Substitute Decision-Making, Lying, and Ethics

May 2017 FFC Meeting

Perley Rideau
The Perley and Rideau Veterans' Health Centre

BUILDING BRIDGES • BÂTIR DES PONTS

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Agenda

1. Examine Capacity and Consent to treatment (Briefly)
2. Review the role and responsibility of the Substitute Decision-Maker (SDM)
3. Evaluate the ethical permissibility of telling lies to residents, given 1) and 2) above.

Capacity

A resident has the capacity to make a treatment decision or decision regarding admission to a care facility if:

- **Understand** the relevant information;
- **Appreciate** the reasonably foreseeable consequences of their decision or lack of decision.

Health Care Consent Act 1996 c.2, Sched. A, s.4 (1-2)

Valid Consent

- The HCCA has several requirements for consent to be valid.

- First is that consent is informed
- Consent is informed when:

  - The resident 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).

If deemed incapable?

We know that…

- The resident must be informed of the finding and proposed Substitute Decision-Maker
- They have the right to challenge both of these at the Consent and Capacity Board.
- The patient must be assisted in their challenge

But who is the SDM and how are they required to make decisions for the patient?

Substitute Decision Making

- If resident has been found to lack decision-making capacity the appropriate substitute decision-maker must be identified and contacted.

- HCCA hierarchy:
  - Guardian or Attorney for personal care. (All POAs are SDMs, but not all SDMs are POAs.)
  - Representative appointed by the CCB
  - Spouse or Partner
  - Child (over 16), parent or individual/agency entitled to give or refuse consent
  - Parent with right of access only
  - Brother or sister
  - Any other relative
  - Public Guardian & Trustee (last resort)

SDM - Characteristics

- SDM must be;
  - Capable
  - Available
  - Willing to assume role
  - Over 16
  - Not prohibited by court order
- The SDM must follow the guidelines of the HCCA
- Challenges can arise when more than one SDM exists and they do not agree with each other.

Principles for SDM giving or refusing consent

- If the SDM is aware of prior expressed capable wishes by the resident while the resident was;
  - Capable
  - Over age 16;

Those wishes must be taken into consideration*

*But are required to be quite specific

Best Interest Standard

A. Values and beliefs

B. Other wishes (i.e. expressed while incapable)

C. Whether treatment likely to:
   I. improve condition
   II. prevent condition from deteriorating
   III. reduce the extent or rate of deterioration

D. Whether condition likely to improve, remain the same or deteriorate without the treatment

E. If benefit outweighs risks

F. whether less restrictive or less intrusive treatment as beneficial as treatment proposed

Common challenges to SDM-ing

- SDMs are poor predictors of residents' treatment preferences
  - Shalowitz et al suggest 68% accuracy of SDM to predict such preferences
- SDM focus on their own values rather than the resident values
- SDM often interpret "Best Interest" in their own way (not in the way of the HCCA)
- May believe that merely being alive constitute best interests

Chidwick et al. (2013).

Common challenges to SDM-ing

- May believe that Religious values are necessarily the resident's values
- SDMs report that residents value suffering
- SDM had unrealistic hope for recovery and communication with residents
- May not meet their obligations as outlined in the Act
- Mistake a resident's values with explicit wishes

Would someone else be a better predictor?

Chidwick et al. (2013).

Question:

Can telling a ‘white lie’ to a resident be in their best interests? Is it ever ethically appropriate to do so?

Lying and SDM-ing

- What exactly is a ‘white lie’:
  - A false claim intended to deceive another person, but in addition attempts to protect the person being lied to, in some way.
  - Oftentimes ‘white lies’ are told paternalistically to prevent some harm from coming to the person being lied to, or even to benefit that person.

Lying and SDM-ing

- Truthfulness, sometimes referred to as *veracity*, is not always included as one of the fundamental principles in medical ethics.
- Is there an absolute duty to tell the truth to residents, in every circumstance?
- Why is telling the truth important?

Lying and SDM-ing

- Where telling the truth is most important is, in part, for the informed consent process.
- If residents are lied to, they cannot make reasoned and informed choices, because they do not have the information they need to do so.

Lying and SDM-ing

- An assumption made here is that the patient or resident in consideration actually has the decision-making capacity to make their own health care decisions.
- In these cases where the resident is capable (sometimes referred to as competent), they have the right to be provided with all the information necessary to make an informed decision.
- They may also have the right to “live at risk.”

Lying and SDM-ing

- What is less clear, is whether ‘white lies’ ought to be permitted in certain circumstances when being told to residents who lack decision-making capacity (competence).

Lying and SDM-ing

- *Case 1:* Mr. Jones is alert, aware, and capable of making his own health care decisions. Although there is an order for medications to treat his heart condition, Mr. Jones refuses these medications daily. On one visit, his family members notice that he is not receiving these medications, and demand that you hide them in his mashed potatoes so that he receives them.

- *Case 2:* Mr. Smith is a resident on your unit with advanced dementia who is no longer able to appreciate and understand his health care decisions. Because of this, he has his eldest daughter – who is his Power of Attorney (POA) – making these decisions on his behalf. Like Mr. Jones, Mr. Smith has an order for medications to treat his heart condition, but refuses these medications daily and swings at any staff member who attempts to come close with those medications; he has thus not been receiving them. On a visit from his POA, she notices that he is not being made to take his medication, and demands that you hide them in his mashed potatoes so that he receives them.

Lying and SDM-ing

- Some questions to ask may be:
  - Does this resident have the ability to make their own health care decisions?
  - Why would we consider telling a 'white lie' to this person in the first place? Whose interests are being served?
  - Is there any benefit to telling a 'white lie'?
  - What harm will come by telling the resident this 'white lie'?
  - What harm would come to the resident if we do not tell them the 'white lie'?
  - Will the benefits of telling a 'white lie' in this situation outweigh the harms?

Lying and SDM-ing

- So, can we justify telling a ‘white lie’ to residents/loved ones?

The ethics answer: It depends.

Contact Information

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