in writing but does not need to be in any particular form
- Must be executed in the presence of two witnesses, but witnesses cannot be attorney or grantor's spouse or partner, child of the grantor, the subject of a property or personal care guardianship, or someone under the age of 18

Is a power of attorney for personal care necessary?

- Not legally necessary but depends
- If you want to appoint someone who will be able to make all "personal care" decisions, not just decisions respecting treatment, personal assistance services, and long-term care
- If you want someone other than the highest ranked person in the hierarchy of substitute decision-makers (for example, you want your sister, not your spouse) (but can't displace a court appointed guardian or Consent and Capacity Board appointed representative)
- If there are two equally ranked decision-makers and you want to avoid the consequences of a disagreement between them (or your preference is one over the other)

What is an advance care directive?

- Sometimes referred to as a “living will”
- Allows a person, while capable, to convey wishes respecting future medical and personal care decisions that may need to be made in the event the person becomes incapable.
- Provides *Charter of Rights and Freedoms* protection to autonomy and liberty in personal care decision-making for incapable persons
- Most common advance care directives are those that outline what treatments a person would want to decline such as artificial life supports but an advance care directive can apply to any category of personal care decision-making (for example can apply to wishes respecting admission to long-term care)

Are advance care directives only legally valid if written down?

- A power of attorney for personal care may include instructions with respect to decisions that the attorney is authorized to make
- But advance care directives need not be in writing
- A person may, while capable, express wishes regarding personal care decisions in a power of attorney, in any other written form, orally or in any other manner
- “Prior capable wishes” take precedence over all other considerations when a substitute decision-maker makes personal care decisions on behalf of an incapable person
- Beware of boiler plate “end of life” clauses in power of attorney for personal care documents

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2. “Ableism” in health care decision making involving people with vulnerabilities

Case B – Terry

- *Terry is a 52-year-old single male with an intellectual and developmental disability (IDD) in the moderate range (mental age equivalence of 6 to 9 years).*
- *He also has cerebral palsy, impaired hearing, & dysarthric speech.*
- *You have been his family physician for one year.*
- *He comes with two long-time group home workers. His only family member is a cousin who lives in another province (not present).*
- *As with Mrs. Murphy, a urologist has diagnosed bladder cancer, which has the same prognosis with a palliative approach (< 2-year survival) and with treatment (> 50% cure)*
- *When Terry met with the urologist, only his cousin was present.*
- *His cousin, who is Terry's substitute decision maker, consented to the urologist's proposal to take a palliative approach.*
- *Terry, & his workers, are upset by their exclusion from this decision.*
- *What has happened? What should happen? What would you do next?*

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"Ableism" is the notion behind social attitudes and practices that devalue or limit the capabilities of people with disabilities.

Ableism

- *scene from "The Peanut Butter Falcon"*
- ***https://youtu.be/UNl9RqjLCwc** (1.30 mins. ff.)*

Ableism

- *After unsuccessful attempts to communicate with Terry about his condition, the urologist deems him to be "incapable" of making this decision.*

- *Considering the excessive difficulties associated with the treatment approach, the urologist then proposes a palliative approach, to which Terry's substitute decision maker (his cousin) consents.*

- *Assuming that this approach to consent & capacity used for typical patients is applied correctly in Terry's case, how does it re-enforce "ableism"?*

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3. Countering ableism in health care decision making of people with vulnerability

A “Capabilities” Approach to Decision Making for people with vulnerabilities

- *In a “capabilities” approach, HCPs attend to Terry’s capabilities by exploring what he needs in order to exercise them as much as possible in the decision-making process*

- *By contrast, the focus of the current approach to consent for typical patients is a mental test to determine whether the patient independently meets an understand & appreciate threshold .*

Countering ableism – accommodate needs

- *Eg, time, place, pace, aids for communicating*
- *When such needs are addressed, some people with vulnerabilities will then be able to exercise their decision-making capabilities independently*
- *They can also authorize consent to treatment.*

Countering ableism – a supported decision making approach

- *Involves people who Terry knows, prefers (eg, friends), and are willing to elicit his values and goals and assist his decision making*

- *At least one decision making supporter can interpret reliably Terry's values and goals*

- *Based on Terry's values and goals, decision making supporters help him to apply them to the specific decision at hand*

Countering ableism: supported decision making

- *allows Terry to exercise his decision-making capabilities "interdependently"*

TABLE 1: Types of decision-making approaches.

PATIENT IS CAPABLE (INDEPENDENTLY OR INTER-DEPENDENTLY) OF MAKING THIS DECISION		PATIENT IS INCAPABLE OF MAKING THE DECISION
INDEPENDENT The patient might need accommodations but is capable of making a decision that is informed and aligns with the patient's goals and preferences.	**SUPPORTED (INTER-DEPENDENT)** The patient is able to communicate goals and preferences that one or more support persons can reliably interpret to help the patient to decide among health care options.	**SUBSTITUTE** Even with available accommodations and support persons, the patient is unable to participate actively in making this decision. The patient needs a substitute decision maker to decide on his or her behalf. In this situation, the patient's life history might provide the substitute decision maker with indications of the patient's goals and preferences. When the substitute decision maker does not know the patient well, he or she should involve family and other caregivers familiar with the patient.[1]

Countering ableism: supported decision making

In Ont., Terry's legal Substitute Decision Maker (his cousin) would need to agree with this approach, the resultant decision, and authorize it (ie, sign the consent form)

Countering ableism
- a supported decision making approach

- ***Given the novelty and high levels of uncertainty, this approach is not recommended for certain life-altering decisions (eg, non-therapeutic sterilization, MAID)***

Countering ableism
- a supported decision making approach

- *"In Lieu Of Guardianship, States Look To Supported Decision-Making"*
- *by Eric Russell, Portland Press Herald/TNS | September 4, 2019* ***https://www.disabilityscoop.com/2019/09/04/in-lieu-guardianship-states-look-supported-decision-making/27113/***

- *Coming soon: "Promoting Decision Making", a point-of-care tool at:* ***www.surreyplace.ca/ddprimarycare/tools***

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Discussion

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Summary

Consent in health care is supported by current medical ethics (emphasizing autonomy) and health law;

Consent from a capable person (or from a substitute decision maker if the person is incapable) is necessary for administering a treatment (except in some emergency situations);

The use of Advance Directives extends consent to treatment to the person's possible future context of compromised capabilities;

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Summary – cont'd

For people living with vulnerabilities (eg, people with IDD), the current approach to consent often excludes those deemed to be incapable, which they experience as ableism;

To counter this, we proposed a richer capabilities approach to decision making;

This involves promoting consent independently (accommodating needs) or interdependently (supported decision making).

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Feb. 12, 2019	Health and Housing Law - Dr. Andrew Bond and Benjamin Ries
March 19, 2019	Health and Family Law - Dr. Kathleen Doukas and Ishbel Ogilvie
April 9, 2019	Health and Income Security Law - Dr. Gary Bloch and Anu Bakshi
May 14, 2019	Health and Immigration Law - Dr. Vanessa Redditt and Jennifer Stone
May 28, 2019	Legal Issues affecting people living w HIV/AIDS - Dr. Gordon Arbess and Ryan Peck
June 18, 2019	Health, Law and Indigenous Peoples - Melissa Stevenson, Dr. Fatima Uddin and Emily Hill
Sept. 10, 2019*	Health and Capacity, Decision-Making, and Advanced Care planning - Dr. Bill Sullivan and Mercedes Perez
Sept. 24, 2019	Health and Employment Law - Dr. Andrew Pinto and Nabila Qureshi
Oct. 8, 2019	Health and Criminal Justice System - Flora Matheson and Promise Holmes Skinner
Nov. 19, 2019	Health and Human Rights Law - Dr. Laurie Green and Kerri Joffe

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