# Refusal of surgery: A case-based review of ethical and legal principles behind informed consent in Canada

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## Introduction

Respect for patient autonomy is an important tenet to the ethical practice of medicine. However, situations arise where there is a strong medical indication for life-prolonging surgery, but the patient refuses, even after a thorough discussion of benefits and harms of the intervention. If the patient is of sound mind, medical interventions that respect the patient's choice should be followed. If the patient has suspected, or known, cognitive dysfunction, the treatment path is less clearly defined. Urologists rarely encounter clinical scenarios where there is discordance between what is medically indicated and what is chosen by the cognitively-impaired patient. Given the rarity of this scenario, urologists may be underprepared about how to ethically and compassionately manage these patients. In this article we present a case and review the ethical and legal principles that should guide surgeons. Some details of this case have been changed to preserve patient confidentiality.

## Case

A 73-year-old male was admitted with a large erosive penile mass consistent with a penile cancer. The mass was invasive and nearing complete urethral occlusion. On clinical and radiographic assessment, there was no evidence of metastases. Following a thorough assessment of this patients' case, it was concluded that pursuing a total penectomy and perineal urethrotomy with curative intent was indicated. This patient had an extensive psychiatric history and was currently experiencing an acute psychotic episode. Upon discussion with this patient he refused all medical and surgical interventions, with reasoning based upon paranoid beliefs that appeared to stem from his acute psychosis.

## Consent

An accepted process for informed consent is well documented, and places equal responsibility on the part of the physician and the patient.[1] In the Canadian legal framework, a physician must explain the nature, expected benefits, and material risks of the treatment -- as well as the

alternative courses of action and the likely consequences of not having the treatment.[1] To be considered legally abiding and valid, a capable patient must voluntarily provide consent after they are fully informed. It is important to note that this concept applies equally to patients both providing affirmative consent to a procedure, or refusing one, as an incapable patient cannot consent in any way.

If a patient is incapable or unwilling to consent during a medical emergency, the path to resolution is more complicated. To be deemed a medical emergency, the physician must document that there is an imminent threat to the life or wellbeing of the patient.[2] During a medical emergency, the onus is on the treating physician to identify whether the patient has an Advanced Life Directive (ALD) and/or a proxy-directive before proceeding with treatment. An ALD, is a document that describes a patient's specific instructions for how their care should be delivered.[3] It can also contain information about their beliefs surrounding care, to help inform decision-making on issues not specifically laid out within the document. In two landmark cases, it was found that a physician must respect these documents, even in an emergency, and should use these documents to guide treatment.[4,5] A proxy-directive, also termed a durable power of attorney (POA) for personal care, is a document which one person grants another person the authority to make medical decisions if they become unable to do so.[6] A proxy-directive typically takes precedence over any ALD in place, although an ALD should ideally help inform the proxy-directive's actions. There is no central repository of these directives, and unfortunately it is up to the patient to have these stored with their lawyers, at their homes, or with loved ones. In scenarios where delay of medical care to attempt to identify these sources would certainly lead to harm to the patient, current opinion would side with the physician proceeding with immediate lifesaving treatment.[7]

Individuals identified as POA over a patient fall under the umbrella term of a substitute decision maker (SDM). If there is no advanced directive/defined proxy-directive, alternate SDMs can be identified to help make decisions for the patient. There is a hierarchy established by each province to identify the most appropriate SDM. In Ontario, substitute decision makers are subdivided into the following order: 1. documented POA; 2. automatic family member; and 3. decision maker of last resort. Within each category, except for substitute decision maker of last resort, there is a further hierarchical order that must be respected (Figure 1). A substitute decision maker of last resort is obtained from the local public guardian and trustee (PGT) office. Once appropriate information is provided, a PGT representative can make decisions on the incapable patient's behalf. In all situations, the substitute decision maker, chooses treatments based on the information they receive from physicians and take into account any values, beliefs, and previously expressed wishes made by the patient while capable.

Most provinces and territories follow a similar substitute decision maker hierarchy, but there are some variations across Canada.[8] Regional variances can be accessed through the advanced care planning online resources produced by the National Advance Care Planning Task Group (advancecareplaning.ca).[8] Although the treating physician is usually responsible for

identifying the most appropriate substitute decision maker for an incapable patient, certain cases merit outside intervention. In cases where there are multiple possible substitute decision makers, for example, multiple children or children and parents, a family can petition the court system to rule on the most competent SDM for the patient. Unfortunately, this can be a slow process.

In non-emergent situations, the treatment team should attempt to address any reversible cause to cognitive impairment. After medical interventions to reduce impairment are exhausted, the previously appointed POA and/or substitute decision maker should be identified, and a decision made to either forgo or proceed with the medical procedure.[9]

**Ethical principles when a patient lacks cognitive capacity**

The ethical principles associated with consent are autonomy, justice, beneficence, and non-maleficence. An autonomous decision, by definition, is one that is made intentionally by a patient with decision-making capacity, who has a full understanding of the proposed treatment, and one that is made without controlling influences.[10] In a situation where a patient is unable to make an autonomous decision, the principles of beneficence and non-maleficence should be followed. More specifically, the risk of benefit from the treatment should outweigh the risk of harm from treatment or the risk of not treating.[11]

Another consideration is how the treatment is perceived by the patient. For instance, two patients who are incapable of consenting to a laparotomy may react differently to a large midline scar. Therefore, upholding the ethical standards of beneficence and non-maleficence can be challenging when the procedure results in body dysmorphism, such as a stoma or penectomy.

It is difficult to predict how a patient will react to a physical change, such as amputation. The ethical principles should be considered upheld if the decision to intervene would be made by most physicians with expertise in the field, and by most patients with a similar disease.

In medical ethics, justice refers to the philosophy that patients be treated equally with respect to need and access to appropriate healthcare.[12] It is important to consider what a capable individual presenting with the same pathology presumably would want, which would ultimately give this patient equal opportunity for treatment.

In these challenging clinical scenarios, it is prudent to clearly document the legal and ethical considerations and the rationale behind the recommendation. These issues should be discussed with the patient and substitute decision maker. Consultation with a medical ethicist is also highly recommended.

**Case resolution**

Following the legal algorithms and ethical principles described, the patient's situation was not considered a medical emergency since there was impending, but no immediate, threat to the patient. The patient voluntarily was admitted to hospital to allow consultation with a psychiatrist. The psychiatrist confirmed that he did not have the capacity to make informed health decisions. Through counseling and medicine adjustments, attempts were made to improve his cognitive capacity, but improvements were not achieved.

The patient did not have an advanced directive and did not have a legally appointed substitute decision maker or known family. With clear documentation of the patient's inability to consent, an appointed public guardian acted as the decision maker of last-resort. With consultation from a medical ethicist, and after reviewing the situation, the public guardian agreed with the proposed treatment plan of penectomy and perineal urethrostomy. The benefit in this case was quite clear; the patient would have the best chance for cure and avoiding urinary retention if he received total penectomy. The harms in this case were less clear. In addition to the physical risk, the emotional and psychiatric effects were of significant concern.

After comprehensive discussion and documentation, total penectomy and perineal urethrostomy was performed. The patient recovered well from surgery with no complication. Psychiatrically we were surprised that the patient accepted his new physical state without overt evidence of emotional trauma. Psychiatric and social supports were put in place to allow for transfer of care outside of the hospital.

## Conclusions

Major surgical intervention is sometimes necessary for patients who are cognitively unable to provide consent. Urologists should be aware of the legal standards and ethical principles that should guide patient management. Consultation with institutional experts, such as psychiatrists and medical ethicists, is highly recommended. When a substitute decision maker is necessary, clinicians should follow their provincial hierarchy.

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## Figures and Tables

***Fig.1.*** Algorithm for assessment of patient with capacity concerns. ALD: advanced life directive; POA: power of attorney.

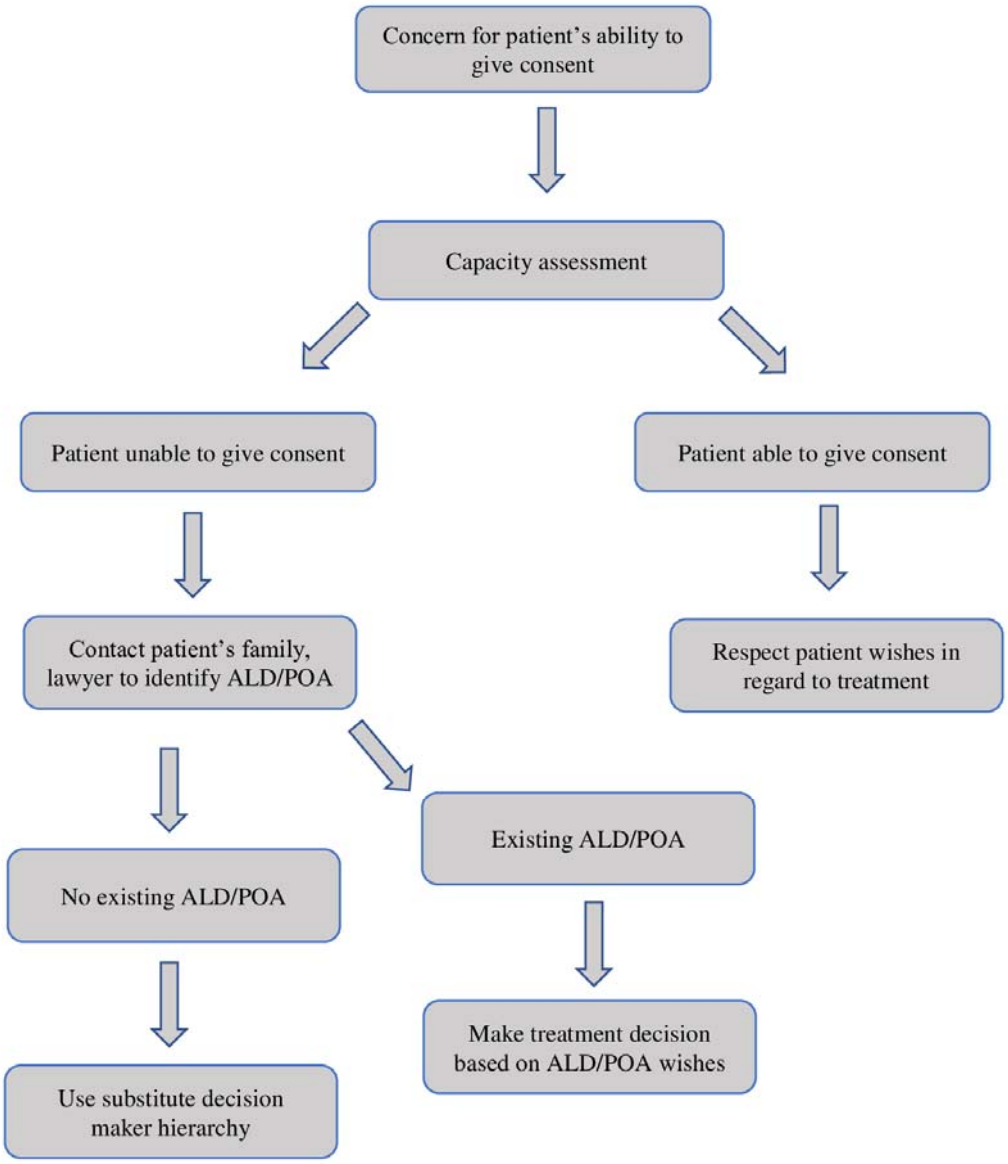

***Fig. 2.*** Substitute decision-maker hierarchy as outlined by Ontario's health care consent act (1996).