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Ethics

Disclosure[1]

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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.

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. Disclosure is an essential component of valid consent

Why is disclosure important?

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)

Elements of disclosure

The necessary elements of disclosure 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.

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1. Summarized from: Etchells E, Sharpe G, Burgess M, Singer P. CMAJ. 1996;155:387-391.

Scope of disclosure

The prevailing standard of disclosure is that of the "reasonable person." 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 i.e. known risk of immediate death or stroke in carotid end-arterectomy. 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.

Waiver

"Waiver" refers to a patient's voluntary request to give up 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 that is why, 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.(3)

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.(4) However, given the legal status of therapeutic privilege it is better for the clinician to offer information and allow the patient to refuse or accept further disclosure.

Supportive evidence

There is adequate evidence that surgical patients want 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.(5) Similar observations have been made with regard to patients' desire for information about anesthesia.(6-8)

Studies have indicated that 6% to 18% of patients prefer not to know about the risks of treatment.(5,6,9) 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,(10-18) whereas written(19-23) or combined written and verbal disclosure(24-27) can improve patients' knowledge. Other aids to disclosure, such as bedside decision instruments(28) and interactive videodiscs,(29) 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, a therapy given over a prolonged period or a prescribed medication i.e. prednisone the disclosure process should continue and should be discussed on a number of occasions to ensure proper disclosure of benefits and risks. 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 available.(30-34)

During the consent process clinicians should routinely address each element of disclosure, giving information about each of the areas described earlier. 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.(35) The clinician can encourage patients in such a situation to involve family members in the consent process. Cultural sensitivity is a complex issue and several review articles are available.(4,36,37)

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.

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