

# Caring for children, focusing on children

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Two First Nations girls with leukemia received a significant amount of media attention in 2014 and 2015. In both cases, the parents refused to continue chemotherapy, the only proven effective treatment; they opted instead for a combination of traditional Aboriginal healing approaches and alternative therapies offered in a facility outside of the country. One child has died; the other relapsed and required chemotherapy to avoid death.

Media reports were polarized, focusing either on the historical legacy of distrust felt by First Nations people when accessing health care, or the need for child protection services to intervene. One article in the *Canadian Medical Association Journal* focused on the legacy of mistrust and methods of countering it, but did not address the legal and ethical duties of physicians in such situations.

The present commentary describes the events, responsibilities of professionals involved and a course of action for physicians when faced with similar circumstances.

**Key Words:** *Aboriginal; Child protection; Duties of paediatricians*

Canadians are saddened by the death of Makayla Sault and concerned about the long-term survival of “JJ” (1). They are First Nations children, each diagnosed with acute lymphoblastic leukemia; their parents consented to chemotherapy at McMaster Children’s Hospital in Hamilton, Ontario, and later, withdrew consent. The atypical response of child protection authorities to these life-threatening situations (1), and an unusual (2) and then ‘clarified’ (3) legal judgment initially engendered considerable media attention and academic discussion (4), which prompted heated rebuttal (5). The present commentary aims to review the academic assessment of the situation, to describe responsibilities of physicians in such cases and to propose a course of action for them.

Makayla Sault was 11 years of age at diagnosis. Her parents consented to one round of chemotherapy after which they took her to Florida (USA) for alternative therapy (6). She returned home and died January 19, 2015 (7). JJ is also an 11-year-old with acute lymphoblastic leukemia and has a predicted 90% to 95% chance of survival with chemotherapy (2). In August 2014, after 10 days of chemotherapy, her family took her for alternative therapy to the same Florida clinic (6). In both cases, the Brant Family and Children’s Services chose not to intervene by seeking court-ordered medical treatment. In JJ’s case, McMaster Children’s Hospital asked the court to intervene (2). The court declined in November 2014, on grounds we will describe, although in April 2015, the judgement was ‘clarified’ and the parties announced that chemotherapy had resumed in March 2015 (3). Whether the seven-month gap in chemotherapy administration between August 2014 and March 2015 will affect the child’s medical outcome will likely never be known.

## Soigner les enfants, se concentrer sur les enfants

Deux fillettes atteintes de leucémie originaires des Premières nations ont obtenu une grande couverture médiatique en 2014 et 2015. Dans les deux cas, les parents ont refusé de poursuivre la chimiothérapie, le seul traitement éprouvé, et opté pour un mélange de médecine autochtone traditionnelle et de médecine parallèle administré dans un établissement situé à l’extérieur du pays. L’une des enfants est décédée et la deuxième a dû subir une chimiothérapie pour ne pas mourir.

La couverture médiatique, qui était polarisée, s’attardait soit sur la méfiance historique des peuples des Premières nations envers le système de santé, soit sur l’importance que les services de protection de l’enfance interviennent. Un article du *Journal de l’Association médicale canadienne* a traité du climat de méfiance et des moyens de le contrer, mais n’a pas abordé les responsabilités juridiques et éthiques des médecins dans de telles situations.

Le présent commentaire décrit les événements, expose les responsabilités des professionnels en cause et propose une ligne de conduite pour les médecins aux prises avec une situation similaire.

In reaction to the initial judgement, a *Canadian Medical Association Journal* (CMAJ) commentary (4) highlighted the richness of Indigenous approaches to healing and emphasized the absolute necessity that health provider interactions with Indigenous patients be based on trust and respect, especially given the awful legacy (8) of residential schools. We agree with their commentary; clearly, the overarching need is for mutual trust. Medical practitioners and institutions must focus on respect for Indigenous patients, their families and community traditions, while accepting that Indigenous leaders are a central part of the attempt to find mutual respect and to focus on the preservation of their young people’s health and lives.

The CMAJ commentary, however, made a number of factual errors and lacked understanding of the legal and ethical responsibilities of all physicians, including paediatricians, when faced with a situation in which parents of any background deny lifesaving treatment for their child.

First, the CMAJ commentary incorrectly described the McMaster Children’s Hospital paediatricians as “asking the court to remove JJ from her parents to compel her to receive treatment” (4). JJ’s mother’s decision not to consent to more chemotherapy (9) created the physicians’ statutory duty to notify the local child protection agency (10). The McMaster paediatricians fulfilled their legal and ethical obligation after exhausting all collaborative efforts, including ethics consultation, to encourage the family to accept that chemotherapy was in the child’s best interests, just as they had done in the case of Makayla Sault.

Second, the Hamilton area court did not, in fact, rule on the child’s rights in its November 2014 decision. The judge held that

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the mother had Aboriginal rights to use traditional medicine (11). Many people viewed this judgment as troubling because it did not focus on the child's right to life. We were pleased that the 'clarification' document stated that "the best interests of the child remain paramount" and "the Aboriginal right to use traditional medicine must be respected" (3). Paediatricians should continue to make the child's welfare their highest priority while respecting parental rights, cultural background and wishes. If conflict occurs, then there are many ways of reaching resolution; legal action is the least desirable. Nevertheless, in life-threatening and/or urgent situations, paediatricians are legally obliged to notify child protection services.

Third, we understand that when trust breaks down, or was never established, it is exceedingly difficult for all concerned to follow through on a long and arduous course of treatment. The description of chemotherapy as "toxic medications with severe adverse effects" (4), without any qualification, obscures the fact that chemotherapy provides, to date, the only evidence-based treatment for the survival of JJ.

The CMAJ commentary authors helpfully referred to the 2012 Health Council of Canada report into barriers to Indigenous people seeking health care services within mainstream health care settings (12). As the publication states, "many Aboriginal people don't trust, and therefore do not use, mainstream health care services because they do not feel safe from stereotyping and racism". A more recent report claims that "Racism against Indigenous peoples in the healthcare system is so pervasive that people strategize around anticipated racism before visiting the emergency department or, in some cases, avoid care altogether" (13). Regrettably, there was a media report of disrespect toward the family of Makayla Sault by a health care worker who allegedly commented sarcastically about a healing ceremony (14).

The CMAJ article engendered seven letters to the editor in response (5). In summary, all authors agreed that there was a legacy of mistrust related to previous actions by the Canadian governments toward First Nations peoples. There was criticism in emotive terms of the acceptance of the child's death as an expression of Aboriginal rights and of the actions that led to her death. One letter states, "As an alternative to chemotherapy (the parents) chose the decidedly nontraditional, nonaboriginal and quite frankly, preposterous "treatment" regimen at a "clinic" in Florida" (15). (This Florida institute was investigated [16]; Florida Department of Health concluded that there is insufficient evidence to pursue legal proceedings [17]). Another letter denounces the "platitudes expressed by Drs Richardson and Stanbrook" stating that they "contribute nothing to the resolution of the challenges faced by both frontline health professionals caring for children with cancer and the families of such children today and in the foreseeable future" (18).

The authors of the letters perhaps do not recognize that a large proportion of Indigenous patients experience difficulties when accessing the health care system. Such difficulties are reflected by Makayla's death and collective fears for the survival of JJ, which mark a watershed moment in Canadian paediatrics and its long history of attempting to deliver excellent medical care to Indigenous children. Our best efforts to ensure that all parents accepted our methods did not succeed in the first case and nearly failed in the second. Paediatricians must accept that Indigenous physicians have a vital role in helping to bridge a vast cultural divide. Respectfully uniting to help children of all cultural and religious backgrounds is a goal to be pursued urgently by Indigenous, medical and social work leaders; we must develop trust such that, in a medical crisis, the best interests of the child are protected.

To this end, training on how to make patients and families of varying cultures feel safe to seek and undergo treatment should be an essential part of early training for all health care professionals. Although ethics committees would probably not approve trials of Indigenous treatments as substitutes for chemotherapy, ethically sanctioned research ought to be conducted into whether Aboriginal medicine helps alleviate some of the discomforts and side effects of chemotherapy.

What should paediatricians do in the future when faced with an Indigenous child needing health care? At the outset, realize that an institutional policy that welcomes and recognises Indigenous culture is useless without an individual commitment to follow through and sincerely welcome the child, the family and community values. Then strive, as always, to achieve a diagnosis and treatment plan, and work collaboratively with the family. Learn about the family's previous contacts with health care and explore the family's expectations. The family's wishes regarding traditional Indigenous supports should be followed. Rarely, a possible negative interaction between prescribed and traditional medications can arise, making a dual approach difficult. If the physician family relationship breaks down, then a paediatrician should access as many supports as possible to help heal the relationship.

Paediatricians will go to great lengths to work with families and to achieve consensus before accessing child protection services. When a child, Indigenous or non-Indigenous, is in a life-threatening situation and all attempts to implement cooperative and effective treatment have failed, a paediatrician's primary duty is to the health and welfare of the child; paediatricians have a legal and ethical duty to report their concerns to the local child protection authority. This vital responsibility should not be taken lightly and a paediatrician should strive to give every child the best chance at good health and a long life.

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