

## Newfound Aboriginal Right to Pursue Traditional Medicine

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### Abstract

This article discusses the newfound aboriginal right to pursue traditional medicine. A 2014 Ontario court decision relating to J.J., an 11-year-old First Nations girl with leukemia, is analyzed. The events leading up to the court case are followed by a description and analysis of the court's decision. The court found, for the first time in Canada, that there is an aboriginal right to pursue traditional medicine on behalf of a child, despite the medical evidence that chemotherapy would almost certainly result in remission while the absence of chemotherapy would almost certainly result in death. This article concludes that the case provides limited guidance for those that find themselves in similar situations in the future, and demonstrates the need for collaborative problem solving when making treatment decisions for children, perhaps through the use of mediators or ethicists.

### Consent Sought for Chemotherapy to Treat Acute Lymphoblastic Leukemia

In 2014, two First Nations children were diagnosed with acute lymphoblastic leukemia. The children were aged 11 and lived near Brantford, Ontario. Regarding one of these children, known as J.J., the healthcare team at McMaster Children's Hospital sought consent to treat her cancer with chemotherapy. J.J.'s mother refused.

While cases where parents withhold consent for medical treatment on behalf of their children are not new, unique to this situation was that the refusal was on behalf of a First Nations child. This article describes how that fact played a significant role and saw an Ontario court identify, for the first time in Canada, an aboriginal right to pursue traditional medicine. The discussion is broken down into the following sections:

1. The events leading up to the court case,
2. The Court's reasons for decision,
3. The potential impact this decision has on similar situations.

### The Disagreement Between the Mother, Healthcare Team, and the Children's Aid Society

Having diagnosed J.J. with acute lymphoblastic leukemia in August of 2014, the healthcare team sought consent from J.J.'s mother to treat using chemotherapy. J.J.'s treating physician, oncologist Vicky Breakey, wrote that with timely medical intervention and considering J.J.'s clinical assessment and ge-

netic test results, there was a 90-95% "cure rate".<sup>1</sup> Others were less confident, saying the five-year survival rate might be only 70% in a similar but not identical situation.<sup>2</sup> All of the physicians agreed that they had not heard of a patient surviving this condition without the use of chemotherapy.

Dr. Philip Hébert wrote the following regarding Makayla Sault, the other First Nations 11-year-old diagnosed with acute lymphoblastic leukemia referred to in the beginning of this article:

*In 1960, children with the disease were given no chance of survival. Now, with chemotherapy and bone marrow transplantation the five-year survival has reached 90 per cent. On the other hand, 80 per cent of children will experience a serious or even life-threatening complication from the intensified treatments now used. Makayla's leukemia was Philadelphia chromosome-positive, a factor that reduced her five-year survival rate to 70 percent.<sup>2</sup>(p126)*

Sadly, Makayla died after being withdrawn from chemotherapy.<sup>3</sup> A court challenge was not initiated in her case.

Initially, J.J.'s mother agreed to treatment with chemotherapy, but 10 days into the 32-day treatment plan she withdrew her consent. It is unclear why J.J.'s mother withdrew her consent, but her position later on stated that she wished to pursue traditional medicine, possibly in combination with chemotherapy.

There is no clear definition of traditional medicine. After withdrawing J.J. from the care of the physicians at McMaster Children's Hospital, J.J.'s mother planned to take her to Florida to undergo a form of alternative medicine. Despite an interim order by the Court that J.J. not be removed from Ontario, J.J.'s mother took her to the clinic in Florida. The Children's Aid Society said that by the time they were aware of the mother's actions, the two were already on their way.

J.J.'s physicians sought the help of Brant Family and Children's Services. Under the *Child and Family Services Act*, the child welfare agency had the power to declare J.J. "a child in need of protection".<sup>4</sup> Brant Family and Children's Services contacted the Six Nations of the Grand River Band Council (Six Nations Band) regarding J.J., but ultimately declined to intervene. The hospital, on behalf of its physicians, brought a court application to have J.J. declared a child in need of protection, in order to treat her cancer with allopathic medicine. Initially, the only parties to the application were the hospital, Children's Aid Society, and the Office of the Children's Lawyer. The Court added J.J.'s parents and the Six Nations Band as parties.

### The Court's Reasoning and The Newfound Aboriginal Right to Traditional Healing

The Court determined that given the evidence of J.J.'s maturity, life experience at age 11, and lack of independence from her mother, as well as the circumstances surrounding the treatment of her specific condition, she was not capable of making this decision herself.<sup>1</sup> As a result, J.J.'s mother was found to be her substitute decision maker.

The Children's Aid Society urged the court to find that the appropriate forum for this dispute was the Ontario Consent and Capacity Board. That Board is an administrative tribunal that sits as a three-person panel comprised of a lawyer, physician, and member of the public. It adjudicates treatment decisions made on behalf of others. The Court, citing earlier cases involving children whose parents were Jehovah's Witnesses refusing blood transfusions for their child, found that when the issue is a matter of child protection, the Court has jurisdiction to decide the matter.<sup>1</sup> As a result, the case was not referred to the Consent and Capacity Board.

The Court then identified the main issue as being whether there were reasonable and probable grounds to believe that J.J. was a child in need of protection, as defined by the legislation. All parties agreed that the only applicable part of the legislation defining a child in need of protection was section 37(2)(e), which reads:

*(e) 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;*<sup>4</sup>

The hospital asserted that J.J.'s mother's decision to discontinue chemotherapy made J.J. a child in need of protection. The Band asserted that s. 35 of the *Constitution Act, 1982* protected J.J.'s mother's right to pursue traditional aboriginal medicine. Section 35 reads:

*35.(1) The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby reorganized and affirmed.*<sup>3</sup>

In the *Canadian Charter of Rights and Freedoms* ("the Charter"), the very first section (s.1) operates to limit the rights contained within the Charter. Section 1 reads:

*1. The Canadian Charter of Rights and Freedoms guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrated in a free and democratic society.*<sup>6</sup>

The Court then correctly noted that section 35, which affirms existing aboriginal rights, is not part of the Charter and therefore is not subject to the limitation contained in s. 1.<sup>1</sup> Justice Edward went on to find that, in accordance with the legal test for identifying an aboriginal right, there was an aboriginal custom of traditional healing that existed before Europeans made contact with the First Nations.<sup>1</sup> Evidence for this was

provided by testimony from Professor Dawn Martin-Hill who holds the McPherson Indigenous Studies Research Chair in the Anthropology Department at McMaster University. She was found to be an expert witness in the area of First Nations traditional medicine.

Further evidence from Dr. Karen Hill, a medical doctor practicing family medicine in the Six Nations Band, was that traditional medicine was still practiced at the Six Nations as it was prior to European contact, and that it formed an integral part of the customs of the Band. After finding that traditional medicine preceded European contact, was maintained to the present day, and that the right had not been extinguished, Justice Edward found that an aboriginal right to pursue traditional medicine existed.

Having affirmed an aboriginal right to pursue traditional medicine, and that J.J.'s mother was deeply committed to those beliefs (as opposed to simply attempting to adopt them at the last minute in order to withdraw her child from allopathic medical care), the Court found that J.J.'s mother's decision to withdraw J.J. from chemotherapy was her aboriginal right.<sup>1</sup> Interestingly, Justice Edward then found:

*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.*<sup>1</sup>(para81)

In an unusual step, lawyers for the Ontario Ministry of the Attorney General, along with the parties to the hearing, asked Justice Edward to "clarify" his decision.<sup>7</sup> This, ostensibly, was to spare the family from the appeal process, which may have reversed the Court's decision, and in any event would have prolonged the matter. In its clarification, the Court found the paramount concern in cases such as this is the best interests of the child, despite the fact that no such wording or analysis was present in its original ruling.<sup>7</sup>

A couple of weeks after the initial court decision was released, J.J.'s mother agreed to consult another pediatric oncologist, at a separate hospital, regarding treating J.J.'s leukemia.<sup>8</sup> She said, "This time, I will be respected. The Court decision gave that to me."<sup>8</sup> News reports indicate that as of April 2015, J.J. was receiving a mix of traditional and conventional medical care, which included chemotherapy.<sup>9</sup> These reports also indicate that in early 2015, J.J. was doing well, though it is unclear how her health is today, as neither J.J. nor her mother have appeared in the media since that time.<sup>10</sup>

### J.J.'s Case Provides Limited Guidance for Future Cases and Demonstrates the Need for Collaborative Problem-Solving

This case is notable for its divergence from similar cases where parents refused potentially life-saving treatment for their children. The primary reason for that divergence is the parent's reliance on s. 35 (aboriginal rights) of the *Constitu-*

tion Act, 1982, as opposed to on the right of freedom of religion contained in the *Charter*.

Another striking feature of this decision is the complete absence of analysis of J.J.'s rights, the legal presumption in favour of life, or even "the best interests of the child" in the original decision. The after-the-fact addendum which provides that of course, the paramount concern must be the best interests of the child makes this case of extremely limited value in terms of providing guidance for those that find themselves in similar situations in the future.

Resting the entire decision on the aboriginal rights section of the constitution also has the putative effect of providing aboriginal parents the absolute right to pursue traditional medicine and forsake allopathic treatment for their children. In Jehovah's Witness and other similar cases involving freedom of religion, Canadian courts found that parents' freedom of religion was not absolute and the state's interest in preserving life prevailed, in certain circumstances. (See, for example, the Supreme Court of Canada's decision of *B. (R.) v Children's Aid Society of Metropolitan Toronto* for how this balancing was accomplished in the context of parents of the Jehovah's Witness faith refusing blood products for their infant daughter.<sup>11</sup>) No such balancing can be done under the aboriginal rights provision because it is not governed by s. 1 of the *Charter*. As a result, in future cases involving an aboriginal right to pursue traditional medicine, courts may need to balance that right with the child's *Charter* right to life and security of the person.

Additionally, commentators have pointed to the fact that the clinic in Florida was not in fact providing traditional aboriginal healing, and so the basis for the refusal of treatment could not properly be said to be in pursuit of an aboriginal right.

Finally, the Court's analysis of the aboriginal right to pursue traditional medicine is questionable. This was the first time such a right was found. Previously, this section was used for hunting and fishing rights, and for enforcement of treaties.<sup>12</sup> The Court's analysis was exceptionally brief considering what was at stake and the lack of prior jurisprudence. With that said, such cases are often conducted under exigent circumstances.

For these reasons, this case would have benefited from appellate review. Unfortunately, that opportunity was denied when the parties agreed that rather than appeal the decision, the addendum affirming that the best interests of the child test applied would suffice.

It must be remembered that this decision occurred against the backdrop of the ongoing recovery from the residential school system. This was a policy by the Canadian government where aboriginal children were removed from their families, band, and culture, and placed into residential schools where they experienced horrific abuse.<sup>12</sup> While not made explicit in this decision, it is clear that Canadian courts should be slow

in removing children, especially First Nations children, from the care of their parents and band, and force Western treatment on them.

While caution is needed, blindness to the realities of the proven benefits of evidence-based medicine can also harm the child. Perhaps what this case best illustrates is the importance of Alternative Dispute Resolution as an alternative to litigation. It is a maxim of law that one can never truly predict what the outcome will be of any dispute that is adjudicated. As a result, the best outcomes are often those crafted by the disputants themselves. To that end, bioethicists and mediators can assist parents and healthcare teams in finding a solution that works for everyone involved.

Accreditation Canada requires a bioethicist be available at all accredited hospitals in Canada. Ethicists do not advise or suggest a particular course of action. Rather, they inform the people involved as to the ethical principles at play, and suggest factors to consider in making a decision. Ethicists are often consulted by families making decisions on behalf of others, or by healthcare teams when there is disagreement or apprehension involved in making difficult decisions. Either the family or the healthcare team can approach a bioethicist to initiate a consultation.

Mediators are neutral third parties who assist two or more parties who are in conflict. The methods that mediators use to resolve disputes vary. It is important to note that mediators cannot make binding decisions or force any party to make a decision. Often, however, their presence, impartiality, and skillful communication result in lasting decisions for all involved that are far more satisfying than an imposed decision made by a tribunal or judge. Mediated decisions are typically more creative and far less costly than ones that result from adjudication.

Given J.J.'s mother's comments and her ultimate decision to pursue both traditional aboriginal medicine and chemotherapy, it seems that she was primarily concerned about being forced into a particular mode of treatment and the impact this would have had on her dignity as a mother and First Nations person. When this is considered in the context of survivors of the residential school system, it seems clear in retrospect that some form of Alternative Dispute Resolution would have been useful in this situation.

Considering the following excerpt from Justice Edward's addendum, one wonders if some form of Alternative Dispute Resolution is in fact the approach that eventually prevailed in this case:

*Written reasons given in a case seek to explain how a court has resolved an issue between parties who appear before it. Sometimes such reasons attract a wider audience. The Attorney General of Ontario was in that audience in this case. There were many calls for the Attorney General of Ontario to pursue litigation; however, the Attorney General chose to engage in a dialogue with the parties that ultimately led to an*

*approach that spoke more to what joins us as opposed to what separates us. The joint submission, that has been read into the record, notes how the province and the family collaboratively worked to form a health care team to bring the best both had to offer to address J.J.'s ongoing treatment. This approach recognizes the province's acceptance of the family's right to practice traditional medicine and the family's acceptance western medicine will most certainly help their daughter. It is simply a recognition of what is in J.J.'s best interest.*<sup>7</sup>(para5)

This case should serve as a cautionary tale. Practitioners who find themselves in similar situations should strongly consider seeking early consultation with an ethicist and the use of a mediator with a background in health law. As perhaps occurred in this case, it should be noted that it is never too late to use these services.

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