K’aila Paulette, a First Nations baby, died of liver failure one month before his first birthday. Standard medical therapy for his liver dysfunction would have been organ transplantation. A liver transplant offered, according to his paediatrician, an 80-85% survival rate.

His mother, Lesley, refused to allow the recommended transplant: partly because the information she gathered put the 5 year survival rate as closer to 60-65%; partly because of quite reasonable fears for his post-transplant quality of life. Mostly, however, her refusal was based upon her somewhat controversial interpretation of native cultural and spiritual values.

Irresolvable disagreement about the appropriate treatment for K’aila led to a court challenge (Saskatchewan v. P. 1990). The court’s verdict was a mixed victory/defeat for both sides. The Paulettes won their case, so their son died without surgery. But the court based its decision on the lack of adequate evidence that medical technology would provide more benefit than harm for this child. Parental authority was upheld, but only because in this particular case medical technology was found to be dubiously beneficial to the child. It seems clear from the court’s reasoning that once a technology improves to the point where it can assure recipients of the likelihood of a good quality of life, the state will be authorized to override parental judgement which appeals to the spiritual/cultural/community values of the parents.

In our pluralistic liberal society, competent adults are legally entitled to refuse life-saving treatment, even in circumstances where the dominant culture feels that their decision is wrong-headed or even foolish. But this individual discretion does not extend to decisions made on behalf of their children. I find this a sensible compromise, which puts me at odds with the contributors to this volume. Indeed, opposition to the court’s rationale in the K’aila case is a major connecting thread for
many of the essays collected here. The authors seem surprisingly united in support of the view that, in a liberal pluralistic society such as Canada, members of minority cultures, whether Native or Hutterite or Chinese, should enjoy the absolute legal right to use their own cultural or spiritual values in deciding when their children’s quality of life is worth maintaining, as well as which technologies constitute an acceptable means to prolong life.

Consider. What if transplant technology could have offered K’aila a 95% chance of living a normal healthy life? What if K’aila’s otherwise fatal condition could have been cured by a single injection of a vaccine with no known adverse side-effects? Disappointingly, the contributors to this volume don’t explicitly confront such tough questions. It seems clear, however, that their near-total commitment to respect for the religious or cultural diversity of minority communities would force them, perhaps regretfully, to give to parents unchecked discretion over their children’s fate, with no protective role for state intervention.

The authors do not discuss the sad case of Tyrrel Dueck, whose Christian fundamentalist parents prevented his receiving, in a timely fashion, the surgery and chemotherapy necessary to save his life, nor is there any careful analysis of the numerous Jehova’s Witness cases involving denial of blood transfusion to their children. The authors would, presumably, uphold parental discretion in all such cases.

If we, the dominant culture, intervene coercively in the name of child protection we must do so by appealing to a set of attitudes and values which are sometimes conflicting and sometimes questionable. The authors are right to remind us that we, members of the dominant culture, have much to learn from the diverse cultures who live alongside us. Our frequently inappropriate use of medical high technology to prolong dying may reflect a pathological refusal to accept the inevitability of death. The Hutterite culture seems altogether more sensible in its view of death and dying. Moreover, our excessive individualism, often leads us to focus exclusively on the doctor-patient
dyad, to the neglect of the patient’s family and sub-culture. When medical decisions must be made, perhaps there is an important role for family and extended community.

Even here, however, some caution is necessary. Whatever the traditions of one’s community, a given individual who happens to be aboriginal or Chinese or Hutterite may not wish to have their family members participate or may not choose to follow the spiritual traditions that prevail in their culture, or may have an idiosyncratic interpretation of those traditions.

The authors are enthusiastically sensitive to the importance of listening to and learning from the wisdom of other cultures. Which is, doubtless, A Good Thing. Their reluctance fully to explore the tough questions, however, means that there is insufficient dialogue in A Cross-Cultural Dialogue on Health Care Ethics. Mostly, I fear, what we hear is the sound of one hand clapping.

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