BIOETHICS FOR CLINICIANS: 2. DISCLOSURE

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Abstract • Résumé

In the context of patient consent, "disclosure" refers to the provision of relevant information by the clinician and its comprehension by the patient. Both elements are necessary for valid consent. Disclosure should inform the patient adequately about the treatment and its expected effects, relevant alternative options and their benefits and risks, and the consequences of declining or delaying treatment. The clinician's goal is to disclose information that a reasonable person in the patient's position would need in order to make an informed decision. Therefore, clinicians may need to consider how the proposed treatment (and other options) might affect the patient's employment, finances, family life and other personal concerns. Clinicians may also need to be sensitive to cultural and religious beliefs that can affect disclosure.

Dans le contexte du consentement des patients, on entend par «divulgation» la fourniture de renseignements pertinents par le clinicien et leur compréhension par le patient. Les deux éléments sont nécessaires pour qu'il y ait consentement valide. La divulgation doit fournir au patient des renseignements suffisants sur le traitement et ses effets attendus, sur des options de remplacement pertinentes, sur leurs avantages et leurs risques, ainsi que sur les répercussions d'un refus de traitement ou d'un retard. Le but du clinicien est de divulguer tout renseignement dont une personne raisonnable dans la situation du patient aurait besoin pour prendre une décision éclairée. Il se peut donc que les cliniciens doivent envisager les répercussions éventuelles du traitement proposé (et d'autres options) sur l'emploi, la situation financière, la vie familiale et d'autres aspects de la vie personnelle du patient. Il se peut aussi qu'ils doivent être sensibilisés aux croyances culturelles et religieuses qui peuvent avoir un effet sur la divulgation.

Mr. C is 61 years old and works as a supervisor at a car assembly plant. He lives at home with his wife. He has been in good health, although he smokes a pack of cigarettes a day. At a routine checkup his physician notes a loud bruit at the left carotid artery. Mr. C, who is right handed, has never had a transient ischemic attack or stroke. A duplex Doppler ultrasound reveals significant stenosis of the left internal carotid artery; cerebral angiography reveals the degree of the stenosis to be 95%. Carotid endarterectomy is recommended; Mr. C discusses this proposal with the consultant vascular surgeon.

Mrs. D is 75 years old and lives at home with her husband. She has a remote history of gastric ulcers and has mild renal insufficiency as a consequence of hypertension. She visits her family physician because of acute worsening of chronic arthritis in her right shoulder. She is having trouble lifting and carrying objects. Her family physician is considering treating Mrs. D with a nonsteroidal anti-inflammatory drug (NSAID).

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Mrs. E is 80 years old and lives alone in an apartment. She is fully independent and has never had a serious illness. She prefers not to see doctors. She is admitted to hospital after falling on the stairs and suffering a fracture of the femoral neck. A consultant in internal medicine diagnoses critical aortic stenosis; this is confirmed by echocardiography. The anesthetist visits Mrs. E to discuss the proposed surgery and anesthesia. When he says that serious risks are associated with the surgery, Mrs. E says she does not want to know about them. She wants her hip fixed because she simply cannot live with reduced mobility. The anesthetist feels that he has a duty to disclose the risks of anesthesia.

Ms. F is 28 years old. She was admitted to hospital 6 weeks ago with an exacerbation of poorly controlled asthma. The hospital internist prescribed long-term oral corticosteroid therapy. Ms. F is now taking prednisone (20 mg/d) and has noticed weight gain and mood disturbance. She thinks that she should stop taking the medication. Her family physician has recently read about a case of avascular necrosis of the femoral head associated with prednisone therapy, but he believes that prednisone therapy is important to control Ms. F's asthma. He wonders whether the risk of avascular necrosis should not be disclosed, lest this information cause Ms. F to stop taking prednisone.

What is disclosure?

"Disclosure," in the context of patient consent, refers to both the provision of relevant information by the clinician and its comprehension by the patient. Both elements are necessary for valid consent.

Why is disclosure important?

Ethics

In keeping with the ethical principles of patient autonomy and respect for persons, disclosure promotes patients' informed and reflective participation in health care decisions. Disclosure also promotes a continuing and trusting relationship between the patient and his or her physician.[1,2]

Law

Elements of disclosure

The necessary elements of disclosure as identified in Canadian statutory[3,4] and common[5] law are as follows: a description of the treatment and its expected effects (e.g., duration of hospital stay, expected time to recovery, restrictions on daily activities, scars); information about relevant alternative options and their expected benefits and relevant risks; and an explanation of the consequences of declining or delaying treatment. The patient must be given an opportunity to ask questions, and the clinician must respond to questions or requests for further information.

Scope of disclosure

In Canada, the prevailing standard of disclosure is that of the "reasonable person."[3–5] This is an objective standard that requires the clinician to disclose information that a reasonable person in the patient's position would need in order to make an informed decision. The concept of "a reasonable person in the patient's position" may be understood by an example regarding disclosure of risks. Mr. C is considering carotid endarterectomy for asymptomatic stenosis of the carotid artery. Carotid endarterectomy has a known risk of immediate death or stroke. These risks must be disclosed, because a risk of death, paralysis or permanent loss of a body function would be relevant (or "material") to a reasonable person. However, Mr. C is within 6 months of obtaining full pension benefits at work. A reasonable person in Mr. C's financial position would also need to know that the risk of having a stroke in the next 6 months would be higher with endarterectomy than with medical treatment.[6] In Canada, the reasonable-person standard for disclosure was established by the Supreme Court of Canada in the case of *Reibl* v. *Hughes*,[5] upon which the case of Mr. C is based.

Waiver

"Waiver" refers to a patient's voluntary request to forego one or more elements of disclosure. For example, a patient may not wish to know about a serious prognosis (e.g., cancer) or about the risks of treatment. Because Canadian legislation and common law do not directly address the issue of waiver, clinicians should proceed cautiously when a patient appears to be requesting a waiver.

Therapeutic privilege

"Therapeutic privilege" refers to the withholding of information by the clinician during the consent process in the belief that disclosure of this information would lead to the harm or suffering of the patient.[7]

The legal status of therapeutic privilege in Canada is uncertain. The case of *Meyer Estate* v. *Rogers*[8] involved a 37-year-old woman who died after intravenous injection of a contrast medium for a routine radiologic procedure. The radiologist claimed therapeutic privilege as a defence against the allegation that he failed to warn the patient of

the risks of intravenous dye injection. The court rejected the defence on the grounds that therapeutic privilege was not applicable.[8] The judge concluded that "the Supreme Court of Canada has not . . . adopted or even approved the therapeutic privilege exception in Canada."[9]

The need for sensitivity to cultural norms may potentially support the exercise of therapeutic privilege. In some cultures therapeutic privilege is widely invoked, and it is unclear whether patients from these cultures should always be subjected to Western standards of consent.[10] However, given the legal status of therapeutic privilege in Canada, clinicians should avoid invoking therapeutic privilege. It is better for the clinician to offer information and allow the patient to refuse or accept further disclosure.

Policy

Disclosure is an essential component of valid consent, and obtaining valid consent is a policy of the CMA[11] and other professional bodies.

Empirical studies

The results of empirical studies of disclosure suggest that patients' desire for information closely agrees with the legal standard for disclosure. In one study more than 80% of a sample of surgical patients wanted to know about the nature of their illness, the reason for the surgery, the nature of the operation, the expected duration of their stay in hospital, the chances of a successful result, the expected time to return to normal daily activities and any special precautions they would need to take after surgery.[12] Similar observations have been made with regard to patients' desire for information about anesthesia.[13–15]

Studies have indicated that 6% to 18% of patients prefer not to know about the risks of treatment.[12,13,16] However, this research evaluated patients who had already decided to proceed with surgery or had already undergone successful surgery and did not address the question of what they wanted to know about risks in order to consent to surgery.

Most studies in this area have found that routine verbal disclosure is not completely effective,[17–25] whereas written[26–30] or combined written and verbal disclosure[31–34] can improve patients' knowledge. Other aids to disclosure, such as bedside decision instruments[35] and interactive videodiscs,[36] are promising but require further evaluation.

How should I approach disclosure in practice?

Disclosure should be viewed as a process rather than as a discrete event. Several encounters between the clinician and patient may be needed before disclosure can be considered complete. For example, Ms. F and her clinician may need to discuss prednisone therapy on a number of occasions to ensure proper disclosure of benefits and risks. If a therapy is given over a prolonged period the disclosure process should continue. For example, if new information relevant to a patient's drug therapy becomes available it should be disclosed.

Effective communication is critical to the disclosure process. If the clinician fosters good communication the patient will be encouraged to provide personal information and express his or her values, goals and fears. A full discussion of effective physician–patient communication is beyond the scope of this article, but several relevant reviews are available.[37–41]

During the consent process clinicians should routinely address each element of disclosure, giving information about each of the areas described earlier (see "Elements of disclosure"). The goal is to disclose any information that a reasonable person in the patient's circumstances would want to know. Depending on the treatment in question, clinicians may need to consider how it, and other options, could affect the patient's employment, finances, family life and other personal concerns.

Disclosure should also take account of the patient's cultural and religious beliefs. For example, in some cultures a family-centred model of decision making is favoured over one centred on the individual.[42] The clinician can encourage patients in such a situation to involve family members in the consent process. Although cultural sensitivity is a complex issue beyond the scope of this article, several reviews are helpful.[10,43,44]

Throughout each disclosure session the clinician should invite questions. Encouraging patients to restate information in their own words is one way to ensure that information has been understood. The clinician should document each discussion, noting the patient's questions and how these were answered. Special cultural or religious considerations are particularly important to document.

The cases

The surgeon asks Mr. C if he has any worries or concerns about the proposed surgery and learns that Mr. C is due for full pension benefits in 6 months. The surgeon discloses that the risk of stroke within 6 months is higher with surgery than with medical treatment. Subsequently, the surgeon and Mr. C agree to continue acetylsalicylic acid therapy, to arrange for Mr. C's enrolment in a smoking cessation program and to re-evaluate the treatment decision in 6 months. The surgeon's note includes the reasons for the decision and a reminder of why Mr. C will return in 6 months.

Mrs. D has no questions about the "arthritis pill" because she trusts her physician, whom she has known for many years. The physician initiates a discussion of the risks — in particular, gastrointestinal bleeding and renal insufficiency. Mrs. D appears concerned, and the clinician invites her to discuss this concern. Mrs. D explains that the shoulder pain must be relieved so that she can care for her young granddaughter, who will be visiting next month. The physician mentions that acetaminophen may also be effective and has a lower risk of side effects. Although pain relief is a high priority, Mrs. D would prefer to avoid side effects, particularly because she was once admitted to hospital because of her gastric ulcer. She agrees to try acetaminophen therapy for 2 weeks and, if there is no effect, to then try the NSAID. The physician makes a note of their discussion and arranges a follow-up appointment for 2 weeks hence.

Mrs. E has asked the anesthetist not to disclose further the risks associated with hip surgery. She says that her goal is to be able to walk and that further suffering from pain and immobility is not acceptable to her. She tells the anesthetist that any further discussion of risks will not change her mind but might upset her. The anesthetist respects Mrs. E's request but tells her that she can change her mind regarding the discussion of risks at any time. He also asks her if there are family members whom Mrs. E would like to involve in the decision-making process. Mrs. E wants her daughters to participate in the decision, and so the proposed surgery and its possible risks are disclosed to them. The entire discussion is documented, including Mrs. E's reasons for waiving further disclosure of the risks of surgery. Mrs. E undergoes uncomplicated repair of her hip fracture and returns home to live independently.

Ms. F should be informed of the risk of avascular necrosis of the femoral head. The clinician should not use therapeutic privilege to justify withholding this information.

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Sept. 15–20, 1996: 18th World Congress of Rehabilitation International — Equality Through Participation: 2000 and Beyond
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18th World Congress of Rehabilitation International, Convention Management, PO Box 2009, Auckland, New Zealand; tel 64 9 360-1980, fax 64 9 376-1980; rehab@conventionmgmt.co.nz

Sept. 15–20, 1996: 25th International Congress on Occupational Health
Stockholm, Sweden
ICOH-Congress, National Institute for Working Life, S-171 84 Solna, Sweden; tel 46 8 730-9100, fax 46 8 82-0556; website: http://www.niwl.se/

Sept. 19–22, 1996: Canadian Anesthestists Society Atlantic Meeting
St. John's
Dr. Jeremy Pridham, 12 Forest Rd., St. John's NF A1C 2B9; tel 709 739-5666, fax 709 739-6086

Sept. 20, 1996: St. Paul's Emergency Conference Day — Bright Lights, Big City: Urban Medicine for the Community Physician
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