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A Guide for Health Care Practitioners in the Assessment of Young People's Capacity to Consent to Treatment

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Abstract

The Health Care Consent Act, 1996, states that every person in Ontario, regardless of age, is presumed to be capable of consenting to or refusing medical treatment unless he or she is found incapable with respect to a specific treatment or plan of treatment. Health care practitioners may find it especially challenging to apply the legal test of capacity to young people. As an aid to assessment, a guide incorporating both legal and medical perspectives has been developed. This article describes the background and context of the development of the guide and explains how it helps practitioners to conduct a simpler, more focused evaluation of capacity in youth. The guide, along with an introduction and comments for parents, is included in an appendix.

Keywords

youth, capacity, consent, treatment, practitioner guide

Introduction

The Health Care Consent Act, 1996 (HCCA) states that every person in Ontario, regardless of age, is presumed to be capable of consenting to or refusing medical treatment unless he or she is found incapable with respect to a specific treatment or plan of treatment (section 4(2)). In other words, capacity is presumed unless there is a specific finding of incapacity. Except in cases of emergency, a health care practitioner proposing a treatment is legally required to obtain specific, voluntary, informed consent from a capable patient before initiating it. If the patient is found to be incapable of giving or withholding such consent, it must be obtained from a Substitute Decision Maker.

Assessing the capacity of a patient to consent to a treatment is a heavy responsibility, made even more challenging when a young person is involved. There is no specific age of capacity. The same legal test of capacity applies for patients of all ages, although the means of assessment may differ.

For a variety of reasons, young patients may wish to refuse treatment, even when their health care practitioner believes it is essential to their health, perhaps even to their lives. The refusal itself does not constitute incapacity. The health care practitioner must assess each patient's capacity to make a treatment decision. If the patient is capable, then the decision of whether or not to follow the health practitioner's recommendation is completely up to the patient. If

the practitioner finds the patient to be incapable to make the decision, it will be made by a Substitute Decision Maker (dealt with in sections 20 and 21 of the HCCA).

The HCCA gives any patient found incapable to consent to treatment, including young people, the right to a hearing before the Consent and Capacity Board of Ontario (CCB), an independent tribunal. At the CCB hearing, the onus is on the health care practitioner to prove that the patient is indeed incapable to make the treatment decision in question.

This article provides some background to the assessment of the capacity to consent to treatment of young people in general and describes the development of a guide that we hope will help health care practitioners in performing such assessments. The guide was developed with consideration of both the medical and legal issues involved. It includes an introduction to the legal test, practical tips for conducting assessments, and information for parents.

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Context

Recent years have seen a movement away from the traditional paternalistic, somewhat protective relationships between physicians and patients toward partnerships that encourage the autonomy of the patient. This trend is evident in the HCCA, whose provisions ensure that the voice of the young but capable patient is heard and respected during discussion of his or her treatment. As often occurs, however, the new legislation has had some unintended consequences that can undermine the therapeutic alliance among the patients, the parents, and the health care team if the situation is not carefully and responsibly managed by all concerned.

Capacity to consent to treatment is a legal term that means the ability to understand relevant information and to appreciate the reasonably foreseeable consequences of accepting or refusing the treatment in question. As a practical matter, the ability to communicate a choice is also required. The clinician's evaluation of capacity must be guided by a duty to respect the patient's autonomy but may also be influenced by a natural desire to serve his or her best medical interests. When the patient's right to an opinion on treatment conflicts with what the practitioner believes is the right course of action, the HCCA requirements can place the practitioner in a difficult position. The practitioner must apply the legal test for capacity; the mere fact that the patient does not wish to accept his or her advice is not, in itself, incapacity. If a doctor finds a patient incapable to consent to treatment, the patient is given rights advice and may request a CCB hearing.

Research provides no definitive answers to the questions surrounding capacity to consent. Some evidence suggests that young people older than 14 years have decision-making ability similar to that of adults,¹ whereas other studies conclude that age is less important as a determinant of capacity than a person's health circumstances.^{2,3} Experience with illness and hospitalization often enhances understanding and ability to reason with regard to medical treatment decisions.¹ Another factor to consider is that adolescence is a period in which the influence of others may strongly affect decision making. Any such influence should be taken into account when an adolescent's capacity is assessed.⁴

Case Studies

The following 2 examples represent cases of young people who appeared before the CCB to contest the finding of incapacity by their health care practitioners. Their identities have been disguised to preserve confidentiality.

A 13-year-old girl with a severe gastroenterological disorder, an ileostomy, and severe perianal disease refuses all treatment. She has been ill for many years and has undergone numerous treatments, some of them invasive and unsuccessful. She is bright and articulate but appears depressed. The gastroenterologist finds her incapable to consent to treatment because he does not believe she is able to appreciate the consequences of accepting or refusing it. She requests a hearing before the CCB.

A 16-year-old boy with Wilson's disease, a disorder of copper metabolism resulting in neuropsychiatric symptoms, including mania and delusional thinking, refuses treatment for his medical and psychiatric condition. His delusions are well contained and he is able to speak clearly. However, he is found incapable to consent to treatment because his doctors believe he is neither able to understand the information necessary to make a decision on treatment nor to appreciate the consequences of accepting or refusing it. He requests a hearing before the CCB.

Rationale for a Guide

As stated above, capacity to consent to or refuse treatment is legally defined as the ability to understand relevant information and to appreciate the reasonably foreseeable consequences of accepting or refusing the treatment in question. Capacity defined in this manner does not depend on age but is inevitably affected by a person's level of maturity, experience of medical settings, social development, and family relationships, among other factors. Given this complexity, it is not surprising that opinions often vary on a young person's capacity to decide on treatment. If an adolescent's decision to accept or decline a treatment plan is reasoned (ie, based on an understanding of relevant information and an appreciation of reasonably foreseeable consequences), even if it may not be a "reasonable" decision from a medical standpoint, he or she is legally capable to make the decision. This resolution between legal and medical considerations, prescribed by Ontario law, is sometimes difficult for health care practitioners and parents to understand and accept.

Issues surrounding the assessment of a young person to consent to or refuse treatment can be troubling for health care practitioners, parents, and patients. Health care practitioners are not generally trained in evaluating cognitive processes or mental health issues in young people but rather in recommending treatment that serves their best medical interests. The HCCA requirement that practitioners determine the ability to make a choice that considers the relevant information and reasonably foreseeable consequences but may not appear to be a "reasonable" choice can present them with a stiff

challenge. As well, parents often experience anxiety about the limits the law imposes on their influence in deciding treatment for their child. Finally, young patients themselves may feel upset or overwhelmed when confronted with a difficult choice.

CCB hearings can present their own difficulties. Tension may arise between medical and legal voices, reflecting different perspectives and understandings of capacity. Sometimes controversy and frustration can develop at a hearing and interfere with the therapeutic alliance that ideally exists among patient, parents, and health care team.

Development of the Guide

A lawyer and vice-chair of the CCB and a psychiatrist member involved for many years with assessment of capacity in youth held several meetings during 2007-2008. Their goal was to prepare a guide to assist health care practitioners in assessing capacity to consent to treatment in youth.

The guide was created in 4 parts (see the appendix). The first part provides a clear, concise, and accessible explanation of the law of capacity to consent to treatment. The second part offers clinical tips for assessing capacity in young people. The third provides important information for practitioners regarding rights advice and application to the CCB. The fourth part of the guide provides information for practitioners to share with parents or guardians who may be confused or distressed by the law and the autonomy it gives their child in medical decision making.

The practical tips for assessing capacity were developed from a literature review⁵⁻¹⁰ and a survey of current assessment tools.¹¹ They were made specific to the assessment and treatment of young patients.¹²⁻¹⁶ For instance, clinicians are advised to express medical information in terms appropriate to the patient's age and level of understanding and to consider family dynamics and relationships with parents as influential in young patients' decisions. The suggested questions are worded in clear and simple language so that patients of any age group can understand and answer them. The questions were designed to gauge several aspects of the young patient's maturity and decision-making ability: comprehending relevant information, foreseeing consequences, and making and communicating a reasoned choice.

The last part of the guide provides information that practitioners can give parents on the basic law of consent and capacity, including their role if named Substitute Decision Maker for their child. It also encourages them to discuss their concerns with the health care team and may thereby protect the relationship between them.

After the guide was developed in draft form, a 3-hour meeting was convened, attended by the psychiatrist and lawyer who worked on it, 2 psychiatrists, 1 pediatrician, and 2 lawyers—all of whom had shown a special interest in and had experience with issues surrounding the assessment of young people's capacity and with the CCB. After some discussion, the group members reached consensus about the content of the guide. They emphasized that it should not be perceived as a rigid instrument or "tool" but rather as a helpful aid to health care practitioners. The final form of the guide was presented, discussed, and evaluated during pediatric and psychiatric grand rounds at 3 centers. Results were highly positive: Of 54 respondents to an assessment form, 51 either agreed or strongly agreed that a guide was needed and 52 that this guide would be helpful in assessing capacity in young people. The following comment was typical: "I think this guide would be helpful for all ages—working through the identified questions would be very helpful in working with elderly as well as adolescents. Thanks!"

Conclusion

By helping health care practitioners evaluate capacity in young people, the guide will enable them to carry out this task with greater effectiveness and confidence and should elicit a favorable response. From a medical perspective, encouraging adolescents to demonstrate reasoning for their treatment decisions can be a therapeutic experience, as can challenging a finding of incapacity by requesting a hearing before the CCB.

This guide was designed to assist practitioners to conduct a simpler, more sharply focused, and more comprehensive assessment of capacity. Documentation of responses to the guide can also provide valuable evidence for the CCB should a hearing be held to review a finding of incapacity. Finally, the guide may reduce conflict and enrich assessment and decision-making experiences for the young person.

Appendix

Guide to Assessing the Capacity to Consent to Treatment of Young People

Part 1: Introduction to the Legal Test. Every person in Ontario is presumed to be capable to consent to medical treatment unless he or she is found to be incapable

(continued)

Appendix (continued)

with respect to a specific treatment or plan of treatment (the *Health Care Consent Act*, section 4(2)).

While capacity does not depend on a person being of a certain age, special considerations apply when one is assessing the capacity of a young person to make a treatment decision.

As with all persons, a young person may be declared *incapable* if a health practitioner is of the opinion that the person

- a. is unable to understand the information necessary to make the treatment decision and/or
- or
- b. is unable to appreciate the reasonably foreseeable consequences of accepting or refusing the treatment in question (the *Health Care Consent Act*, section 4(1)).

A capable decision, while not necessarily a “reasonable” decision, is a reasoned one. The ability to make a reasoned decision develops over time with the ability to evaluate and use information and to employ abstract thinking. Other aspects of the ability to make a reasoned decision are the wish and ability to take responsibility for a decision and the belief that one has some control over one’s life (including decision making). All of these evolve as a person matures.

Incapacity to make a treatment decision should not be confused with:

- a. youth,
- b. refusal of treatment recommendations,
- c. request for alternative treatments,
- d. existence of a disability, or
- e. the existence of a psychiatric or neurological diagnosis.

Part 2: Practical Tips for Assessing the Capacity to Consent to Treatment of a Young Person

A. Provision of Information

You must explain to the young person in detail the condition for which you are proposing treatment and how it affects him or her. Also, you must explain what the proposed treatment is, and its expected benefits and material risks. All this should be carefully documented in the chart, in as much detail as possible.

B. Ability to Understand Relevant Information

Asking certain questions may help you to assess this. It is best to record the answers *verbatim* in your notes, and to ask follow-up questions as necessary. Some suggestions:

1. Do you know why we are proposing treatment for you?
2. Do you understand the treatment we are proposing? Please tell me what you know about it.
3. What do you understand to be the expected benefits of the treatment?
4. Are you aware of any risks of the treatment?
5. Are you aware of any other types of treatment?

C. Ability to Appreciate Reasonably Foreseeable Consequences

As with the first part of the capacity test, asking certain questions may be helpful in assessing this. It is best to record the answers *verbatim* in your notes, and to ask follow-up questions as necessary. Some suggestions:

1. Are you having any problems right now for which you might benefit from treatment?
2. How do you think the proposed treatment will affect you?
3. What will happen if you do not take the treatment?

D. Other Considerations

Capacity assessments often take into account more than just the answers to a series of questions.

Information may be gathered over time, which contributes to the capacity assessment. For example, a young person’s behavior may suggest an inability to appreciate the reasonably foreseeable consequences of a treatment decision. Also, information about a young person’s relationship with his or her parents and its effect on his or her decision-making ability may sometimes be relevant.

Another important consideration in assessing capacity is whether the young person is able to express a consistent choice about the treatment in question.

All information considered in the assessment of capacity should be carefully and completely recorded.

Part 3: Important Information for Health Practitioners Re: Rights Advice and Application to the Consent and Capacity Board (“CCB”)

The health practitioner who is proposing a treatment must presume the person is mentally capable of making a decision about the treatment. If however

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Appendix (continued)

he or she determines that the patient is incapable with respect to the specific treatment proposed, a substitute decision maker is named.

The person found incapable must be told that he or she has a right to have the finding of incapacity reviewed by the CCB.

Where the patient is a patient in a psychiatric facility, that information will be given by a Rights Advisor, pursuant to Regulations made under the *Mental Health Act*.

Application forms and other information concerning the CCB can be found on its Web site at <http://www.ccboard.on.ca> or by calling 416-327-4142 or 1-866-777-7391.

Information for Parent(s) or Guardian(s)

Attached is an information sheet for health care practitioners to use in discussing the question of a young person's capacity to consent to treatment with the young person's parent(s) or guardian(s).

Capacity of a Young Person to Consent to Treatment

Information for Parent(s) or Guardian(s). According to the law of Ontario, there is no minimum age of capacity to consent to treatment.

Everyone is presumed to be capable to consent to treatment, unless found incapable. If your child is capable to consent to treatment, then the decision of whether or not to accept that treatment is his or hers alone.

Your child's health care team will have to assess his or her capacity to consent to treatment. They may wish to talk to you as part of this, to better understand your child's decision-making skills and experience.

Capacity to consent to a treatment means having the ability to understand the information relevant to making a decision about the treatment, and having the ability to appreciate the reasonably foreseeable consequences of the decision.

If your child is found incapable to provide consent, you may be asked to provide consent. This is an important responsibility. The *Health Care Consent Act* (at s.21) sets out the principles you must follow in doing so, and you should review those, or ask your child's health care team to explain them to you. Section 21 of the *Health Care Consent Act* is accessible on line at the following url: http://www.elaws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm#BK26

If your child is found incapable to provide consent, he or she may decide to apply to the *Consent and Capacity Board* for a review of that finding. You may be asked

to provide information at the *Consent and Capacity Board* hearing. Your child's health care team will explain the process to you, and any role that you might have in that process. You may also consult the *Consent and Capacity Board's* Web site at www.ccboard.on.ca or call 416-327-4142 or 1-866-777-7391 for information.

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