

Consent, Capacity, and Substitute Decision-Making: Ethical Fundamentals

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Land Acknowledgement

- Our work takes place across southeastern Ontario, which includes the ancestral and current homes of numerous and diverse Indigenous peoples. Providence Care is situated on the traditional and ancestral lands of the Algonquin, Anishanaabe, Haudenosaunee, Mississauga, and Wendat peoples. We thank all the generations of people who have taken care of this land for thousands of years. We recognize and deeply appreciate their historic connection to this place. Today, this land is still home to many First Nations, Metis people, and other global Indigenous Peoples and we are grateful to have an opportunity to live, work and continue stewardship on this land.

Disclaimer

- This document contains general, summarized information about the law and guidelines in this subject area, from the author's layperson perspective. The author is not a lawyer or a legal authority, and this document does not offer or constitute legal advice. There are no guarantees made about the accuracy or comprehensiveness of the information contained in this document.

Agenda for Today

- 1) Key Terms
- 2) Ethical Foundations & Legal Background
- 3) Cases and Strategies

1. Key Terms

Consent: To give consent is to give permission. For example, when a client/patient/resident gives consent to a treatment proposed by a clinician, they are giving permission for the clinician to administer that treatment to them.

- Required for many (but not all!) healthcare-related decisions for clients/patients/residents
- Must always be obtained from a person who is capable with respect to the relevant decision
- Must be given voluntarily, with access to relevant information, without manipulation or coercion

1. Key Terms

Capacity: To have capacity with respect to a specific decision means to be mentally capable of making that decision.

- Sometimes called *decisional capacity*
- Not identical with any particular diagnosis
- Can fluctuate through time
- Depends on decision (consider *type* and specific decision)
- Different standards for different types of decision
- Different roles responsible for assessing capacity, depending on the decision

1. Key Terms

Substitute Decision-Making: Substitute decision-making involves making decisions on behalf of someone who is not capable of making those decisions for themselves. Someone who is legally empowered to make a particular decision for an incapable person is called that person's *Substitute Decision-Maker* or *SDM*.

- For most purposes in healthcare, SDM is a *reactive* role: involves giving/refusing consent to proposals/recommendations from clinicians
- SDM's obligated to make decisions in ways that take account of the wishes, values, and interests of the incapable person
- In general, SDMs not entitled to demand particular services on behalf of an incapable person

Agenda for Today

~~1) Key Terms~~

2) Ethical Foundations & Legal Background

3) Cases and Strategies

2. Ethical Foundations and Legal Background

- Consent is a basic part of the ethical and legal standards that govern decision-making processes in healthcare. Healthcare practitioners and organizations have ethical obligations to obtain informed consent for many decisions about their clients'/patients'/residents' care. For example, with very few exceptions, informed consent is required before:
 - administering medical treatment
 - sharing personal health information
 - admitting a person to long-term care

2. Ethical Foundations and Legal Background

Consent is important for many reasons. However, three particularly important ethical considerations underlie requirements related to informed consent:

- *Individual autonomy*
- *Dignity of the person*
- *Trust*

By adhering to consent-related requirements, healthcare providers promote trusting relationships and show respect for the autonomy and dignity of those they serve.

2. Ethical Foundations and Legal Background

The ethical significance of capacity and SDMining is directly linked to the ethical importance of consent:

- If a person is incapable with respect to some decision, obtaining consent from them is a poor way of respecting their autonomy.
- We respect the autonomy of an incapable person by obtaining consent from the appropriate SDM (and by insisting that SDMs make decisions in accordance with the wishes and values of the incapable person!).
- Institutionalized practices of assessing capacity and seeking consent from SDMs where necessary are ways of responding to the fact that people are not always able to make their own decisions.

2. Ethical Foundations and Legal Background

In Ontario, much of the ethical groundwork for thinking about consent, capacity, and SDMING in healthcare has been factored into a set of inter-related laws governing healthcare decision-making:

- *Health Care Consent Act* (HCCA – treatment, admission to care facilities, personal assistance services)
- *Personal Health Information Protection Act* (PHIPA – collection, use, and disclosure of personal health information)
- *Substitute Decisions Act* (personal care and property)

2. Ethical Foundations and Legal Background

Ethical and legal complexity of standards governing consent, capacity, and SDMING give rise to lots of (understandable!) confusion. Healthcare practitioners need to juggle many factors:

- Different standards of validity for consent to different types of decision (e.g. 'informed' vs. 'knowledgeable')
- Different standards of capacity for different types of decision (e.g. consent to treatment v. appointing a POA)
- Different distributions of responsibility for assessing capacity
- Different implications of findings of incapacity

Agenda for Today

~~1) Key Terms~~

~~2) Ethical Foundations & Legal Background~~

3) Cases and Strategies

3. Cases and Strategies

The same ethical and legal complexity considered above gives rise to many different types of ethical issue on the ground, and (unfortunately) there's no single recipe or procedure for solving them all.

However, there are some big-picture rules of thumb we can bear in mind...

3. Cases and Strategies

- The patient's/client's/resident's wishes, values, and priorities should be at the centre of decision-making in healthcare; when in doubt, return to discussion about the person and her wishes and values.
- Support patients/clients/residents in participating in advance care planning and goals of care discussions, and document those discussions thoroughly.
- While consent is central to healthcare, it is not the case that *everything* in healthcare is a matter of consent; be clear about where/when decisions call for consent, rather than negotiation, psychosocial engagement, etc.

3. Cases and Strategies

- While patients/clients/residents should be presumed capable, it is important to be willing to address capacity questions head on.
- Where capacity is in doubt, be clear about whose role it is to assess capacity, and what the implications of a finding of incapacity would be; thoroughly document discussions and assessments of capacity.
- To the extent possible, link discussions about capacity to specific decisions
- Avoid the trap of thinking about capacity in all-encompassing terms

3. Cases and Strategies

- Always be clear about who the “formal” SDM is.
- Be clear about scope and responsibilities of the SDM role; communicate these early and clearly to SDMs.
- When seeking consent from SDMs, focus discussions on the wishes and values of the incapable person, and document thoroughly.
- Be clear with SDMs about clinicians’ responsibilities to patients/clients/residents, and be willing to discuss steps available to ensure SDMs complying with principles of SDMing.
- Avoid the trap of the “all-deciding SDM”.

3. Cases and Strategies

(1) Nadia is a 62-year-old female admitted to hospital following a stroke. She has lost significant mobility on her left side, but the clinical team is optimistic that, with therapy, she can regain sufficient mobility to live safely at home. Nadia has consented to a plan of care involving PT and OT, but she frequently declines to participate in therapy, saying that she's too tired, or that she doesn't care about getting better. Alex (Nadia's brother, and only family member), is asking the team to be more insistent, telling them "You have my consent to push her harder; she has to get better."

3. Cases and Strategies

(2) Susanna is an 85-year-old female admitted to hospital with dementia. Susanna's daughter, Laura, is her main support person, visiting Susanna on the unit every day. Susanna's son, Michael, lives in another province and is not able to visit; he frequently calls the unit asking staff for updates about his mother. However, Laura has recently told the team that they are not to share information about Susanna with Michael. The team is concerned because it has recently been determined that Susanna cannot be fed safely by mouth, and Laura is insisting on a feeding tube, saying "I'm the SDM, and I am telling you that we must keep Mom with us as long as possible."

3. Cases and Strategies

(3) Thomas is a 67-year-old client of a community mental health team. Team members attend Thomas's home daily to assist him in taking his meds. For several months now, at the insistence of Thomas's son, Greg, the team has also been supporting Thomas in taking a variety of "natural supplements". However, team members are growing increasingly distressed, as Thomas seems to dislike the supplements. However, when asked directly about this, he says he doesn't mind taking them. The team has raised the issue with Greg, but Greg became angry, saying "I will not consent to stopping the supplements."

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