

Notes and Comments

THE STEPHEN DAWSON CASE: WHOSE DECISION IS IT ANYWAY?

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Moviegoers may recall a recent Hollywood film, *Whose Life Is It, Anyway?*, starring Richard Dreyfuss in the role of a sculptor totally paralyzed from an auto accident. From his hospital bed, he insists upon his right to die. He demands that life-sustaining treatment be withdrawn because he regards life as a quadriplegic as a fate worse than death. Since he persists in his determination to die, the outcome is inevitable. A mentally competent adult cannot be treated against his will, and a judge summoned to his bedside orders the hospital to honor his plea.

In other words, the decisive question is not whether the quality of the patient's life is such that he is frankly better off dead. What settles the matter is simply that, since it is his life, it is his choice. His legal position is thus distinguishable from that of Stephen Dawson, the severely handicapped six-year-old boy, whose case was widely publicized across Canada last March.¹ On March 18th, Stephen underwent brain surgery after Judge Lloyd McKenzie of the British Columbia Supreme Court overruled a provincial court decision that the operation would constitute cruel and unusual treatment in violation of the Charter of Rights and Freedoms.

Unlike the sculptor, Stephen could not speak for himself because he is a severely retarded child, who in addition is blind, deaf, and suffers from cerebral palsy. His parents, who were his natural legal guardians, had refused to consent to the surgery required to repair the shunt draining fluid from his brain. Their refusal was grounded in their conviction that his continued existence was a fate worse than death. However, Judge McKenzie ruled otherwise. He held that the surgery must proceed because a disabled child is entitled to the law's protection to the same degree as is a normal child. He further held that since the proposed surgery was in the nature of appropriate and routine medical care, it could not lawfully be withheld from Stephen simply because he was severely handicapped.

In so ruling, the B.C. court followed the same path as the English Court of Appeal in a 1981 decision. In that case, *In re B*,² the Court overrode parental objection to find that a ten-day-old girl born with Down's syndrome (mongolism) could not be denied the surgery necessary to repair a life-threatening intestinal blockage. The Court held that the sole question was whether the recommended surgery was in the infant's best interest. Its decision was grounded in its findings that, if treated, the infant could live the normal life span of one afflicted with mongolism, and further that there was no evidence that such an existence would prove intolerable.

It is imperative to emphasize that neither the B.C. nor English case involved the plight of a terminally ill patient. In fact, Judge McKenzie went

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1. *Supt. of Family & Child Service v. R.D.* (1983), 145 D.L.R. (3d) 610, [1983] 3 W.W.R. 618, 42 B.C.L.R. 173, 4 C.H.R.R. D/1386, 34 R.F.L. (2d) 34 (S.C.); rev'g (sub nom. *Re S.D.*) (1983), 42 B.C.L.R. 153 (Prov. Ct.).

2. [1981] 1 W.L.R. 1421 (C.A.).

out of his way to explain that the case before him did not present a 'right-to-die' issue. The reason was that Stephen Dawson's condition was chronic but not terminal. He was critically ill, but the proposed surgery was clearly sufficient to restore him to his chronic state. Such was also the situation in *In re B*.

Terminal illness, on the other hand, is a different matter. The law has never required that dying patients be treated with maximum effort until the last flicker of life finally fades. If the patient is a mentally competent adult, his demand that treatment be withdrawn is legally binding. However, even if he is comatose (and hence mentally incompetent), the physician is not legally obliged to continue medically useless treatment whose sole purpose is to attest to the wonders of modern medical technology. After the B.C. court ruling, Stephen Dawson's father asked, "Where does technology stop?" While not permitted to stop for his son, it is not legally bound to continue when it can do nothing for a dying patient beyond prolonging the inevitable.

Regrettably, Canadian law has neglected to spell out that treatment is not mandated in such cases. Although not the law on the books, it is the law in practice simply because there is tacit legal awareness and acceptance of the suspension of vigorous but useless treatment for dying patients. It is, however, advisable that society state its public policy for the record, so that physicians need not fear legal repercussions when they surrender their hold on terminal patients and permit nature to take its inevitable course. It is for this reason that the Law Reform Commission of Canada has recently proposed an amendment to the Criminal Code. The recommended provision is that no physician be required to apply treatment that is "therapeutically useless in the circumstances and is not in the best interests of the person for whom it is intended."³

However meritorious the proposal, it is obviously not relevant to the case of Stephen Dawson. Stephen was not terminally ill, and his parents never denied that medical benefit would accrue from the contested brain surgery. Their view was simply that he was better off dead. There are two unusual features to the Dawson case, but this parental sentiment is not one of them. Rather, they are: (1) that the parental reluctance to consent to life-saving medical treatment invariably arises when the defective child is newborn; and (2) that the issue was resolved beyond the confines of the parental/physician relationship. The former is illustrated by *In re B*, while testimony to the latter is the stark fact that *In re B* is the only reported case in Anglo-Canadian law on the question of pediatric euthanasia.

The issue that will occupy the balance of this case comment can be extracted from an early press report on the *Dawson* case, which commented that the court action "upsets doctors who see (it) as interference in a decision that should be made jointly by a physician and parents." In other words, who decides?

Law Reform Commission of Canada, *Euthanasia, Aiding Suicide, and Cessation of Treatment*, Report No. 20. (Ottawa: The Commission, 1983), 32.

If anything, the Dawson case indicates that the time has come to take a long hard look at the nature of such life-or-death decision-making by parents and physicians. And, in this regard, what very quickly becomes apparent is that the person at risk — inevitably a handicapped newborn — is denied the protection of fundamental justice. Consider, for example, the Criminal Code. It defines the behaviors that are prohibited so that the public may know the rules that must be obeyed. One may use the term *substantive justice* to describe a system that broadcasts the rules or guidelines that govern the actions of its subjects. However, substantive justice while necessary is not sufficient because there must be a mechanism in place that enables the rules to be fairly and consistently applied. Such is *procedural justice*. In other words, procedural justice requires the presence of a forum endowed with the tools to apply the rules already in place, which is why we have courts, judges, attorneys, and trials conducted in accordance with rules of evidence.

In the case of defective newborns, we find neither substantive nor procedural justice. There is an absence of articulated rules or guidelines that need be applied to the question when life-sustaining medical treatment may properly be withheld. Likewise, there is no stipulated procedure mandating the framework within which the decision-making process is to function.

In addition, treatment decisions in this context are arrived at in a highly individualized, *ad hoc* fashion, which precludes the operation of yet another criterion of justice: that like cases be treated alike. Assume, for example, two infants born with Down's syndrome and life-threatening bowel obstruction; and that both sets of parents object to the recommended surgery (a fairly common scenario, as reflected in the *In re B* case). Baby A dies because the physician believes that parents know best. Baby B lives because the physician wishes the surgery done and exercises the force of his personality and authority to persuade the parents to that end. Some parents play an active role in the process. Others thrust the responsibility upon the medical staff. Some physicians express the philosophy that, in cases of severe handicap, parental wishes should control the outcome; others that doctor knows best and should persuade the parents to his point of view. Still other physicians believe that it should be a joint decision.

Furthermore, physicians present a broad range of opinion as to whether various handicaps are sufficiently devastating to warrant the withholding of life-sustaining treatment. And well they should, since the question whether a particular infant's life is worth living is by nature not subject to medical resolution. It is rather a moral question, and the medical profession can present no special credentials to render such a decision.

Clearly, it is time for a public hearing on the practice of pediatric euthanasia. What the *Dawson* case proves is the necessity for the appointment of a board of inquiry to examine that practice and to formulate an appropriate public policy response. However constituted, the particular composition of the board is not relevant here, although suffice it to comment that the Law Reform Commission of Canada would appear well suited to the task.

Of immediate concern, however, is the board's terms of reference; and in this regard, one must emphasize that the primary question is not, "Who decides?" for we cannot address that question until we know what is being decided. That is, the identity of the decision-makers is relevant to the implementation of procedural justice; applying rules already in place. On the other hand, the threshold concern must lie in the domain of substantive justice; formulating the rules in the first instance.

Our initial inquiry thus becomes whether the withholding of treatment should be forbidden altogether, or whether it is appropriate public policy to formulate rules or guidelines permitting its practice in selective cases. At this point, it should be noted that, in both *In re B* and *Dawson*, there is implicit recognition that a blanket policy mandating treatment in all cases may not be warranted. In the English case, the court stated that the issue was "whether the life of the child (was) demonstrably going to be so awful" as to justify withholding treatment, or whether her life was "still so imponderable" as to require the converse.⁴ In *Dawson*, Judge McKenzie made emphatic reference to this passage, as well as to its elaboration in the following dictum by the English court: "There may be cases . . . of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion".⁵ In fact, he resorted to this approach as the major pillar supporting his conclusion that Stephen's plight was not so hopeless as to obviate the proposed surgery.

Assuming the creation of the proposed board, one may anticipate that it would not opt for a blanket prohibition against the withholding of treatment absent the policy judgment that medical intervention was always in the child's best interest. The question is therefore whether there are defects so catastrophic that discretion in this regard should be permitted to affect case management. If the board determines that such defects do in fact occur, it clearly would be obliged to specify each of those conditions in terms that are translatable into the medical fact-finding processes of diagnosis and prognosis. Admittedly, this would prove an awesome and monumental responsibility, but it is not beyond accomplishment. At this point, it is enough to add that the quest would require the solicitation of not only medical, nursing, and psychiatric expertise, but also the testimony of specialists in such disciplines as occupational therapy, social work, psychology, sociology, moral philosophy, and theology.

If the board does find that such devastating disease categories do exist, its next step would be to institutionalize the process for deciding particular cases in which the decision to let die is a considered option. At this stage, the board might well conclude that the courtroom should serve as the forum of last resort. This would reflect the sentiment that case-by-case litigation is inadvisable in this context. In other words, that the typical judicial proceeding, with its narrow focus on the facts and its reliance upon technical

4. *Supra* n. 2, at 1424.

5. *Ibid.*

rules of evidence presented in a highly formalized and adversarial setting, is hardly the appropriate atmosphere for resolution of this kind of case.

There is, however, a middle ground approach between fully dressed judicial involvement on the one hand, and the informality and rudderless direction of the *status quo* on the other. That alternative is the establishment of special hospital committees to hear such cases. The committees would in effect sit as administrative tribunals. They would contain both medical and lay personnel; and it would be advisable for the proposed board to produce guidelines with respect to membership and operational procedures.

If the committee, in its application of the stipulated medical criteria to the particular case, opts for withholding treatment and the parents concur, that should resolve the matter. In such case, the committee should then be required to submit a full report of its proceedings to the provincial attorney-general. However, if the committee rules otherwise and the parents cannot be persuaded to accept the treatment decision, they should have the option to seek judicial resolution of the issue.

In conclusion, this commentator submits that the claims of fundamental justice and sound public policy dictate the implementation of the general scheme outlined in this comment. The mechanisms of 'life-or-death' decision-making affecting defective newborns have functioned far too long under the clouded vision of public responsibility. Yet, justice cannot flourish in an atmosphere of impaired visibility. In truth, it forfeits its very entitlement when it comes cloaked in the shadows of clandestine judgment. Thus far, the fate of severely handicapped infants has been determined in the twilight zone of private, *ad hoc* decision-making. It is time that the shadows be lifted, and the twin spotlights of substantive and procedural justice brought into focus upon the contemporary practice of pediatric euthanasia.

