Advance Care Planning: What Does it Mean to YOU?

Annual Clinical Day
December 8, 2018

Special thanks to Dr. Nadia Incardona, Frank Wagner, and Bob Parke
- Identify or confirm SDM
- Discuss values, beliefs, a person’s concept of a good life or quality of life, perceptions of benefits, burdens, acceptable trade-offs

- What is most important to the person (goals)?
- Are there previous conversations (e.g., ACP) that help you define the person’s goals for care now?
- How do these goals fit with available treatment options?

- Look for prior capable wishes that apply to the decision to be made (e.g., from ACP or POA document)
- Informed consent process
- Incorporates patient values into the decision-making process

(Dr. Nadia Incardona, 2017)
Case

- Mrs. M is an 85 year old woman
- Entered the hospital through ED due to a fall
- Right hip fracture
- Refuses surgery
- During her admission on a medical floor she starts to experience delirium and increased reason for medical concern
- Goals of Care conversations commence with her daughter
- Her daughter say, “She would want everything”
Disclosure(s)

• Rosanna Macri
  – HRH Ethicist
  – U of T Affiliations
  – Committees including the Advance Care Planning Community of Practice in Canada

“We’ve discussed honesty as a policy, but, so far, it hasn’t gained any momentum.”
Objectives

• To explore the complex nature of Advance Care Planning
• To validate the importance and moral weight placed on end of life decisions and caregivers:
  – Understanding and unpacking values and wishes for future healthcare
  – Identifying the right SDM
• To help develop comfort and language in practice
• To help understand and bridge the gap between community and hospitals
Advance Care Planning in Canada

Talking About End-of-Life Care

Presented by Speak Up

Start the conversation about end-of-life care

www.advancecareplanning.ca
Bioethics involves critical reflection on moral/ethical issues arising in the areas of health care and research toward:

- deciding **what** we should do
  - What decisions are morally right or acceptable;
- explaining **why** we should do it
  - Justifying our decision in moral terms;
- describing **how** we should do it
  - The method or manner of our response

(Dr. Barb Secker)
So what does ethics have to do with ACP?

• Imagine
  » Serious car accident
  » Sudden hemorrhage
  » Diagnosed with dementia

• How do you define living?
• How do you define quality of life?
• If you can imagine any of these happening to you, what do you think may be most important to you in those moments/situations?
Poll the Audience

• How many of you have completed a will?
• How many of you have completed an advance directive?
What is “the good” that you want to achieve?

- Provide quality end-of-life care
- Reduce suffering (as defined by the patient), respect their wishes, and lessen conflict and distress.
- Give people the space and opportunity to think about last wishes
- Help patients/families with the language to have these conversations
What is an Ethical Issue?

*the Bioethicists say: any situation in which you…*

- Encounter conflicting values, beliefs, goals or difficult alternatives
- Are unsure about what we should do or why we should do it
- Are concerned that rights are being violated or persons not being respected
- Have conflicting obligations or responsibilities
- Are concerned with fairness or justice
Signs of an Ethical Issue:

- My gut tells me something’s wrong
- I can’t sleep at night or I take my anxiety at work home with me
- Conflict arises between co-workers
- I start questioning my own or others’ basic beliefs like religion, culture or ‘up-bringing’
- There are no easy or right answers to the problem
Ethical Decision Making 101

- **What?**
  - Diagnosis
  - Treatment Decisions

- **Who?**
  - 1. Patient
  - 2. SDM

- **How?**
  - 1. Prior Wishes
  - 2. Best Interests
The Who: If Capable

1. The patient/client
   - If capable ... what does this mean legally

• Consent = Informed decision-making involves has 3 components:

  1. Disclosure – the provision of all relevant information and the comprehension of this information by the patient
  2. Capacity - the patient’s ability to understand information and appreciate potential consequences of their decision
  3. Voluntariness - the patient’s right to come to a decision freely (without force, coercion or manipulation)
The Who: If Incapable

2. The Substitute Decision Maker (SDM)
   – An SDM is a person at least 16 years of age who is available, capable and willing to make the incapable person’s decision.
   – Well defined hierarchy in the Health Care Consent Act and Substitute Decisions Act
   – Legally assigned Attorney for Personal Care (POA) takes precedence
   – If no POA has been designated, the next of kin become decision makers (e.g. If there are 5 children ALL will share in decision making if they want)
**Substitute Decision Maker Hierarchy**

- **Court Appointed Guardian**
- **Attorney for Personal Care**
  - Representative appointed by Consent and Capacity Board
  - Spouse or Partner
  - Parents or Children
  - Parent with right of access only
  - Siblings
  - Any other relative
- **Public Guardian and Trustee**

**Legally Appointed SDMs**

**Automatic Family Member SDMs**

**SDM of last resort**

*(Dr. Nadia Incardona, 2017)*
Clarifying POA Documents

- Power of Attorney is a legal document that gives someone else the right to make decisions on the patient’s behalf
  - Property
  - Personal Care

- [https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf](https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf)
If SDM ranking is part of the HCCA why bother with a POA?

Answer:

• Because your patient wants the person who knows them best!

  e.g. multiple children; best friend vs. husband; etc.

  What if two or more persons of equal ranking disagree about whether to give or refuse consent?
How does your patient decide who will be their Attorney for care?

Answer:

• Values
• Religious Beliefs
• Age
• Trust
• Relationship
Poll the Audience

• How many of you have assigned Attorneys for Personal Care and Finances/Property?
• How many of you talk about advance directives with your patients?
Ethical Decision Making: the HOW

*The most ethical way is EARLY if possible

1. Prior expressed capable wishes applicable to the current decision
   – Advance care planning & Goals of care conversations
     • Advance directives/Living wills
     • Verbal communication/Conversations
     • Understanding patient/client values and beliefs

2. Best interests of the person
Advance Care Planning

Goals of Care Discussion

Treatment Decisions

- Identify or confirm SDM
  - Discuss
    - values, beliefs
    - a person’s concept of a good life or quality of life
    - perceptions of benefits, burdens
    - acceptable trade-offs

- What is most important to the person (goals)?
  - Are there previous conversations (eg ACP) that help you define the person’s goals for care now?
  - How do these goals fit with available treatment options?

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(Dr. Nadia Incardona, 2017)
How do we have these conversations?

• Be mindful of manner and tone of conversation
• Start the conversations early and often
• Share information in a way that helps patient and/or SDMs understand
• Respond to all questions
• Content:
  – Importance and benefit of ACP
    • Exploring your values, wishes and beliefs
    • Choosing the right SDM
    • Preferences for the location of death (including manageable options)
    • Attitudes towards certain medical interventions (e.g., resuscitation, ventilation, organ donation, etc.)
  – Importance of documentation and dissemination
  – Importance of reviewing the ACP throughout the patient’s life
Advance Care Planning: Values
The Really Difficult Questions

• What is most important to the person?
• How would the individual weigh benefits and burdens?
• What would suffering look like?
• Are we prolonging life or death?
• Is it time to shift from quality of life to quality of death?
• How would your loved one define life or quality of life?
• **How we do things is sometimes more important than what we do**
Importance of Advance Care Planning

- Patient/client suffers “traumatic transfer”
- Patient/client and family at odds with each other
- Patient/client and family lose trust with health care team
- Decrease quality of life
What are Goals of Care?

- Full Cardiopulmonary Resuscitation
  - Appropriate investigation/interventions including attempted resuscitation
- Specific Interventions
  - All appropriate investigations/interventions including admission to ICU for intubation/ventilation, vasopressors and BiPAP excluding attempt to resuscitate
- Medical Care
  - All appropriate investigations/interventions excluding attempt to resuscitate and ICU admission
- Comfort Care
  - All investigations/interventions which promote maximal comfort and symptom control and maintenance of quality of life excluding attempt to resuscitate ≠ NO CARE
Friendly Reminder

- To avoid traumatic transfers, if no resuscitation is decided upon, ensure a Ministry of Health and Long-Term Care “Do Not Resuscitate Confirmation Order” form is complete and patient/family knows to have it easily available.
Considering someone’s best interests

- Consistent with the persons’ values and beliefs
- Most beneficial and least harmful solution
- Considers both quality and quantity of life
- Is there a less invasive option?
# HRH Seniors Care Resources

## Acute Care Inpatient Services
- Specialized Geriatric Units
- Geriatric Consultation Services
- Clinical Practice Leader for Geriatrics
- Geriatric Psychiatrist
- LOFT Behaviour Support Transition Resources (BSTR)
- Reactivation Care Centres (RCC)

## Ambulatory Care Services
- Geriatric Emergency Management (GEM) Nurse
- Nurse Lead Outreach Team (NLOT)
- Geriatric Outreach Team (GOT)
- Healthy Living (Seniors) Clinic
- Falls Prevention Clinic
- Geriatric Mental Health Outreach Team

## Community Service
- Health Links
- Central LHIN Home and Community
- Ontario Telehealth Network (OTN)
Ontario Resources

• Ministry of the Attorney General – POA documents
  https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf

• Ministry of Health and Long-Term Care – Do Not Resuscitate Confirmation Order

• Community Legal Education Ontario
  www.cleo.on.ca

• Advocacy Centre for the Elderly (ACE)
  http://www.acelaw.ca/

• Speak Up Campaign (Canada/Ontario)
  http://www.advancecareplanning.ca/about-advance-care-planning/
  https://www.makingmywishesknown.ca/
Take Home Messages

• When possible plan early. Discuss these issues with your loved ones and your patients when everyone can participate

• Make sure everyone knows who the legal SDM is

• Don’t wait for the crisis to occur to consider these important aspects of care for the first time

• Everyone involved (patients, loved ones, caregivers, healthcare providers) will experience a better outcome when these issues are discussed in a non-crisis situation, using an ethical decision-making lens
Questions/Comments