

Who decides for the child? The case of Tyrell Dueck
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Everyone wanted the best for Tyrell Dueck: his parents, his doctors, the courts. But legal disputes take time, even when the process is speeded-up. Now, it's too late for chemotherapy to work. There are, however, important lessons to be learned.

Questions of "who decides" are among the most controversial in medical ethics. Public opinion seemed strongly to favour allowing the Dueck family to decide. However, Madam Justice Rothery disagreed. She ruled that Tyrell was a child in need of protection. However unpopular, this was the right decision in the special circumstances of this case.

Traditionally, our society simply assumed that parents were the best judges and guardians of their children's health and well-being. Today, there is an increasing awareness of the dark reality that parents are sometimes dangerously irrational, neglectful, or abusive. Society continues to place a high value on family integrity, but we recognize that not all parents are loving, and that even loving parents sometimes behave in ways which require state intervention to protect the child.

For example, parents who choose to have their daughters genitally mutilated are forbidden by law from following this practice. Although we are a pluralistic society, committed to respecting a variety of faiths and traditions, there are limits. If you are a competent adult, you are legally permitted to make decisions about your own life that others may regard as foolish or wrong-headed. However, where children are concerned and society judges that there is a high likelihood of serious harm, the right of parents is overridden.

What about the right of children to decide for themselves? Are they not competent to make their own medical decisions?

As medical ethics evolves, there is a growing awareness of the desirability of involving children in the decisions that effect their lives. Respect for the autonomy of children is an important value, especially when, as in the Dueck case, the proposed treatment is highly aggressive and distressing.

It is misleading, however, to think of "competence" as an "on/off" switch. A person, may be competent to make some, but incompetent to make other, kinds of decisions. The question that should be asked is whether a particular child is competent to make difficult medical decisions, on which its own life may depend. If a child insists that he is cured of bone cancer, despite massive scientific evidence to the contrary, this suggests that he is in a state of acute denial. If a child appears to be heavily dominated by the scientifically eccentric beliefs of his parents, then it is the duty of a judge to rule that the child requires protection.

Imagine that the facts of the case were different. Suppose that a child could be guaranteed of cure simply by taking a pill, with no bad side-effects. Would anyone defend the right of a child or his family to refuse such a benign intervention? Family autonomy is clearly not an absolute value.

Suppose, on the other hand, that the distressing treatment proposed for a child with cancer has only a 5% chance of cure. Given the invasive nature of the therapy, if the chances of success are poor, society ought to respect the wishes of the family to refuse treatment. When reasonable people would disagree about what is best for the child, the state has no business intervening.

Doctors estimated that if Tyrell had been given chemotherapy and leg amputation in a timely way, the chances for cure would have been 65%. Would **reasonable** parents refuse medical treatment for their child with such favourable odds? Almost certainly not. It is in such

circumstances that courts recognize a duty to override parental wishes.

The most troubling aspect of Judge Rothery's decision was the possibility that the treatment would have had to be performed coercively. Critics who invoked the nightmare image of a child, strapped down on the table, resisting fiercely while the doctors cut off his leg have, perhaps, been watching too many Second World War movies; such surgery is always performed under anaesthetic. Granted, it is still not a pretty thought, but the alternative is even grimmer: a child dead of bone cancer when his life could probably have been saved.

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