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 manage these patients ethically and compassionately. 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 radiographical assessment, there was no evidence of metastases. Following a thorough assessment of this patient's 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, capable patients 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 (Fig. 1). 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 that 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 patients to have these stored with their lawyers

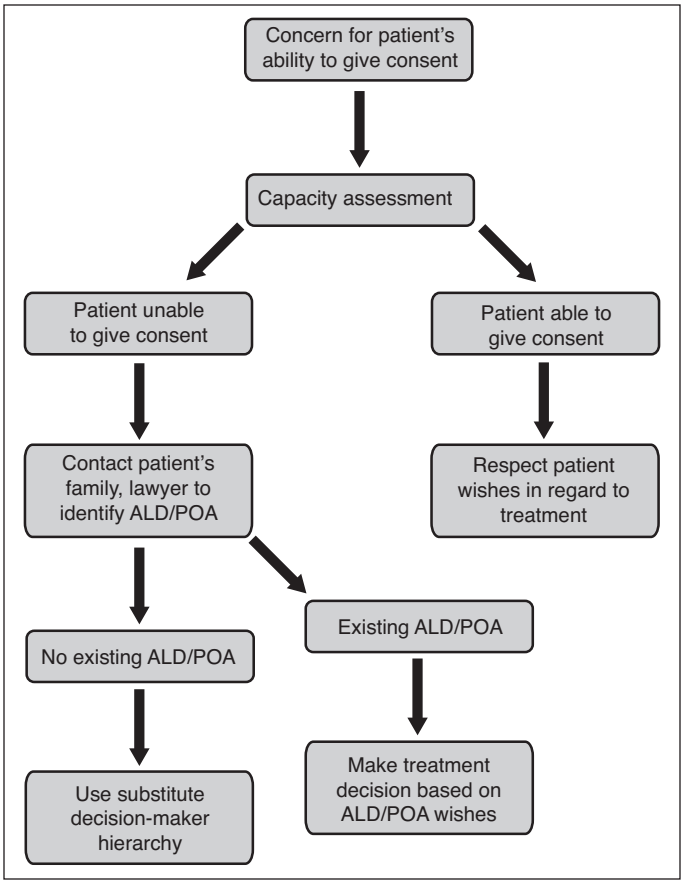

Fig.1. Algorithm for assessment of patient with capacity concerns. ALD: advanced life directive; POA: power of attorney.

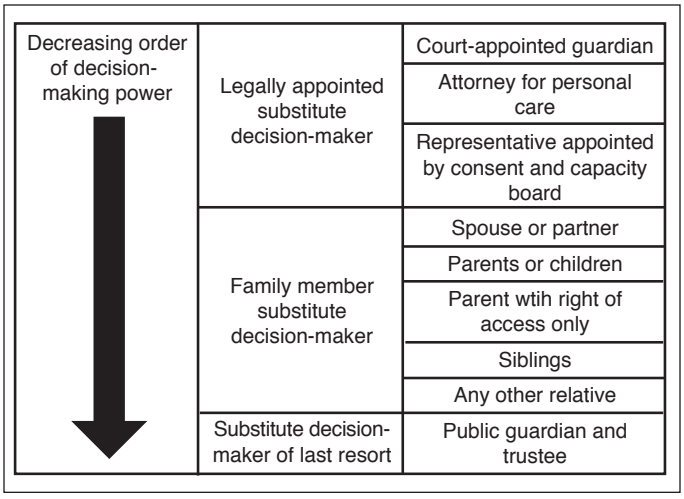

Fig. 2. Substitute decision-maker hierarchy as outlined by Ontario's Health Care Consent Act (1996).

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 (Fig. 2). 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 received from physicians and takes 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 counselling 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.

Competing interests: The authors report no competing person or financial interests related to this work.

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IN MEMORIAM

CUAJ honors its members and friends who have passed away. We invite colleagues of the deceased to submit brief remembrances. Please limit your notice to 200 words. Send your notice to **journal@cua.org** or fax it to **514-395-1664**.

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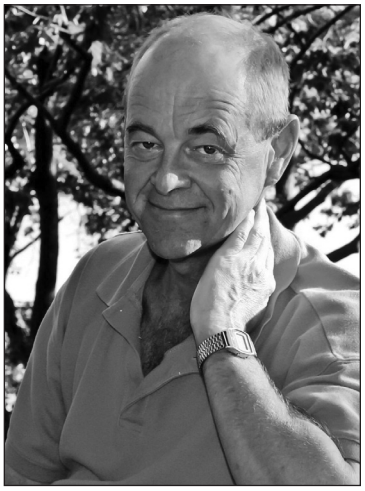

Denis Henry Hosking

Canadian urology has lost a major leader of recent years with the passing of Dr. Denis Hosking.

Denis was born in Dundee, South Africa, attended schools in Pietermaritzburg, and after a year of military service in the South African Air Force, entered medical school at the University of Cape Town, graduating in 1972. While at medical school, he met Dianne (Dee) and they married in 1974. After working in hospitals in South Africa for three years, he and Dee moved to the U.K., where he underwent further surgical training and became a fellow of the Royal College of Surgeons of Edinburgh. The couple then moved to Winnipeg, where Denis accepted a position as a general surgery resident at the University of Manitoba.

Denis eventually transferred to the urology program, and then worked under the leadership of Ernie Ramsey, who became an important mentor. Denis achieved his FRCSC in 1982. After a further year of training in clinical urolithiasis at the Mayo Clinic-Rochester, he returned to Winnipeg to accept a position as an assistant professor of surgery in the Section of Urology. He remained a urologist at the Health Sciences Centre for the rest of his career.

In 1990, he was appointed head of the Section of Urology for the hospital and the university, positions he held until 2010. He was promoted to full professor of surgery in 1998. He held numerous positions in the department and faculty, primarily focusing on medical education and clinical service provision. It is fitting that the Department of Surgery at the University of Manitoba has established the Hosking award for the resident best exemplifying the CanMEDS roles.

Denis's academic achievements were focused on metabolic stone disease and surgery for renal stones. He coined the term "stone clinic effect" to describe the change in incidence of recurrent stone disease by just being seen in a dedicated stone clinic by a clinician skilled in managing these patients.

The 80s was an exciting time to be a urologist. Denis was an active participant in the development and evolution of the technology used to treat stones, including percutaneous renal surgery, ureteroscopy, and intracorporeal lithotripsy. Winnipeg was one of the early Canadian centers to acquire extracorporeal shock wave lithotripsy. Frustrated by his dependence on radiologists to obtain access for percutaneous renal surgery and not having availability of the technology to permit antegrade access himself, Denis became skilled at and published on the retrograde approach. He is one of the few urologists to publish on his experience with ureteroscopic stone removal with sedation only. This demonstrates that not only did he have "gentle hands" as a surgeon, but clearly had a skilled team in the Urology Centre to achieve such success. Denis was particularly proud and recognized the importance of the team he built in Urology. He especially valued the support he received from the operating room

staff, the nurses in the urology clinic and treatment areas, the radiology technicians, and the office staff. He considered every member of the team essential in providing the best possible patient care.

Beyond his clinical practice, Denis was a leader in Canadian urology. He was local organizing chair of the 1992 CUA annual meeting in Winnipeg, the only time the CUA has met in that city in 75 years. He was elected secretary of the CUA that same year and became noted for his accurately detailed, exhaustive minutes, recording every opinion of every member of the committee, even when those opinions changed during the discussions. He was president of the CUA in 1999–2000 and presided over the scientifically and socially successful meeting in Kelowna. Denis was an examiner for the Royal College in urology for many years and was chief examiner during the transition from the traditional two-part examination to the Comprehensive Objective Examination, which introduced the OSCE exam to urology. In 2008, he was awarded the CUA award for lifetime contributions to urology.

Denis enjoyed most sporting activities, although despite living in Winnipeg, never developed an appreciation for curling. He would try any sport, including skiing. Apart from the usual team sports played at school, he enjoyed tennis, squash, and developed a lifelong love of golf while still a schoolboy. He could be relied upon to participate in the annual golf tournaments at the CUA meetings. On one occasion, he won the tournament, and that was at the joint BAUS-CUA meeting in 1986 in London, U.K. In later years, Denis loved golf holidays down at Hilton Head Island.

Among his other interests, he enjoyed motorcycling and white-water kayaking. He twice completed the gruelling 120 km Dusi Canoe Marathon from Pietermaritzburg to Durban, South Africa. Outside of sports, he had great interest in photography and bridge.

Denis was committed to his adopted city and although growing up in a sub-tropical climate, where ice is only found in freezers or cold drinks, he never seriously contemplated living anywhere else. He was forever grateful for the opportunities he was given in Winnipeg and would relish describing the effects of the frigid sub-zero temperatures to anyone who had not personally experienced this degree of cold.

Those who knew him will remember him as a vibrant individual with an aura of mischief, a wicked sense of humor, and rapier sharp wit. He was not shy to be provocative and share his carefully considered opinions when he thought it necessary to stir up the session. His South African accent would thicken depending on the intensity of the discussion or the quantity of fluids that had been consumed. Colleagues and residents respected him as a gifted teacher, an outstanding leader, and a very thoughtful and skilled clinician. Most of all, he was a person of substance and integrity.

He faced the realities of his myeloma diagnosis in 2009 with dignity, courage, and forbearance. The last years were challenging but never did he complain about his plight.

He is survived by Dee, his children Nolan and Michelle (Paul Van Caeseele), and grand-children Luke, Mark, and Eric. He will be missed by his many colleagues, former residents, and friends across Canada and around the world.