



MBIPHEN

INFORMED CONSENT

ETHICS ISSUE QUICK REFERENCE

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The Case

Quick summary

- What happens when a patient refuses consent for a life-saving procedure?
- What is informed consent?
- What are health care provider obligations when consent is declined?

Ryan, a 20-year-old man is admitted to hospital with an acute abdomen and urgent need for surgery to remove an infected appendix.

Over the course of several hours, the team holds a series of discussions with Ryan about his treatment options. Although he clearly understands the likely consequences, which include sepsis and death, Ryan consistently refuses consent for surgery, saying he has faith that if God wants him to live, he will live.

Ryan has no significant medical or psychiatric history. A consulted psychiatrist declares Ryan competent to make his own health care decisions. Ryan's family try unsuccessfully to convince him to consent to the surgery but he remains steadfast.

As he gets sicker and sicker, the team needs to decide how long they will honour Ryan's wishes.

The Issue

With very few exceptions, health care providers may not perform any act of care without the informed consent of the patient* or their substitute decision maker (SDM).

Under Canadian law, it is a criminal offence to impose a medical intervention that the patient does not want. Patients may even refuse life-saving treatments, that is, therapies without which they will die, providing they are fully informed of the purpose, risks, and benefits of the procedure.

Informed consent is a process that requires ongoing discussion. Merely signing a form will not meet the ethical standards for informed consent.

In order for a consent to be fully informed, the following conditions must be met:

- The patient must be capable of understanding the reasons, benefits and material risks of the procedure, and must be capable of using this information to make a decision,
- Information on the specific act to be performed must be provided in a way the patient understands, and,
- The decision must be given freely, voluntarily, and without any coercion or pressure.

Ethical uncertainty can arise for health care providers when patients decline treatments that appear to be in their best interests, especially when it is likely (or certain) that the patient will die without.

Consent can be withdrawn at any time by the patient.

*The term "patient" is used throughout this document, but should be considered synonymous with "client" or "resident"



For more information, see the reference list on page 4.



Ethics Issue Quick Reference: Informed Consent

Ethical Principles in Informed Consent

Ethical conflicts over informed consent can occur when there are differences of opinion on what is in the best interests of the patient. When a patient declines to consent to a procedure the care team recommends, there are a number of ethical principles to consider.

1. **Respect for autonomy:** there is a strong obligation to honour the patient's wishes. For informed consent, the patient's wishes must be based on enough relevant information to allow them to form an opinion. This is also the reason we make sure a decision is freely made, without coercion or unreasonable pressure.
2. **Beneficence:** we also have a duty to do good, or to provide a benefit to the patient. Informed consent ensures the patient understands the benefits of the proposed intervention and agrees that they are worth the risks.
3. **Non-Maleficence:** on the other side, we must avoid causing harm. Inadequate information may mean the patient is unaware of possible harms of the intervention. Those risks may change a patient's opinion about whether they want the treatment.

Declined consent does not mean all care stops. It is the provider's role to determine what care *is* acceptable to the patient (e.g. comfort care) and to ensure the patient receives that care while continued discussions occur.

Other Ethical Theories

Besides principles, there are other reasons to ensure consent for a treatment is well-informed.

- **Relationships:** communication between health care providers and patients builds and maintains trust. Informed consent conversations are an opportunity to demonstrate mutual respect and caring and to even out power imbalances.
- **Quality health care:** ensuring there is a good understanding of the reasons, benefits and risks associated with a health care intervention is part of good care.
- **Consequences:** providing care without consent can damage trust and result in unwanted procedures. However when it is an emergency, and the patient is likely to die without the treatment, it is acceptable to proceed without consent, if the patient is also not able to give it, unless the health care provider has good reason to believe that the patient would have refused treatment (e.g. health care directive, Jehovah's Witness transfusion card)
- **Rules/duties:** informed consent policies are based on law and the duty to provide only those interventions which the client desires. Provision of treatment when a client has refused it can result in legal charges against the health care provider.

Approaches for Resolving Conflicts

When there are disputes, it is important to ensure the conditions for informed consent are being met. This means that the health care provider must

- Commit to the process. Do not expect a resolution with one try. You may need to go back several times.
- Ensure the patient is capable of appreciating the information and of making a decision. A formal competency assessment may be necessary.
- Use multiple methods to give relevant information (e.g. verbal, written, video, translated if necessary, etc.).
- Be conscious of any real or apparent pressures to decide a particular way. Address them if noted. This includes from providers and family. Consent *must* be voluntary.



For more information, see the reference list on page 4.

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When the Patient is not Capable

Informed consent is required for all interventions, and is especially important when the patient is not competent to make health care decisions for themselves.

If a patient is incapable of appreciating the information required to make an informed decision, a substitute decision-maker (SDM) is appointed to provide (or refuse) consent. A SDM participates in decision-making on behalf of the patient/resident/client. The task of a SDM is to faithfully represent the known preferences or, if the preferences are not known, the best interests of the patient. Most of the time, a SDM is a family member or close friend, either named by the patient or based on the hierarchy described in the Vulnerable Persons Act or the Mental Health Act.

When a SDM is considering consent, they speak for the patient. Any reference to “patient” therefore includes SDM where applicable.

Best Interests

Informed consent conflicts can take different forms. Often, they involve patients who are not capable of making their own health care decisions, and whose SDM does not seem to be acting in the patient’s best interests.

There are three different ways that an SDM can decide whether or not to consent to an intervention on behalf of a patient.

1. Deciding as the patient previously directed, when competent. This usually follows the instructions in an Advance Directive or Advance Care Plan. The decision reflects the patient’s known, documented preferences, as determined before he or she became incapable.
2. If the patient’s wishes are not known specifically, the SDM can make the decision based on what they think the patient would say if they were capable. These decisions reflect what the SDM knows of the patient’s values and personal preferences. This is considered a *substituted judgment*.
3. If wishes are not known and it is not possible for a SDM to make a substituted judgment, the SDM can consider the patient’s *best interests*. These decisions aim for what a reasonable person would consider to be an acceptable quality of life.

When the Patient Continues to Refuse or Decline Consent

If a patient refuses consent for a recommended procedure or intervention, it is important for the health care provider to understand the reasons for the refusal and to work to address any concerns the patient has. It can be especially difficult when the patient will likely die without the intervention.

Consent is a process. It may take a number of conversations before a patient or SDM is comfortable making a decision. When a decision is made, it is important to review it regularly to ensure it still reflects the patient’s wishes and/or best interests.

Even when consent is declined, and the health care provider is satisfied all conditions were met to ensure it is an informed decision, care that the patient does find acceptable (e.g. comfort care) continues. Without adding pressure or coercion, the provider may revisit the decision as often as is feasible in order to ensure it still fulfills all criteria. For example, it may make sense for a provider to speak with a competent patient alone, to ensure that there has been no undue pressure from family to make a decision with which the patient is not truly comfortable.

Questions for discussion or consideration

When faced with a conflict about informed consent, it may be helpful to discuss the following questions with the team and/or patient/SDM:

1. What is the nature of the conflict?
2. Who is the ultimate decision maker? What will best support and demonstrate respect for that role?
3. What best reflects the patient's preferences? Is there any justification for overriding those preferences?
4. Is the patient competent to make their own decisions? If not, who is the SDM? Do they appear to be acting in the patient's best interests?
5. Has the patient (or SDM) been provided with enough relevant information? Do they understand it? Is there any evidence they are not making a voluntary decision?
6. Are there any rules, duties or obligations that constrain or support the health care team's options?
7. What are the consequences of each of the decision options? Does the patient/SDM fully appreciate all that are germane to their decision?
8. How can the informed consent process best encourage positive patient-provider relationships? What will demonstrate mutual respect and caring?
9. What is the plan if the intervention is declined?



For more information on any of the points in this document, please contact us, or talk with your library about the resources on this list.

Resources

For further information on Informed Consent, competence, capacity, and substitute decision-making please see:

- Beauchamp & Childress (2009) *Principles of Biomedical Ethics* 6th ed. Oxford University Press: NY
- WRHA Policy: <http://home.wrha.mb.ca/corp/policy/files/110.000.005.pdf>
- Manitoba Mental Health Act: <http://web2.gov.mb.ca/laws/statutes/ccsm/m110e.php>
- The Vulnerable Persons Act: <http://web2.gov.mb.ca/laws/statutes/ccsm/v090e.php>
- The Health Care Directive Act: <http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php>
- Ontario Capacity Assessment office: Q&A <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacityoffice.asp>
- Mental competence: www.legal-info-legale.nb.ca/en/uploads/file/pdfs/Mental_Competence_EN.pdf

MANITOBA PROVINCIAL HEALTH ETHICS NETWORK

www.mb-phen.ca

Phone: 204-926-1312

E-mail: ethics@wrha.mb.ca



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Manitoba Provincial Health Ethics Network