

Making Life & Death Decisions for Children

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Later Life Learning
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Themes

- Medical Treatment cases for children raise complex & challenging practical, conceptual, ethical issues
 - Courts are not the best forum for making individualized decision, often in the face of medical uncertainty and in situations where prognosis may be uncertain and changing, but this forum of last resort
 - Some cases may reflect inadequate trust between parents and MDs
 - Difficult for parents, doctors, children, judges and legal scholars
 - Individualized decisions or clear rules?
- Who should decide & how? Who should “have a say”?
 - Parents or guardians
 - Doctors
 - Children’s Aid Society
 - Child
 - Does age and nature of decision matter?
 - Autonomy vs Right to Protection (UN CRC)
 - Role of advocates for children
 - Limited Recognition of Constitutional rights of child (*Manitoba v AC*)
 - Court

Sources of Law for these decisions

- Legislation
 - child protection legislation
 - legislation on capacity to consent to medical treatment
- Common law
 - Some aspects of medical treatment law are based on common law
- Constitutional law
 - Right of Parents
 - Rights of Child
 - Freedom of religion & Aboriginal Status

Context matters

- How important are parental values and religious beliefs?
- How to enforce an order for long term, complex treatment without parental support?
- Ending treatment vs aggressive treatment
 - Experimental treatment and research
- Does child want parents involved/notified?
 - Contraception and abortion

Right of competent adult

- A competent adult has the right to consent to or refuse medical treatment
- *Malette v Schulman*, [1990] OJ 450, affd Ont CA
 - Unconscious adult woman in emergency. Card in purse says:
 - JEHOVAH'S WITNESS: NO BLOOD TRANSFUSION.
 - Nurse shows card to MD, but he says that she needs blood transfusion to live; starts transfusion
 - Daughter arrives & asks MD to stop but transfusion continues
 - Doctor saved her life but \$20,000 damages for assault
 - “However scared life may be Certain aspects of life are properly held to be more important than life itself.” (Donnelly J)

Parental Rights

- Parents have the **constitutionally protected** right to relationship to child and to direct education, religion, health care and upbringing of their children free from ***unwarranted*** state intrusion. (Charter 2, 7 & 35): *G (J.) v New Brunswick (SCC 1999)*
- Limitations on parental rights may be justified under s.1 of the Charter based on need to protect children, but onus is on the state to justify action.

Parent's Inherent Common Law Rights

Parental Rights & CAS role

- Parents have presumptive right and responsibility to make health care decisions for their children
- Child welfare legislation allows Children's Aid Society to take guardianship of child (court application for child "in need of protection")if the parent:
 - ” the child requires medical treatment to cure, prevent or alleviate physical harm or suffering and the child's parent or the person having charge of the child does not provide, or refuses or is unavailable or unable to consent to, the treatment;” (Ontario CFSA s. 37(2)(e))

Who decides about complex treatment for a child with biliary atresia?



Re K.P., [1990] SJ 708 (Prov Ct)

Child 10 months old diagnosed as suffering from biliary atresia, a severe disease of the liver organ. The prognosis is that the child will die within the next six to twelve months. Child lived with aboriginal parents in Saskatchewan.

- Only chance for survival is a transplant operation, in London, Ontario. Requires assessment & wait.
 - 25% die before transplant.
 - 70-75% of the transplant recipients live 1 year
 - 60-65% of transplant recipients live 5 year.
- Life after a liver transplant is “not normal.” There is a reduced or diminished quality of life. The recipient will require continuous immuno-suppressive drug therapy.
 - 10 X greater risk of cancer
 - possibility of delayed growth, infertility, kidney complications etc.

Re K.P. – Evidence

- Parents decide not to have transplant and child protection agency brings court application.
- Treating MD (pediatric gastroenterology) testified that “standard and accepted treatment” for end-stage liver disease is liver transplantation. 6/9 of his transplant patients of past 7 years still alive.
- **MD from McGill (also pediatric gastroenterology) testified that** “the process of liver transplantation was a substitution of a terminal fatal disease for a treatable yet chronic disease,” with “stormy periods.” The “transplant recipient cannot expect a full, normal, active life...
- In his opinion, the parents' views warrant respect. A parental decision to either give or withhold consent for a transplant operation is legitimate.”
- The support, consent, and co-operation of the parents in the treatment choice is an essential ingredient for proper and successful care of the child.

Re K.P. – Decision (1) – Arnot Prov Ct J

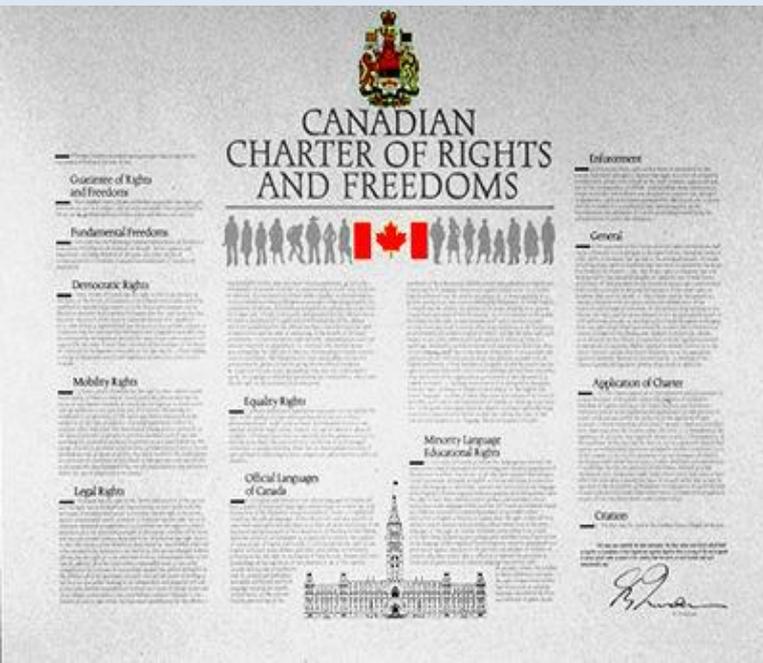
- “Parenting is a difficult vocation. Parents are constantly called upon to intervene and make difficult choices for the longterm well-being of their young children. The parents in this case have faced the most difficult choice a parent will ever have to face.”
- “They impressed me with being honest, forthright, intelligent and reflective. They are concerned about the uncertainty of the diminished quality of life a successful candidate has. In light of these concerns, they have chosen to withhold consent for a transplant operation and have opted for the treatment and supportive care program.”
- “The mother feels that the transplant is an extraordinary feat of medical science which attempts to prolong life in the face of inevitable death....She feels it is wiser and kinder to her child to allow his death to be dignified. She dearly does not want to lose this child, but she has resigned herself to that fact. She asks, **"Are these extraordinary medical procedures for prolongation of life the way society is supposed to deal with questions of life and death?"**

Re K.P. – Decision (2) – Arnot Prov Ct J

- The mother is rational, objective, and balanced in her assessment of the situation. The father of the child is a Dene Indian. The mother is a Mohawk Indian. The parents brought the child to Poundmaker Indian Reserve to seek out traditional Indian medicine. The parents' reasons for withholding consent are clearly personal and not cultural.
- The Minister is “critical” of the parents' choice. He feels the transplant surgery is in the best interests of the child. There is a 100 percent certainty of death for this child without the surgery.
- This case can be distinguished from the Jehovah's Witness blood transfusion cases. In the case of a liver transplantation operation, a much more demanding decision is required. There are two medical choices available for the parents on behalf of this child in this case. The parents have after thoughtful and careful consideration made a decision. The Minister seeks to substitute his decision which is opposite to that of the parents.
- The Minister has failed to satisfy the court principally **because the parents' decision is wholly and completely within the bounds of current medical practise**. Hippocrates said, "Life is short, the art is long, timing is exact, experience treacherous, judgment difficult." This is just as true today as it was in 400 B.C.



Recognizing & Limiting Rights of Children & Parents



R.B. v C.A.S, [1995] 1 SCR 315

- Child born four weeks prematurely and had various ailments.
- When S.B. was a month old, her haemoglobin level had dropped to such an extent that the attending physicians believed that her life was in danger and that she might require a blood transfusion to treat potentially life-threatening congestive heart failure.
- Jehovah's Witness parents refuse to consent
- At emergency court hearing head of ophthalmology at the hospital testified that he suspected the child had infantile glaucoma and needed to undergo exploratory surgery within the following week to confirm the diagnosis. S.B. received a blood transfusion as part of the examination and operation for the suspected glaucoma. Child recovered, order terminated and child returned to parental care

R.B. v C.A.S, [1995] 1 SCR 315

- Although issue was moot, goes to SCC
- SCC: **“The right of parents to rear their children according to their religious beliefs, including that of choosing medical and other treatments, is a fundamental aspect of freedom of religion,** guaranteed by the Charter s. 2(a). The child welfare legislation deprives the parents of the custody of their child, seriously infringed on the parents' freedom to choose medical treatment for their child in accordance with the tenets of their faith.
- **This infringement was justified,** however, under the Charter s. 1. The state interest in protecting children at risk is a pressing and substantial objective. The process contemplated by the Act is carefully crafted, adaptable to a myriad of different situations, and far from arbitrary. “

Parents Have Right to Fair Process

JM v Alberta [2004] A.J. No. 776

- Neonate – 3wks old – Jehovah’s Witness parents (Philippino)
- MD decides that blood transfusion needed; as parents refuse to consent, MD contacts child welfare
- MD refuses parental request to consult out-of-town MD’s who might advise on other treatment
- Parents get 1 hr notice of hearing & judge refuses adjournment for lawyer – makes child temporary ward; transfusion performed & baby lives

- In course of appeal, lawyers for parent learns that prior to proceedings being commenced – note in CPS file
 - "p/c Dr. McMillan. [He] believes [parents] want 'full hearing' often v. unpleasant experience may bring expert lawyer, problem in past has been relative junior of department counsel compared with seniority of expert lawyer"
 - - L. Smith, a social worker of Child and Family Services
- Appeal court quashes the order (symbolic victory as child transfused, but may affect future cases)
 - Rapid hearing violated Charter rights of parents
 - No damages as original action in Prov. Ct.
- Doctor not negligent – treatment medically acceptable – but violation of constitutional rights of parents to have hearing without fair disclosure to parents & court of MD's attitudes and perhaps time to adjourn to give parents chance to get counsel & other MD's.
- Case also illustrates how agency & MD's ally against religious (and ethnic) minority parents

Rights of Adolescents to be involved in medical decisions

Mature minor

- Common law recognizes right of a “mature minor” if they have capacity to “understand the information relevant” and “appreciate the reasonably foreseeable consequences” of a decision to have treatment or not
- Typically used by MD’s and nurses to provide health care, contraception and abortions to teenagers without notice to parents

A.C. v. Manitoba, 2009 SCC 30

- Devout Jehovah's Witness girl 14 years, 10 mo. suffering from lower gastrointestinal bleeding caused by Crohn's disease. Her doctor believed that internal bleeding created an imminent, serious risk to her health and perhaps her life.
- Girl & her parents refuse blood transfusions
- 3 psychiatrists concluded that C was an individual "with the capacity to give or refuse consent to her own medical care"
- Man CFSA allows court to authorize medical treatment if under 16 years and in child's "best interests"
- Trial judge orders treatment, considering capacity irrelevant.
- Man CA & SCC dismiss appeals, but SCC gives AC costs throughout

Abella J. (for 4/7)

- If a child's "best interests are interpreted in a way that sufficiently respects his or her maturity in a particular medical decision-making context, the constitutionality of the legislation is preserved...it depends on the **court's assessment of the adolescent, his or her circumstances and ability to exercise *independent* judgment, and the nature and consequences of the decision at issue.** But I am nonetheless strongly of the view that in order to **respect an adolescent's evolving right to autonomous medical decision-making**, a thorough assessment of maturity, however difficult, is required in determining his or her best interests."

Abella J. (for majority)

- "it is a ***sliding scale of scrutiny***, with the adolescent's views becoming increasingly determinative depending on his or her ability to exercise mature, *independent* judgment. The more serious the nature of the decision, and the more severe its potential impact on the life or health of the child, the greater the degree of scrutiny that will be required."
- "maturity" is an imprecise standard, given "the inherent imprecision of childhood and adolescent development."

Abella J.

- Extensive discussion of social science literature
- Abella's judgement requires a court to consider a child's capacity and wishes, but not bound by to follow wishes even if minor has "capacity"
- Most likely to *not* follow child if
 - Lack of independence
 - Decision involves relatively non-invasive treatment (ie short term) with good prognosis [eg. blood transfusion] as opposed to imposing long term invasive course of treatment [eg chemotherapy].

Minority views (1): Protection

- **McLachlin CJ (& Rothstein J concurring):** The legislative decision to vest treatment authority regarding under-16 minors in the courts is a legitimate response to heightened concerns about younger adolescents' maturity and vulnerability to subtle and overt coercion and influence. This concern with free and informed decision-making animates the legislative scheme and expresses the state's interest in ensuring that the momentous decision to refuse medical treatment by persons under 16 are truly free, informed and voluntary. Age, in this context, is a reasonable proxy for independence.

Minority views: Mature child

- **Binnie J. (dissent):** A young person with capacity is entitled to *make* the treatment decision, not just to have “input”. CFSA violates ss. 2(a) and 7 of the *Charter* and is not saved by s.1

Who decides when to “pull the plug”?



Chalifoux v. Alberta Health Services

2014 ABQB 624

- Ava was born in May with thanatophoric dysplasia or dwarfism, a usually lethal defect where bones do not grow properly. Among other effects, it prevented the baby's chest from accommodating her lungs, making it all but impossible to breathe without a ventilator. Sedated because of the breathing tube down her throat, she was subject to repeated procedures and tests that would cause pain and discomfort
- Nurses provide 24 hour care and report that "she is at times unsettled, displays painful face expressions and has a silent cry,"
- Mother is from Driftpile First Nation northwest of Edmonton. In jail for some periods after child born. Visits sporadically, usually spent no more than an hour with her when she did, and told doctors she "did not want to become attached to the girl".
- Parents had 4 previous children. One died of SIDS and three in care

Ava: View of Doctors & Nurses

- One physician described Ms. Chalifoux as “fragile and grief-stricken” after she lost one baby to sudden infant death syndrome in 2012, and another to stillbirth in 2013.
- **MDs** take the position that it is in Ava's “best interests to discontinue mechanical ventilation support and to provide palliative care and comfort measures for her until she passes away.”
- “ethically inappropriate to force continued intensive care interventions” on the child on a child who was suffering from treatment and had a terminal condition with no known cure.
- **“every additional day that Ava is on mechanical ventilation adds to her suffering, places her at risk from potentially uncomfortable and distressing complications of intensive care, and that such mechanical ventilation places her at risk of having to undergo further procedures that would increase her discomfort and distress**

Ava: Litigation

- Treatment team tries to involve mother and her family in decisions, but communication infrequent.
- Judge: “Discussing care for Ava with her parents has been a challenge for her physicians and the health-care team,”
- July 8 mother received a letter from doctors saying that they would remove the baby from the ventilator two days later.
- Mother seeks injunction to prevent termination of ventilation. She states daughter is a “fighter” and that she is “hoping for a miracle.”
- Father visited twice, given notice of proceedings & did not appear but sent letter supporting mother’s position
- Consultant neonatologist retained by Mom agrees that it is very unlikely that Ava would survive if endotracheal tube removed.
- Temporary injunctions for 5 weeks as litigation proceeds.
- Court allows cessation of ventilation and Ava died shortly after the artificial breathing machine was unplugged,

Ava: Ruling – Justice Debra Yungbirth

- Judge has authority under family law statute and *parens patriae*
- Appropriate test is that of the “best interests of the patient,” taking into account:
 1. The medical condition of the patient;
 2. The recommended medical treatment
 3. The wishes and beliefs of the patient, if they are known; and
 4. What is just and equitable in all of the circumstances.
- Wishes of parents must be considered, but court concludes that lack of visits and grief over loss of previous children compromised” their ability to make best interests decisions.
- Removing her from life support was the “kindest” and “most appropriate” option available. “The focus should be on changing Ava’s care to comfort and palliation...”
- The girl’s best interests was primary consideration but also took account of the “great moral distress” of staff caring for the child.

11 year old Aboriginal girl with cancer



McMaster Hospital v Brant FCS

2014 ONCJ 603

Child, age 11, was a member of the Six Nations of the Grand River. She was diagnosed with acute lymphoblastic leukemia that caused cancer in the bone marrow and was being treated with chemotherapy.

Doctors believed that she had a 90-95% chance of cure with chemotherapy. The mother withdrew her consent for the continuation of the child's chemotherapy treatment and indicated her plan to treat the child with “traditional medicines.”

CAS accepted this decision but the hospital commenced a court application for a declaration that the child was “in need of protection.” The mother took the child away first to a Florida treatment centre and then back to her home, and did not participate in the proceedings. The Band was notified and together with the CAS opposed to application. CAS concluded that she was a devoted mother and suggested that the matter should be referred to the Health Capacity Consent Board to determine whether the child had capacity to make this decision.. CAS investigation reveals that the family are committed traditional longhouse believers who integrate their culture into their day-to-day living. In short, their longhouse adherence is who they are and their belief that traditional medicines work is an integral part of their life.

Hearing

- Edward J concluded that the treatment team correctly concluded that the child lacked capacity to decision, and this issue was for Family Court not Consent Board..
- Professor Dawn Martin-Hill, McPherson Indigenous Studies Research Chair at McMaster University and was qualified as an expert in the area of First Nations' traditional medicine. She testified that the use of traditional medicines by Six Nations was practiced prior to European contact, and that it was integral to their culture.
- Dr. Karen Hill, a family doctor who was born and practiced at Six Nations. Despite being schooled in "western medicine", she operates a medical practice on Six Nations with Alba Jamieson, who practices traditional medicine.
- “The point is traditional medicine continues to be practised on Six Nations as it was prior to European contact and, in this court's view, there is no question it forms an integral part of who the Six Nations are.”

Hearing – Decision

Constitution Act:

35.-(1) The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby reorganized and affirmed.

- Edward J.: “The traditional medicine practiced on Six Nations remained as it was prior to European contact, and was **an integral part of the Six Nations' identity**. The child could not be found in need of protection when her mother, as her substitute decision-maker, had chosen to exercise her constitutionally protected right to pursue their traditional medicine over the applicant's preferred course of treatment of chemotherapy
- The court concluded that the mother’s decision to pursue “traditional medicine” for her daughter is “her aboriginal right. Further, such a right cannot be qualified as a right only if it is proven to work by employing the western medical paradigm. To do so would be to leave open the opportunity to perpetually erode aboriginal rights.”

Implications?

Decision queried by many commentators. Only gives rights to Aboriginal parents

Was CAS concerned about enforcement with community?

What is the responsibility of the provincial and federal governments, and the First Nation?

For some, was this more about politics than this child?

Was there a breakdown in communication between doctors and mother? Can it be restored?



Some References

- Bala, “The *Charter of Rights* and Family Law in Canada” (2001), 18 *Can. Fam. L. Q.* 373 - 428.
- Bala & Leckey, “The *Charter* and Family Law – The First Three Decades: A Delayed but Profound Impact” (2013) 32 *Canadian Family Law Quarterly* 21-52.
- Bala, Leverette & Bala, “Minors and Capacity to Treatment, in Hy Bloom & Richard Schneider, *Law & Mental Disorder: A Comprehensive and Practical Analysis* (Toronto: Irwin Law, 2013), Chapter 50, 1079 – 1090.
- Houston, “Case Comment on *Manitoba v A.C.* ” (2009) 65 R.F.L. (6th) 397.