MARGINAL CAPACITY: THE DILEMMAS FACED IN ASSESSMENT AND DECLARATION

Vincent Ho

In Brief • En bref

Ontario is adopting informed-consent legislation that reflects increasing emphasis on patient autonomy and self-determination. Capacity assessment and declaration by physicians and other health care professionals are pivotal under the new legislation. While grossly capable or incapable patients provide few management difficulties, marginally capable patients provide a challenge for physicians who must assess capacity, and decisions concerning them emphasize the ethical dilemma involved in any declaration of incapacity. Our 1994 Logie Medical Ethics Essay first-prize winner, Vincent Ho, examines the issues that clinicians must consider when assessing marginally capable patients.

L'Ontario est en train d'adopter une loi sur le consentement éclairé qui reflète l'accent croissant placé sur l'autonomie et l'autodétermination. L'évaluation et la déclaration de l'aptitude par les médecins et d'autres professionnels de la santé sont critiques dans la nouvelle loi. Alors que les patients nettement aptes ou inaptes posent peu de difficultés de gestion, ceux qui sont marginalement inaptes posent un défi aux médecins qui doivent évaluer leur aptitude, et mettent en évidence le dilemme éthique que pose la déclaration d'inaptitude. Le gagnant du premier prix de notre Concours Logie de dissertation en éthique médicale de 1994, Vincent Ho, examine les questions que les cliniciens doivent considérer dans l'évaluation de l'aptitude des patients marginalement inaptes.

The Dr. William Logie Medical Ethics Essay Contest is open to undergraduate medical students studying at Canadian universities. The contest, named in honour of Canada's first medical graduate, is sponsored by CMAJ. *The following essay won the $1000 first prize in the 1994 competition.*

In 1992, the Ontario government obtained royal assent for a legislative package comprising the Consent to Treatment Act,[1] the Substitute Decisions Act,[2] the Advocacy Act[3] and the Consent and Capacity Statute Law Amendment Act;[4] proclamation of the new laws is expected early in 1995. At the crux of the legislation is the assessment and declaration of a person's capacity to consent to or refuse treatment by any health care practitioner. Capable persons will be able to make valid decisions about present and future treatment themselves, but incapable persons will require a substitute to act on their behalf and an advocate to protect them.[5] The laws affect many health care providers, particularly physicians, and reflect changes both in health care and in societal values.

Since the time of Hippocrates, physicians have been entrusted to act in the best interests of the patient, usually in a paternalistic physician–patient relationship.[6] Until the 1970s patients rarely questioned physicians' decisions, and often their wishes were not solicited. However, changes in medicine necessitated changes in the physician–patient relationship to protect patients from the potential of physician self-interest or abuse of power:

- The growth of medical specialization detracted from the development of ongoing, trusting relationships between some physicians and patients.
- Technologic advances produced treatments with greater risks and side effects, and made the "best" treatment a debatable issue.
- Medicine was increasingly viewed as a profit-oriented profession.

New emphasis on the values of autonomy and self-determination in society led to the development of the patient's right of informed consent to medical treatment. This, coupled with the vulnerability of the ill, suggested the need for a new physician–patient partnership in decision making.[7] Under the new laws, physicians were not authorized to provide any treatment without the valid informed consent of the patient, with the exception of cases involving children or incapable patients, or emergency situations.[8] To protect the patient and to promote autonomy, it is presumed in law that capacity is present unless the physician can prove the opposite.[9] For physicians in the clinical setting, assessing and declaring incapacity in a patient is

Vincent Ho is a fourth-year medical student at the University of Toronto.

of paramount importance because of the harm that would be done if capable patients were deprived of the right to make a decision or incapable patients were allowed to make decisions harmful to their best interests.[10]

Legally, patients are considered capable if they can understand relevant information concerning medical treatment and appreciate the reasonably foreseeable consequences of a decision or failure to make a decision.[1] Weisstub used the terms "capacity/capable" instead of "competency/competent" to focus attention on the functional parameters and abilities of the person in the context of a specific decision;[10] the new Ontario legislation also adopts this terminology. Since capacity concerns how a person uses information to make a decision, the prerequisite to capacity is information disclosure by the physician.[11]

Freedman described two approaches to capacity: concept and policy.[11] In the concept approach, the standard of capacity is to delineate the capable from the incapable in an effort to decide who belongs to which category.

In the policy approach, the standard of capacity is used to achieve practical goals such as preservation of the balance between autonomy and best interests through informed consent. The policy view incorporates social considerations and societal biases along with functional considerations in the standard of capacity.[11] The physician approaches capacity at a concept level in the assessment stage, and at a policy level when deciding to act on the assessment by declaring a person capable or incapable.

With the new legislation, grossly capable or incapable patients pose little assessment difficulty for physicians[12] and policy decisions, such as procedural guidelines to be followed after such findings, are clearly defined. However, between capacity and incapacity is a grey zone — "marginal" capacity.[11]

Hypothetical case scenarios describe seven factors that can influence the assessment of capacity, approaching them in the context of the new laws: decision-specific capacity, fluctuating capacity, pain factor, denial factor, influence of psychiatric illness, influence of medications and other conditions confused with incapacity.

Vincent Ho

Decision-specific capacity

The terms competent or capable are often mistakenly used to describe a person's overall decision-making abilities; if a person is found incompetent, it may be assumed that the person needs a substitute to make *all* decisions. This global view of capacity is not supported empirically[13] and capacity must be viewed as decision specific: a person may be capable of making decisions in some areas of life, but not in others. In the medical context, this also means that a patient may be capable with respect to some treatments and incapable with respect to others.[1]

Case 1: A 42-year-old married woman is admitted involuntarily for treatment of schizophrenia and alcoholism. She mistakenly believed that her husband was having an affair and had committed her to the hospital so he could steal her money. She was not eating and had trouble sleeping. To treat the alcohol withdrawal, insomnia and psychosis, the physician approached her for consent to administer minor tranquillizer and antipsychotic medications. She understood that she had a drinking problem and was not sleeping well, and was able to understand how the minor tranquillizer would ease withdrawal symptoms and help her sleep, and the consequences of accepting or refusing this treatment. However, she refused antipsychotic medication because she believed that her husband's lover had poisoned this drug, along with her food. The physician deemed her capable to consent for minor tranquillizers, but incapable for antipsychotic drugs because that refusal was a product of delusional beliefs. This allowed some treatment to be initiated. Treatment for the psychotic condition was initially deferred, with a decision on how to proceed to be made later.

A physician must determine when a patient may be capable of making one decision and incapable of making another. Capacity is specific to the nature and complexity of the decision and the psychologic factors involved.

Fluctuating capacity

Like mental status, capacity is not a fixed state. A person's capacity may fluctuate according to a multitude of factors, such as the illness the physician proposes to treat.[14] A person may be incapable with respect to a treatment at one time and capable at another.[1]

Case 2: A 74-year-old widower with Alzheimer's disease was admitted to hospital when his functioning deteriorated and personal hygiene was neglected. He had confused and muddled thoughts and was paranoid about the government. He could not reach a decision about where he wanted to live when he left hospital, nor could his children reach a consensus. His daughter wanted him to sell his house and move to Northern Ontario to live with her; his son wanted him to remain in Toronto, although he was not

able of providing the intensive supervision that the daughter offered. The patient's cognition and functioning improved significantly on Sundays when his son visited. Capacity assessments made on Sundays found the patient consistently capable, rational and more cooperative than on other days of the week. One Sunday, while the patient was capable, the attending physician elicited and recorded the patient's wishes upon discharge — to sell his house and move into a nursing home in downtown Toronto, the city he had lived in most of his life. At time of discharge the patient was still mildly confused, but community resources were mobilized to ensure his safety and the son offered some support. The patient's wish was respected.

The new laws give legal authority for patients to extend their autonomy into periods of incapacity by making advance directives and express wishes and by arranging living wills and powers of attorney during periods of capacity. Such advance directives should be encouraged and documented by physicians for patients at risk of incapacity. Considering the grave implications of findings of capacity or incapacity, assessment of capacity should involve thorough evaluations over time.[14]

Pain factor

Intense pain can influence mental functioning and assessment of capacity. Primarily, pain is a psychologic state that is sensory or emotional in origin; damage to the body is not itself pain, although it has an impressive causal relationship to pain.[15] Patients may be consumed by intense pain, and unable to focus on issues other than relief.

Case 3: A 65-year-old woman with lung cancer that had metastasized to her spine was in extreme pain and when approached to consent for palliative treatment she refused and said: "No more, I want to die!" The physician decided to treat her with morphine as an emergency procedure without consent because the patient was experiencing such severe suffering. When the pain was under control, the physician approached her again, seeking consent for palliative treatment. Now lucid and able to understand the treatment proposed, she stated that she did not want further treatment. The physician found her to be capable and respected her decision.

The new laws will allow physicians to act in an emergency to relieve such suffering.

Denial factor

Great difficulty arises when assessing and treating patients who deny their illness.[16] Inexperienced assessors often miss subtle forms of incapacity when a patient is articulate, coherent and shows some understanding. However, patients may be severely impaired in decision making if they deny having the illness for which treatment is being proposed.[12]

Case 4: A 46-year-old woman presented with a breast mass and fine-needle aspiration revealed an invasive ductal carcinoma. The patient became very withdrawn when confronted with the diagnosis. When she was approached to provide informed consent for surgery, she refused treatment, stating that she did not want to undergo anesthesia because of the risk that she might not wake up. As this was pursued further, she stated that she didn't need surgery because there was nothing wrong with her breast except some extra fat; she denied having breast cancer. Further inquiry revealed that her best friend had recently died from breast cancer and the patient was terrified that if she had breast cancer, she would surely die. After repeated discussions that explored her fears, she was able to appreciate the prognosis of breast cancer and the chance of survival with and without treatment in the early stages of the disease. She overcame her denial, accepted that she did have breast cancer, and then was considered capable of giving informed consent for surgery.

There may be ethical drawbacks in requiring patients to recognize their illness in order to be considered capable, and such issues must be carefully considered at the policy level when deciding to declare a patient incapable. This standard approaches a catch-22 situation — a patient's denial of the need for treatment is taken as evidence of that very need.[16] However, on the concept level, it is clear that this patient's earlier refusal of treatment reflected her lack of insight into her condition, which rendered her incapable of consenting or refusing.

Influence of psychiatric illness

Like any others, patients with psychiatric illness are presumed capable of making decisions. Ontario's current mental-health laws could allow persons committed to a psychiatric institution to refuse treatment that would permit their freedom to be restored.[17,18] Patients with psychiatric illness may be cognitively intact but their decision-making capacities may be compromised; for example, paranoid or depressed patients are often able to express themselves coherently and create internally consistent systems within their delusional or pessimistic worlds that may conceal subtle incapacity.[12]

Case 5: A 50-year-old man had a major depressive episode that was not helped by medication. He was asked to consent to electroconvulsive therapy and seemed to grasp the 80% success rate and the stated side effects. He refused treatment, stating that he didn't want to experience the side effects of trying something that would not work for him. Further discussion revealed that he assumed he was doomed to be in

the 20% group. The physician declared him incapable of providing consent because his appreciation of the risks and benefits reflected his affectively induced pessimism and guilt.[12]

Psychiatric illness is an important confounding factor in capacity assessment and the physician must assess its influence.

Influence of medications

Many drugs affect cognitive functioning and capacity. Psychotropic and other medications can alter the chemical milieu of the brain and affect consciousness, memory, perception and thought processes. Conversely, psychotropic drugs can restore one's capacity, although the benefit is neither guaranteed nor without risks. It is difficult to identify and recognize the subtle influence of such medications on capacity because the side effect may be rare and the mechanisms of action are often idiosyncratic.

Case 6: A 47-year-old woman with insulin-dependent diabetes mellitus has undergone kidney transplantation. She was receiving high doses of steroids to suppress graft rejection. She was euphoric, restless, had an increased activity level and felt powerful. She began refusing her insulin because she believed that her diabetes had been cured and that she no longer needed it. The physician deemed her incapable because her refusal was a product of her steroid-induced mania. She was declared incapable and treated with insulin. As the steroids were tapered to maintenance levels, her affective disorder resolved and she was again capable of consenting to insulin treatment.[19]

Other conditions confused with incapacity

Those vignettes described marginally capable persons in whom physicians might miss subtle forms of incapacity. Conversely, physicians may presume persons to be incapable when in fact they are marginally capable. Assessment of such cases is largely based on social and cultural concerns and other issues of policy rather than the complex and variable functional parameters that reflect the concept level of capacity. Physicians must be aware of their own social and cultural biases when assessing capacity in the following categories:[10]

- Mentally disordered, including patients with psychiatric illnesses, dementia and organic brain disorders. There is a strong tendency to declare mentally disordered persons globally incapable, particularly when they have been involuntarily committed to a psychiatric facility.
- Developmentally handicapped. Because of societal stigma, people with developmental mental impairment may be incorrectly assessed as having global incapacity.
- Geriatric patients, including patients with medical and psychiatric illness.
- Minors. The new legislation codifies the common law and does not legislate an age of capacity, shifting focus from chronologic age to functional capacity to make a specific decision.
- Persons unable or unwilling to communicate. In our multicultural society, many people cannot speak an official language. Additionally, people may be angry at the medical staff and uncooperative during assessments.
- Eccentric patients. The rationality of a decision is not the criterion for a finding of incapacity. However, a decision that is not "reasonable" would warrant a closer examination of capacity.[20] A person may attach unique values to any factor and reach a decision that a physician may consider eccentric and "unreasonable." Again, the assessment of capacity is not focused on values but on functional parameters of thought processes, understanding and appreciation. The physician must guard against assessing incapacity because a patient's decision does not conform to societal norms.

Discussion

There are many pitfalls in assessing patients with marginal capacity or with conditions confused with incapacity, but it is the policy level that poses the greatest dilemma for physicians because of the grave implications that come with declaring capacity or incapacity.

For the marginally capable person, capacity at the concept level may be dubious and assessment difficult. If the patient is declared capable, the physician may be called on to respect either the person's wish to undergo a risky treatment protocol or to forgo a low-risk, life-sustaining treatment — either of which may be an ill-advised decision that could cause serious bodily harm. Alternatively, if a declaration of incapacity is made, the patient may be protected from the harmful consequences of a poorly considered decision. In dubious cases of marginal capacity, the latter policy decision would appear to be less harmful and in the best interests of the patient. Physicians may be tempted to curtail the inquiry into capacity and choose to "play it safe" by declaring the patient incapable.

However, I believe, as do others,[11] that great harm may be inflicted when physicians indicate that patients' opinions and decisions are of no worth by declaring them incapable. Such injury to the psyche and self-esteem is not medically measurable in the way loss of a limb is, but the psychologic, emotional and spiritual damage is very real. Such harm may be ignored by physicians who are too eager to carry out medically indicated treatment. "Playing it safe" is a pretence under which physicians escape from assessment difficulties and from thinking through the ethical dilemma associated with declaring someone capable or incapable.

For these reasons, it is important to

insist on the claims of autonomy and self-determination when making decisions at the policy level.[11] This is true not only for the marginally capable but also for those who have been assessed incapable at the concept level. Unless there is an overwhelming good that can be achieved for the patient, the physician may decide to respect a patient's wishes, even if he or she is clearly incapable at the concept level, in order to avoid the unmeasurable harm caused by declaring incapacity.

Case 7: A 65-year-old man was cachectic because he was paranoid and was not eating well in the nursing home. In hospital, he refused vitamin supplements because he believed that they were "poison," but began to eat a balanced diet. The physician considered declaring the patient incapable and seeking consent from a substitute decision maker, but decided to take no action on the vitamin therapy because of the likely benefit of the balanced diet that the patient was now eating.

Conclusions

When the new Ontario laws are proclaimed, capacity assessments and declarations will be a prominent part of medical practice. Assessment of capacity at the concept level is complicated by numerous clinical issues and factors, and those who are marginally capable highlight the ethical dilemma that comes with balancing the values of autonomy and best interests at the policy level, where the declaration of incapacity must not be used to "play it safe."

Furthermore, even if a patient is incapable at the concept level, there may be no need to declare this unless an overwhelming good can be achieved that outweighs the potential harm inflicted upon one's self-esteem and psyche by the declaration of incapacity.

Special thanks to Dr. Brian Hoffman, director of the Psychiatric Day Hospital, Mount Sinai Hospital, and associate professor at the University of Toronto, for his supervision when this manuscript was being prepared.

References

1. Bill 109, *Consent to Treatment Act*, 2nd Sess, 35th Leg Ont, 1992
2. Bill 108, *Substitute Decisions Act*, 2nd Sess, 35th Leg Ont, 1992
3. Bill 74, *Advocacy Act*, 2nd Sess, 35th Leg Ont, 1992
4. Bill 110, *Consent and Capacity Statute Law Amendment Act*, 2nd Sess, 35th Leg Ont, 1992
5. Singer PA, Choudhry S: Ontario's proposed consent laws: 1. Consent and capacity, substitute decisions, advance directives and emergency treatment. *Can Med Assoc J* 1992: 146: 829–832
6. Finkelstein D, Karsh Smith M, Faden R: Informed Consent and Medical Ethics. *Arch Ophthalmol* 1993; 111: 324–326
7. Drane JF: Competency to give an informed consent: a model for making clinical assessments. *JAMA* 1984; 252: 925–927
8. Draper RJ, Dawson D: Competence to consent to treatment: a guide for the psychiatrist. *Can J Psychiatry* 1990; 35: 285–289
9. Wasylenki D: Competency to con sent to treatment. *Ann R Coll Physicians Surg Can* 1988; 21: 203–207
10. Weisstub DN: *Enquiry on mental competency: Final Report*. Queen's Printer for Ontario, Toronto, 1990
11. Freedman B: Competence, marginal and otherwise: concepts and ethics. *Int J Law and Psychiatry* 1981; 4: 53–72
12. Gutheil TG, Bursztajn H: Clinicians' guidelines for assessing and presenting subtle forms of patient incompetence in legal settings. *Am J Psychiatry* 1986; 143: 1020–1023
13. Searight HR: Assessing patient competence for medical decision making. *Am Fam Physician* 1992; 45: 751–759
14. Appelbaum PS, Roth LH: Clinical issues in the assessment of competency. *Am J Psychiatry* 1981; 138: 1462–1467
15. Merskey H: Psychiatry and chronic pain. *Can J Psychiatry* 1989; 34: 329–336
16. Roth RH, Appelbaum PS, Sallee R et al: The dilemma of denial in the assessment of competency to refuse treatment. *Am J Psychiatry* 1982; 139: 910–913
17. McKinnon K, Cournos F, Stanley B: Rivers in practice: Clinicians' assessments of patients' decision-making capacity. *Hospital and Community Psychiatry* 1989; 40: 1159–1162
18. Appelbaum PS: The right to refuse treatment with antipsychotic medications: retrospect and prospect. *Am J Psychiatry* 1988; 145: 413–419
19. Balthazor JE: Steroid psychosis and hepatic encephalopathy in liver transplant: Which is which and what do you do? *Crit Care Nurs Q* 1991; 14: 51–55
20. Roth LH, Meisel A, Lidz CW: Tests of competency to consent to treatment. *Am J Psychiatry* 1977; 134: 279–284