

³⁴ *Hutchinson, ibid.*, paras. 22–23; *Hastings, ibid.*, para. 31; *Baici, ibid.*, para. 8.
³⁵ *Hutchinson, ibid.*, para. 26; *Hastings, ibid.*, para. 32; *Papatheodorou, ibid.*, paras. 17 and 20.
³⁶ *Hutchinson, ibid.*, para. 30.
³⁷ *Hastings, ibid.*, para. 33.
³⁸ *The Constitution Act, 1982*, Schedule B to the *Canada Act 1982 (UK)*, 1982, c. 11.

³⁹ *P.S. v. Ontario*, [2014] O.J. No. 6151, 2014 ONCA 900, para. 3.
⁴⁰ *Ibid.*, para. 202.
⁴¹ *Supra* note 24, para. 8.
⁴² *HCCA*, *supra* note 3, s. 1.
⁴³ *Ibid.*

The Capacity to Consent to Treatment in Youth: A Retrospective Lens

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Evaluating a youth patient’s capacity to consent to treatment often proves challenging for health care practitioners. Over the years, and in the course of my work as a child psychiatrist in hospitals, I have often been asked to help practitioners understand and assess this capacity of their young patients. In addition, as a psychiatrist member of the Consent and Capacity Board of Ontario (“CCB”), I have had the opportunity to observe the issues that have arisen for youth, their families, and the health care team in providing treatment in the context of the *Health Care Consent Act, 1996* [*HCCA*].¹

The *HCCA* presumes that anyone of any age has the capacity to consent to treatment.² According to the *HCCA*, “capacity” is the ability to

- understand the information that is relevant to making a decision about treatment; and
- appreciate the reasonably foreseeable consequences of a decision or lack of decision.³

In addition, the *HCCA* prescribes a comprehensive process for navigating issues of capacity. Some practitioners assume there is a magic age for capacity before which it is assumed that a young patient is not “mature” enough to consent to treatment. However, maturity and capacity are not synonymous terms. Because adolescents reach social,

emotional, and cognitive maturity at different rates, chronological age does not necessarily indicate maturity or capacity. It *may* be the case that a mature youth is also a capable youth but that is not always a given.

In 2010, I co-authored a paper aimed at establishing guidelines to assist practitioners in the clinical assessment of capacity to consent to treatment.⁴ Unlike that paper, this article will focus on my own perspective on some of the key issues relating to capacity as well as issues that medical and related practitioners continue to face in this aspect of clinical work. These are my personal views on what has worked well and what has brought fresh challenges.

Supporting Autonomy in Young Patients

Over the years, one of the key themes for me has been how the *HCCA* and its processes can foster autonomy in youth patients, and how, as I will illustrate in the first of the vignettes that follow, the exercise of that autonomy can impact clinical outcomes.

By presuming capacity, the intention of the *HCCA* was to entrust the capable person, including the capable adolescent, with the legal right to make decisions about his or her treatment. It was believed that a capable adolescent who consented to treatment

would be asserting their autonomy and this would positively impact clinical outcomes.

Said differently, since youth patients are presumed capable of making treatment decisions (according to the *HCCA* and unless incapacity is otherwise demonstrated), undertaking thorough capacity assessments becomes even more important, tied as they may be to autonomy and improved clinical outcomes. Supporting autonomy in a capable youth who needs treatment can be empowering and contribute to a positive outcome by giving him or her a voice in his or her clinical care. The relationship between health care provider and patient is now much more collaborative. It has moved away from the paternalistic, somewhat protective model, to one that fosters the patient's autonomy. In recent years, self-management principles have been applied to the care of patients with chronic medical illness. They emphasize the need for patients of all ages to become more involved in managing their care, including deciding on their treatment. The importance of this involvement cannot be overemphasized: it improves patient knowledge and reduces the passivity and helplessness often associated with chronic medical illness. The more the patient is involved with his or her care, the more ownership he or she will take in health care decisions in both medical and mental health conditions. This ownership frequently translates into closer adherence to treatment recommendations and eventually to better outcomes in medical and mental health conditions.

Factors Contributing to the Complexity of Decision Making in Youth

Part of why many health practitioners continue to struggle with capacity assessments is because in order to assess capacity, they must evaluate the decision-making ability of their youth patient. They may also struggle with the notion that a young patient who can make reasoned decisions (*i.e.*, meet the test under the *HCCA*) is capable of consenting

to receive or refuse treatment *even if that decision may seem unreasonable to the practitioner or to the patient's parents.*

The fact that decision-making in youth is influenced by a number of factors also compounds the difficulty that a practitioner may face when trying to assess capacity. Does the patient really understand the information that is relevant to making a decision about the treatment? Does he or she appreciate the reasonably foreseeable consequences of a decision or lack of decision? Research has shown that a young person's ability to reason is influenced by cognitive, social, and emotional factors including treatment context, seriousness of the illness, impact of the personal dependency, effect of chronic pain, relationships, value systems, and cultural and religious background.⁵

In addition, it is important to note that

- Fear and anxiety affect decision-making for anyone facing a serious illness and treatment decisions.
- The diagnosis of a psychiatric disorder is not sufficient to determine incapacity. The health care practitioner must show how the illness specifically challenges decision-making. For example, a severely depressed patient with cognitive slowing may not be able to process the information necessary to make a treatment decision *if* an aspect of the depression (such as cognitive slowing) can be shown to make the patient incapable with respect to understanding the information necessary to make a treatment decision.
- Voluntary decision-making is emphasized in consent to treatment. However, we have learned that, in adolescence, decision-making is often influenced by parents or peers and is part of normal development and not necessarily a sign of undue influence.

- Young people may approach clinical decision-making with a sense of invulnerability associated with their age.
- Scientists are beginning to explore the biological immaturity of the adolescent brain.⁶
- Parents are very important during the Assessment of Capacity to Consent to Treatment for their child. They should be considered therapeutic allies, able to provide information and support in assessing capacity in their child. This is especially true when they disagree with the decision made by an adolescent. Conflict should be minimized.⁷

Clinical Vignettes Reflecting Some of my Observations

The following vignettes are illustrative of two of my key insights over my many years of work. The first is that sometimes a finding of incapacity by a practitioner is grounded more in a patient's feeling of powerlessness and being voiceless in his or her own care than an inability to understand information and appreciate the consequence of a treatment decision. The second insight relates to the importance of honouring the decision of a capable youth patient and keeping the family as therapeutic allies, even when their capable child makes a treatment decision with which they disagree.

Supporting Autonomy in Youth Who Are Ill and Require Treatment

Example 1

Several years ago, a 13-year-old girl, an only child, was admitted to hospital several times for a severe and unusual gastrointestinal condition. She had required an ileostomy, had persistent and severe perianal disease, and suffered chronic pain. Her parents were divorced and every encounter was marked by intense conflict. She lived with her mom but saw her dad frequently. At home, she seldom left the

house and did not attend school. She was in hospital for months at a time where she underwent a number of medical procedures, some successful, others not.

During her most recent admission she was offered treatment such as sitz baths, medications, and general medical care. She angrily refused this treatment and was hostile to the health care team. It was difficult to enter her room because it was kept dark and because of her poor hygiene and consequent odour.

Concern was expressed that the patient might not be capable of consenting to the treatment proposed to address her condition. Her gastroenterologist evaluated her as being incapable, finding her uncommunicative, severely depressed and angry, and unable to rationally weigh the risks and benefits of her treatment or consider alternatives. A second opinion from the psychiatrist concurred with the original capacity finding.

The girl then applied to the CCB for a review of the finding. During the period leading up to the hearing, the patient became interested in the hearing and the voice it would give her. She became more verbal, asked questions, co-operated with the lawyer who represented her, and began to take better care of her medical condition. She seemed empowered and motivated by the process of going to the CCB. At the first hearing, she was much more articulate, reasonable, and well-groomed. The CCB judged her capable. After this experience, the patient showed greater interest in her care and became more involved with her treatment, especially when delivered by a nurse with whom she had developed a trusting relationship. This example demonstrates the positive impact of giving the adolescent a voice. Her doctors and nurses spoke to her carefully and listened attentively in order to complete the capacity assessment. The impact on the autonomy of this young girl had not been anticipated and was a welcome outcome of the process. Young people want to have a voice in their treatment.⁸

Example 2

In the second example, a young man makes a reasoned decision and is deemed capable. His parents disagree with this judgment, along with the health care team, and conflict results.

The patient, a 16-year-old boy with chronic liver disease and two failed liver transplants, refused a third transplant. This adolescent male, who came from a culture that deeply distrusted Western medicine, was offered a third transplant and refused to accept it. He understood the condition from which he suffered and the treatment he was offered. He said that based on the information he had heard and read, his chances of survival were poor and he did not want to suffer the pain of undergoing the transplant. His parents were upset. They felt their son's decision was unreasonable since there was a chance of survival. They believed we should not have evaluated him as being capable to consent to treatment.

However, we found the young man capable of refusing the treatment because he understood enough to make an informed decision and appreciated the consequences of refusing. In view of his family background, we faced the challenge of respecting the young man's right to refuse treatment while supporting his relationship with his parents. One of the concerns of the drafters of the *HCCA* was that, in circumstances such as this, it might have the unintended effect of alienating youth from their parents, especially if the parents disagreed on a treatment direction made by the youth. Entrusting young people with their rights, while protecting the parent-child relationship is of paramount importance.

Applying the *HCCA* can at times feel as though we are isolating the youth from parents. The youth's decision needs to be voluntary, and he or she should not be subject to undue influence. But the question arises: what does a truly voluntary decision mean in practice? Most normal adolescents are heavily influenced when making decisions

– by both parents and peers – as they begin to develop their own identity and move toward independence. While the assessment of capacity should be free from influence, an adolescent from a close and supportive family will likely listen to the opinions of family members and then use the information to make their own decision. We cannot forget parents when we assess capacity in their adolescent children. They have a vital role to play: they can provide a history of factors that would be taken into account during the assessment and help their child make an informed decision if capable to do so.

In this case, the parents were distrustful of and angry with the health care team. They needed support to understand the *HCCA* and why it was important to allow their son to make his own decisions. The social worker spent a great deal of time working with the parents. The result was that the capable young man refused the transplant but did not forfeit his family's support. When he passed away, it was in the bosom and comfort of his family.

Refusing Treatment: Why Do Some Young People Turn Down Care?

Psychiatrists are most commonly asked to carry out a capacity assessment when a patient is refusing treatment. It is important for practitioners to understand what might actually be driving a youth's refusal to consent to treatment. Refusing to consent to treatment could be

- an expression of a capable youth who both understands the illness and treatment and has decided, using a reasoned approach, that he or she does not want the treatment;
- an expression of an overwhelming anxiety that takes the form of “shutting down” and translates to, “No, I am afraid I can't do that or I am afraid I can't cope with the pain”; or
- associated with a psychiatric process such as clinical depression that can bring on

thoughts such as the following: “I refuse that treatment, I don’t deserve it, everything is hopeless, I am worthless, I am bad, no one really cares for me.” Or, alternatively, a disorder such as oppositional defiant disorder or conduct disorder where “no” means “I refuse to accept your authority”.

In addition, young people who are overprotected may want to express their autonomy: “I want to express my independence by refusing the treatment. In every other way I am so dependent.” Or, some young people feel so invulnerable that they feel able to take all kinds of risks because of their youthful power and immaturity. They refuse treatment because, in their minds, they will never suffer negative consequences: “I am a big risk-taker and I will take this risk and refuse treatment”.

Ideally, when treatment is refused, *i.e.*, the patient says “no”, the practitioner feels confident that the refusal is a demonstration of capacity as was in the case of the young man who refused a third liver transplant. He went through a *reasoned* process, considering the information available and understanding the risks, benefits, and alternatives of the proposed treatment. The opinion we formed after gathering information from his parents and other sources was that he was not impulsive and generally made reasoned decisions. In this situation, “No, I refuse” were the words of a capable adolescent saying he has considered the issues, understood the information, and appreciated the foreseeable consequences of the decision. He was capable as defined by the *HCCA* and could refuse treatment. Although others may have seen his decision as unreasonable, it was ultimately respected.

When Consenting to Treatment Is Not Necessarily a Sign of Capacity

Practitioners should be aware that acceptance of treatment is not in and of itself evidence of a youth patient’s capacity to consent to treatment. Patients

who are overly compliant and consent to treatment without understanding either the condition they suffer or its treatment may be, in fact, incapable. For example, I once saw a 14-year-old patient with a copper metabolism disease that affected her brain functioning and manifested as mania in mood, thought, and behaviour. She was later diagnosed with Wilson's disease. In her manic state, her euphoria impeded her judgment and she happily accepted all treatment. However, the clinician felt she was *too* compliant and suggested a capacity assessment be done. Ultimately, the patient was found incapable and a substitute decision-maker was named. In this particular case, consenting to treatment was not a sign of capacity but rather a red flag for the practitioner to inquire more deeply.

New Research Regarding Cognition in Young Adolescents

New research in psychiatry and neurobiology suggests that, during adolescence the areas of the brain responsible for decision-making and executive control are not yet fully mature.⁹ These include specific regions associated with motivation and impulsivity, both of which are associated with decision-making. During maturation, the rate of change in the adolescent brain varies from one area to another. These research findings lead us to ask the question: Are we asking adolescents to make important treatment decisions when their brains are not ready to do so?

Are these kids neurologically ready for the *HCCA*? This question is especially compellingly when faced with a 13-year-old patient with anorexia nervosa whose brain is starved for example. What is the neurological impact of starvation on thinking and emotions? Indeed, her starvation may affect her ability to make decisions. Since cases such as this are far from uncommon, we need a better understanding of them from a neurological point of view.

Concluding Thoughts

The *HCCA* gives capable young people a voice in their medical care. Prior to its coming into force in 1996, there was an assumption that adolescents were generally not capable of consenting to treatment because of their age. At that time, there was also the concern that the presumption of capacity would cause conflict between youth and their parents, or between the health care team and the families. However, in my experience, the *HCCA*'s capacity process has helped the health care team give careful thought as to how best to involve young people in their care. The *HCCA* and its processes have not only had a positive impact on medical outcomes but have supported and advocated for young people at a vulnerable time in their lives.

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¹ S.O. 1996, c. 2, Schedule A.

² *Ibid.*, s. 4(2).

³ *Ibid.*, s 4(1).

⁴ R. Geist and S. Opler, "Practitioners in the Assessment of Young People's Capacity to Consent to Treatment", *Clinical Pediatrics* 49, no. 9 (2010): 834–839.

⁵ T. L. Kuther, "Medical Decision-Making and Minors: Issues of Consent and Assent", *Adolescence* 38 (2003): 343–358.

⁶ C. A. Nelson and M. Lucina, *Handbook of Developmental Cognitive Neuroscience*, 2nd ed. (Cambridge, MA: MIT Press, 2008).

⁷ R. Geist and S. E. Opler, "A Guide for Health Care Practitioners in the Assessment of Young People's Capacity to Consent to Treatment", *Clinical Pediatrics* 49, no. 9 (2010): 834–839.

⁸ M. Britto *et al.*, "Do Adolescents with Chronic Illness Want to Make Decision about Their Treatment", *J. Adolesc. Health* 34 (2004): 20.

⁹ *Supra* note 6.

Provisions for Long-Term Involuntary Hospitalization for Mental Illness Is Unconstitutional: *P.S. v. Ontario*

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In a major decision, a five-member panel of the Ontario Court of Appeal has declared that the involuntary institutionalization of persons with mental illnesses for periods longer than six months under the *Mental Health Act* [*MHA*]¹ is contrary to s. 7 of the *Canadian Charter of Rights and Freedoms* (the "Charter").² Leaving the decisions about the liberty, treatment, and rehabilitation of such individuals to the discretion of treating practitioners and institutions, with the independent review restricted to whether the individuals were a danger to themselves or others, was a denial of fundamental justice. Procedural protections must include the authority for an independent body to "make orders regarding security, privileges, therapy

and treatment, or access to and discharge into the community".³

The facts in *P.S. v. Ontario* undoubtedly had a major impact on the result.

The appellant had a very difficult childhood. He was the victim of physical and sexual abuse at the hands of close relatives. He was placed in a succession of foster homes beginning at age three.⁴

He became deaf shortly after he was born.

The appellant was convicted of several sexual offences involving children in the 1980s. In 1992, he was sentenced to 45 months in prison for sexually assaulting a 12-year-old boy in the washroom of a Y.M.C.A. The appellant received no therapy or counselling during his prison term.⁵

The appellant's involuntary committal [under the *Mental Health Act*] began in 1996 on the day he was to be released