Pharmaceutical care and access to health information decisions involving minors: Characterizing the pharmacist's obligation to the patient

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Introduction

Should a pharmacist seek parental consent or involvement prior to providing care to minors? Are pharmacists obligated to provide parents with access to their minor children's protected health information?

We have encountered a great deal of confusion regarding the answers to these questions in classroom teaching and clinical practice. In this article, we aim to provide some clarity through a discussion of Canadian legal rules and applicable pharmacy practice guidelines governing medical decision-making and health information access requests involving minors. The discussion will also address the nature and scope of a pharmacist's obligation to parents seeking involvement in health care decisions affecting minors or access to a minor child's protected health information.

Minors and medical decision-making

In Canada, the responsibility for defining the age that demarcates childhood, or minority, from adulthood, or majority, lies with the provinces. All provinces have enacted laws that set the age of majority at 18 or 19 years. The age of majority is generally applied in determining a person's ability to legally engage in certain activities or relations regulated by law, such as the purchase of alcohol and voting in elections. However, legal relations involving minors do not always depend on age considerations alone or at all.

The role that age considerations play in the context of medical decision-making involving minors is the subject of a complex legal regime

that includes variant provincial statutes¹⁻⁶ and court rulings. Applicable statutes generally do not stipulate a specific age at which a person attains the legal right to make medical decisions (see Table 1 for a summary of the relevant rules). Rather, the dominant approach used to determine whether a person can make his or her own medical decisions is based on the legal concept of "capacity,"¹ although some exceptions do exist. In Quebec, persons 14 years or older may consent alone to medically necessary care⁶; in New Brunswick, persons 16 years or older are treated the same as adults with respect to consenting to medical treatment⁵; and in Manitoba, a minor 16 years or older is presumed capable of making medical decisions unless evidence to the contrary exists.³ However, these exceptions simply extend the same "presumption of capacity that applies to adults"¹ to minors, as a determination regarding capacity must still be made by the health care provider prior to providing treatment or care to any patient, regardless of the patient's age.

Capacity, in legal terms, refers generally to a person's ability to understand information relevant to making decisions about medical care and to appreciate the consequences of making or not making those decisions. Applicable legal rules provide little or no guidance on what factors or elements one ought to consider in making capacity determinations, but leave the matter to the discretion of the health care provider. Thus, a health care provider may consider a variety of factors, including age and the outcome of consultations with the minor. While age may be the sole or principal consideration in the case of

We often get questions from students and health professionals about whether parents are legally permitted to access their minor children's health information or make health care decisions on their behalf. We wrote this article to respond to the matter.

Les étudiants et les professionnels de la santé nous demandent souvent si les parents ont le droit, aux termes de la loi, d'accéder aux renseignements médicaux de leurs enfants mineurs ou de prendre des décisions quant aux soins à recevoir au nom de l'enfant. Cet article répond à cette question.

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DOI: 10.1177/1715163513481316

KNOWLEDGE INTO PRACTICE

- Age is mostly a number when it comes to health care and access to health information decisions involving minors. A capable minor can make his or her own health-related decisions.
- Parents do not have an automatic right of access to their children's health information. Provincial laws generally allow pharmacists the discretion to disclose or refuse to disclose a child's health information to parents.
- Pharmacists should consult with and obtain consent from capable minors prior to disclosing their information to others.
- If a capable minor does not object, pharmacists may also seek parental involvement in care decisions involving minors, as this accords with good clinical practice.

young minors, such as infants and toddlers, other considerations, such as level of maturity and expressions of independent thought, are likely to matter in the case of adolescents. Other attributes, such as mental health problems and disabilities, may complicate capacity determinations; mentally incompetent persons, regardless of age, are less likely than the competent to be judged capable of making their own medical decisions. However, disability (and, for that matter, the mere presence of mental health issues) ought not to attract differential treatment unless it has a direct bearing on the minor's ability to understand and appreciate the consequences of a particular medical decision.

Courts in Canada and elsewhere have developed legal doctrines to guide capacity determinations involving minors, including the "emancipation" and "mature minor" principles. Emancipation applies when a minor is no longer dependent on his or her parents or legal caregivers, such as when he or she moves out of the parent's house, finds work or assumes primary responsibility over his or her own needs.^{1,7} The mature minor principle, much like statutory definitions of capacity, is used to assess whether a minor is mature enough to "understand and appreciate the consequences of a proposed medical procedure."^{1,7,8} Age considerations may be relevant to this assessment but are not determinative. The mature minor principle is routinely applied to capacity determinations in provinces such as Alberta, where there are no specific statutory provisions dealing with minor medical decision-making capacity.⁸ By contrast, Ontario legislation specifically defines capacity

and relies on the concept as a basis for all medical decision-making.²

Professional practice standards may also provide useful guidance in making capacity determinations. The Alberta College of Pharmacists' *Standards of Practice for Pharmacists and Pharmacy Technicians*, for instance, enjoins pharmacists to consider age, among other factors, in deciding whether to deal with a patient directly or through an agent.⁹ If the pharmacist chooses the latter, he or she must determine whether dealing with the agent is in the patient's best interests. This determination may be based on factors such as the express wishes of the patient, the patient's condition, age and mental state and the patient's availability.⁹ Implementation of these factors will likely vary with practice contexts; pharmacists who work in community settings (compared with pharmacists working as part of a clinical care team) may be more inclined to prioritize age in facilitating primary care outcomes (such as filling a prescription or providing advice).

Where it is determined that a minor is incapable of making a health care decision, then the responsibility falls to a substitute decision-maker, typically the parents or legal guardians.¹ Provincial statutes also authorize persons appointed under a power of attorney, close relatives, child welfare authorities or the courts to act as substitute decision-makers in specified circumstances. Under Manitoba law, for example, a court may authorize medical examination or treatment of a minor apprehended as "a child in need of protection" if doing so is in the best interests of the child, but only if the child is younger than 16 years.¹⁰ If 16 years or older, the child's consent is required before the court order can be made, except where the child lacks legal capacity to provide consent. In Ontario, the list of persons who can provide or refuse consent to treatment on behalf of a decisionally incapable person includes legal guardians, persons appointed under an attorney for personal care, a spouse or partner, a sibling or other relative or a legal representative appointed by the Consent and Capacity Board.² In all cases, substitute decision-makers must act in the best interests of the minor and not in their own interests.

Minors can bring and have brought court challenges against decisions made on their behalf by others, usually on grounds that the substitute decision-maker acted in excess of statutory authority or that the statute authorizing a substitute

TABLE 1 Legislated minimum age for medical decision-making, by province

Province	Minimum age
British Columbia	Not specified by statute. However, a minor can consent to health care if deemed capable to do so and if care is in minor's best interests.
Manitoba	Minors 16 years or older presumed capable unless the contrary is shown.
Quebec	Not specified by statute. However, a minor aged 14 years or older may consent alone to medically necessary care.
New Brunswick	Not specified by statute. However, persons aged 16 years or older are treated as adults for the purpose of consenting to treatment.
Alberta, Saskatchewan, Ontario, Nova Scotia, Prince Edward Island	Not specified by statute. Approach generally based on common law or statute-based determinations of capacity.

decision violates human rights guaranteed by the Canadian Charter of Rights and Freedoms. In *A.C. v Manitoba (Director of Child and Family Services)* (2009), for example, a 14-year-old Jehovah's Witness with complications from Crohn's disease unsuccessfully challenged a treatment order that required her to receive potentially life-saving blood transfusions without her consent.¹¹ The principal issue in the case was whether applicable Manitoba laws, which in such circumstances authorize courts to order medical treatment if it is in the best interests of a minor younger than 16 years, unjustifiably interfered with the minor's constitutionally guaranteed rights and freedoms.

Courts in several provinces have ruled on a variety of issues that arise in relation to medical decisions involving minors, including questions regarding 1) state or government involvement in treatment decisions made by decisionally capable minors, 2) the limits of parental "discretion to depart from medical recommendations"¹ when making medical decisions on behalf of decisionally incapable minors and 3) whether decisionally capable minors can request or refuse treatment without parental involvement.

There is some judicial consensus on the answer to the first issue; in *Walker (Litigation Guardian of) v Region 2 Hospital Corporation* (1994), the New Brunswick Court of Appeal ruled that a court cannot vary or overrule a mature minor's decision regarding consent to medical treatment. A Saskatchewan court reached a similar conclusion in *Re Dueck* (1999) but found that

the minor in the case, a 13-year-old with cancer whose decision to refuse treatment was influenced by his authoritative father and the belief that God had healed him, lacked capacity. However, the Alberta Court of Appeal took a slightly different turn in *U(C)(Friend of) v McGonigle* (2003), concluding that "while a court may be unable to exercise its *parens patriae* ["parent of the nation"] jurisdiction with respect to a mature minor," the provincial legislature may exercise its general jurisdiction to enact laws that vary or oust a mature minor's decision to refuse potentially life-saving treatment. The latter decision has been criticized for allowing legislative interference with the civil rights of mature minors, and some believe any legislation that purports to do so will not survive constitutional scrutiny.¹¹

The courts have also upheld mature minors' decisions to refuse treatment without state interference where the decision is motivated by nonmedical reasons, such as personal or parental religious beliefs (as is common in cases where Jehovah's Witnesses refuse blood transfusions). This rule may not apply to decisionally incapable minors; very recently in *Alberta (Child, Youth, and Family Enhancement Act, Director) v D.L.* (2012), a case involving a toddler in a persistent coma as a result of allegedly being starved and assaulted by her parents, Justice Ross of the Alberta Court of Queen's Bench ruled that the parents' refusal to consent to withdrawal of life support due to religious beliefs should be ignored because the child was "too young to have ever

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- L'âge n'est qu'un chiffre lorsqu'il est question de décisions quant aux soins à recevoir et à l'accès aux renseignements médicaux concernant un mineur. Un mineur apte est tout à fait capable de prendre ses propres décisions en matière de santé.
- Les parents n'ont pas automatiquement le droit de consulter les renseignements médicaux de leurs enfants. Les pharmaciens peuvent légalement communiquer ces renseignements aux parents ou refuser de le faire.
- Les pharmaciens devraient consulter les mineurs aptes et obtenir leur consentement avant de divulguer des renseignements à un tiers.
- Si un mineur apte ne s'y oppose pas, les pharmaciens peuvent encourager les parents à participer aux décisions en matière de santé concernant le mineur, puisque cela cadre avec les bonnes pratiques cliniques.

made her own individual religious commitment" and her parents' beliefs were "contrary to [her] best interests in a fundamental way."¹²

On parental disagreement with the medical team's recommendations, Canadian courts have consistently held that the state can intervene in medical decisions to protect and preserve a minor's best interests contrary to the wishes or consent of the parents. In assessing what is in a minor's best interests, courts tend to give more weight to the recommendations of the medical team caring for the minor and to alternatives that protect, promote or preserve the minor's life, health or well-being. Other considerations include the wishes and beliefs of the patient, if known, and what is just and fair in the circumstances of each case. The courts have rejected parental wishes that are contrary to a child's best interests; in the Alberta case discussed above, Justice Ross held that the parents' decision to keep their daughter on life support was more likely motivated by the desire to avoid murder charges if the child died rather than by the child's best interests.

On whether capable minors can request or refuse health care without parental involvement, judicial opinion is generally favourable. In *C(JS) v Wren* (1987), for example, an Alberta court upheld a decisionally capable minor's request to seek an abortion against her parent's wishes. However, Quebec, British Columbia and New Brunswick statutes contain provisions that require either parental consent or a health care provider's approval if a decisionally capable

minor is seeking treatment that is not medically required, poses serious health risks, may cause grave or permanent effects or is determined not to be in the minor's best interests.⁴⁻⁶ The latter rule reflects some discomfort with allowing persons who have not reached the age of majority to make medical decisions that may be detrimental to their welfare, but is difficult to reconcile with legal rules governing autonomous decision-making in the medical context.

To sum up, existing legal rules and professional practice standards generally support allowing minors who have gained capacity for independent decision-making to make their own medical decisions. These rules also allow for parental involvement and/or health care provider intervention, especially in situations where the treatment sought is not medically required or likely to cause serious harm to the minor. While the application of these rules will vary by province and depend on the care situation, we recommend that pharmacists seek parental involvement when providing routine care to minors. This accords with good clinical practice and ensures that those primarily responsible for the minor's welfare are not left out of the clinical or care encounter. For the same reason, parental involvement should not be ruled out in challenging cases, such as where a decisionally capable minor seeks a consult on potentially harmful or controversial over-the-counter medication (e.g., Plan B, "wake-up" pills, nutritional supplements or herbal products). In such situations, pharmacists should strive to balance the wishes of the minor (i.e., where applicable legal rules permit some flexibility) with considerations such as the complexity and potential effects of the treatment sought, previous encounters with the minor and his or her parents, as well as promoting and protecting the minor's best interests. The expanding scope of pharmacy practice, which includes enhanced prescribing and immunizing duties, may necessitate the involvement of more parties in the medical decision-making of minors, such as in the case of mandatory consultations with colleagues and/or the minor's family physician or primary care team.

Minors and access to health information

British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick and Newfoundland and Labrador have enacted legislation to deal specifically with the collection,

BOX 1 Points to consider before releasing a minor's medical information to parents

The parents of a 13-year-old girl have requested their daughter's medication information from you. They suspect she may be sexually active and are wondering if she has filled any prescriptions for oral contraceptives. They also want you to notify them prior to providing any pharmaceutical care to their child.

RELEVANT CONSIDERATIONS:

- The parents do not have an automatic right of access to the requested information. There is also no *unqualified* legal basis for making such a request.
- The pharmacist is not legally or ethically obligated to provide the precare notification unless satisfied that a) the minor involved is incapable of making her own medical decisions, and/or b) that such a request is in the minor's best interests, and/or c) that the parents are acting as the minor's legal representatives or substitute decision-makers.
- Under most provincial legislation, the decision to disclose the requested information is left entirely to the pharmacist's discretion. However, such disclosure is not permitted where the purpose is merely to satisfy the parent's curiosity.
- The pharmacist may disclose without the minor's consent if the information is needed to provide continuing treatment or care to the minor or prevent or minimize harm to others. However, this seems unlikely in the present scenario. If the disclosure request pertains to continuing treatment or care, the pharmacist should consider whether disclosure is warranted in light of the sensitive nature of the information sought, the minor's age and previous experiences with the minor and/or parents. Any disclosure should be documented.
- If the minor is present when the request is made, the pharmacist should determine whether she is capable of consenting to the disclosure. If yes, then her consent should be obtained prior to disclosure.

use and disclosure of personal health information held by health care providers and organizations. In the remaining provinces and territories, the collection, use and disclosure of health information are governed primarily by privacy and access to information statutes. The federal Personal Information Protection and Electronic Documents Act, which applies nationwide to all organizations engaged in commercial activities, also regulates aspects of the subject.¹³ Most of these statutes contain substantially similar provisions on the obligations of health care providers when disclosing their clients' health information. For ease of analysis, our discussion will focus only on Alberta's Health Information Act (HIA),¹⁴ but we will highlight distinctive provisions from other jurisdictions, where relevant.

Similar to the rules governing medical decision-making discussed above, privacy and health information statutes rely generally on the concept of capacity (defined similarly) as the basis for assessing whether a person can make decisions regarding collection, use and disclosure of personal

health information. Minors who demonstrate capacity can generally control access to their personal health information, including giving, withholding or revoking consent to collection, use and disclosure of the information. Under the HIA, a person younger than 18 years can exercise any of the rights or powers conferred by the statute if it is determined that the person is able to understand the nature of the right or power and the consequences of exercising the same. In Ontario, access decisions made by a "capable" minor will prevail over conflicting decisions made on the minor's behalf by certain substitute decision-makers, including parents.¹⁵

The responsibility for making capacity determinations falls on health information custodians (i.e., persons or institutions that have custody and control of protected health information, such as pharmacies, pharmacists and hospitals). Where a custodian makes a determination that a minor lacks capacity, the HIA allows parents to act as that minor's legal representative. Parents acting as such can exercise the rights or powers

TABLE 2 Professional guidelines governing release of minors' health information to third parties

Organization	Guidelines
Alberta College of Pharmacists	No specific guidelines. However, pharmacists have an ethical obligation to: respect each patient's right of confidentiality, protect each patient's privacy during a consultation, inform each patient of how his or her information will be used or disclosed, and disclose information only with patient's consent, unless otherwise authorized by law.
Saskatchewan College of Pharmacists	Pharmacies must develop consistent guidelines for and exercise caution when releasing minors' health information to parents or guardians. Factors to consider in assessing whether a release of information amounts to an unreasonable invasion of the minor's privacy include nature of the prescription involved, age/maturity, previous experience with minor and legal guardian, and the minor's express wishes.
National Association of Pharmacy Regulatory Authorities: Model standards of practice for Canadian pharmacists	The pharmacist should provide privacy "for patients who desire and/or require it."

in the act on behalf of the incapable minor and to the full extent allowed to capable persons. Minors with capacity can also designate their parents as legal representatives, either by granting them a power of attorney or by simply executing a written authorization to that effect.

The HIA requires persons seeking access to health information held by a custodian to submit an access request to the custodian. An access request can only be made by or with the consent of the person to whom the information relates, or by that person's legal representative. The act specifically mandates the custodian to refuse disclosure if information is requested about an individual by anyone other than that individual (or his or her legal representative). It follows therefore that parents do not have an automatic right of access or to request access to their minor child's health information unless they are acting as the minor's legal representative (see Box 1 for an example illustrating the application of the foregoing principles).

Parents acting as legal representatives could be denied access to their minor child's health information in certain situations. Under the HIA, custodians are granted discretion in specified circumstances and mandated in others to refuse disclosure. Discretionary circumstances include

situations when the disclosure would cause "immediate and grave" harm to the minor's "mental or physical health and safety," pose a threat to another individual's health or safety and/or to public safety, lead to a breach of confidentiality, compromise government operations or prejudice the "use or results of particular audits, diagnostic tests and assessments."¹³ Mandated refusals include situations where the applicant is seeking information that belongs to another person (without legal authorization), where the information sought relates to procedures or results of an investigation, disciplinary proceedings, practice reviews or inspections relating to a health service provider, or where the information sought is a sealed record of government deliberations. Where a custodian refuses an access request, the applicant may ask the Privacy Commissioner to review the decision. Under Saskatchewan law, custodians must refuse disclosure if it amounts to an unreasonable invasion of the minor's privacy.¹⁶

Parents who are unable to bring an access request under the HIA may still be able to gain access to some of their "legally capable" minor child's personal health information. This is possible under rules that authorize custodians to disclose "individually identifying diagnostic, treatment or care information"

for specified purposes without the consent of the person to whom the information belongs. Legally authorized purposes include providing continuing treatment and care to the minor and averting or minimizing imminent danger to the health and safety of another. However, even if a legally authorized purpose exists, custodians can still refuse disclosure. The reason for this is that the HIA allows custodians unqualified discretion to permit or refuse disclosure without reason. Unlike access request denials, the HIA does not provide any recourse for a refusal to disclose in these circumstances.

Some professional colleges have issued guidance dealing with the release of minors' confidential records to third parties, including parents. A notable example comes from the Saskatchewan College of Pharmacists, which requires pharmacies to develop consistent practices for handling privacy issues concerning minors and to exercise caution when considering the release of personal health information to a person representing himself or herself as a minor's legal custodian¹⁷ (see Table 2 for a summary of other practice guidelines). The Saskatchewan guidelines also provide a nonexhaustive list of factors to consider when dealing with third-party requests for access to a minor's health information, including the nature of the prescription in question (sensitive prescriptions necessitate more caution), the minor's age or level of maturity (expectations of privacy increase with advancement in age or maturity level), the pharmacist's past experience with the legal custodian and minor (e.g., the presence of both parties at previous meetings with the pharmacist) and the express/recorded wishes of the minor. These guidelines reflect the understanding that pharmacists have legal and ethical obligations to protect the confidentiality of all information released to them regardless of the age of the person to whom such information relates.

Canadian case law also provides some guidance on access decisions involving minors. In *McInerney v McDonald* (1992), the Supreme Court of Canada held that physicians are bound by a legal duty to hold their patients' health information in confidence and to provide

patients with access to that information upon request because health information is "highly private and personal to the individual" and "in a fundamental sense one's own, for an individual to communicate or retain as he or she sees fit."¹⁸ This ruling applies to decisionally capable minors and will preclude disclosure without consent (except to the extent allowed by statute).¹ Parents are generally entitled to access for the sake of making medical decisions on behalf of their decisionally incapable minors, subject to the statutory limitations discussed above. The same applies to noncustodial parents (i.e., parents who have lost custody of a child through divorce or separation), provided the access privilege has not been varied by agreement, a court order or legislation.^{1,19}

Conclusion

Applicable legal rules and pharmacy practice standards permit minors who meet certain legal requirements to control their own health care and access to health information decisions. As a result, parental consent or involvement is not automatically required but depends on and varies according to the degree of control allowed to minors under applicable rules. Pharmacists facing questions posed in this policy review should first assess the minor's capacity to make his or her own care and access decisions prior to involving third parties, including parents. However, pharmacists should also seek parental involvement whenever circumstances permit, especially if the minor does not object to this course of action. Where the minor objects, it is acceptable clinical practice to discuss the matter with him or her, but care must be taken not to inappropriately influence the decision. Where a decision is made to deal with third parties, pharmacists must ensure that they are acting under legal authority and in the minor's best interests and comply with legal and ethical rules that govern substitute decision-making and/or disclosure of personal health information. Changes in current pharmacy practice will likely necessitate additional measures, such as mandatory consultation with colleagues and/or the minor's family physician or primary care team.■

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Acknowledgments: We are grateful to Sarah Burningham and an anonymous peer reviewer for comments on drafts of the paper. All errors are ours.

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