NEONATAL INTENSIVE CARE: THE DILEMMA FOR MEDICAL LAW

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Canada’s mortality rates for low birth weight and deformed newborns used to be extremely high. A short while ago, many Canadian doctors thought that this was natural. The low birth weight infant suffered from immaturity of the respiratory system which made breathing problematic. High mortality in deformed populations was perceived to be nature’s way of eliminating its mistakes. Only in very selective cases did Canadian doctors intervene with the then available medical techniques.

Great advances in all departments of pediatric medicine radically changed the survival potential for low birth weight and deformed newborns. With this progress, many practitioners modified their views about treating seriously ill children. In 1962, under pressure from medical staff, hospitals in Toronto and Montreal established experimental neonatal intensive care centres to combat high rates of infant mortality and long-term disability. The neonatal intensive care centre is a small, highly specialized, interdisciplinary facility within the hospital, charged with primary responsibility for treatment of serious pediatric cases.  

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3 Neonatal units may or may not be integrated with obstetric facilities (which may have programs to identify high risk expectant mothers). Integrated units are referred to as “perinatal” facilities. It appears that Alberta, Quebec and Nova Scotia have been persuaded to combine fetal-obstetric care with neonatal intensive care: see Geckie, Alberta Medical Association Approves Improvements in Maternal Care, 117 C.M.A.J. 927 (1977); Perinatal Intensive Care after Integration of Obstetrical Services in Quebec: A Policy Statement of the Quebec Perinatal Committee (Quebec: Ministry of Social Services 1973); Scott & Goddard, Assessment of the Role of Antenatal Referral in Reduction of Neonatal Deaths. 11 Ann. Roy. Coll. Phys. Surg. Can. 79 (1978) (Abstract of paper presented at the 47th Annual Meeting of the Royal College of Physicians and Surgeons of Canada, Vancouver, 26-28 Jan. 1978). Ontario still constructs non-integrated neonatal units, such as the Children’s Hospital of Eastern Ontario, despite convincing evidence that the units perform best when integrated: see P. Swyer, supra note 1, at 180; Regional Services in Reproductive Medicine: The Report of the Joint Committee of The Society of Obstetricians and...
The first units were remarkably successful in preventing infant mortality and long-term disability. Consequently, the neonatal intensive care concept spread throughout Canada. Today, twenty-nine units are in place. Several more are under construction or in the planning stage.

Although neonatal units experience a diverse case load, the majority of cases referred are low birth weight babies suffering from respiratory distress. These cases pose a dilemma, because techniques for estimating their progress are unreliable. In one-third of extreme asphyxiation cases, newborns, unlike adults, recover completely, even if spontaneous respiration is absent for thirty minutes. Two-thirds, however, suffer severe damage, destroying, in many cases, all capacity for socialization and self-awareness. Many become ventilator-dependent vegetables. A similar problem arises with the smaller number of infants admitted for anomalies distinct from immaturity.

The success of Canadian neonatal intensive care has been accompanied by intractable ethical and legal dilemmas. Neonatal intensive care makes life possible where, just yesterday, it would have been unimaginable. It ranks among our foremost achievements that nature's rejects are brought into the human family. However, neonatal intensive care also generates grossly deformed survivors, many of whom require permanent institutional care and never achieve a cognitive existence. Consequently, many Canadian doctors think that some seriously ill children should not be treated. All of the neonatal units practise selective treatment. With children considered unsalvageable, beyond feeding and warmth, care is simply withheld. The child is allowed, and in some cases even assisted, to die.

Gynaecologists of Canada and the Canadian Pediatric Society on the Regionalization of Reproductive Care in Canada 21-22 (P. Swyer & J. Goodwin eds. 1973). Full integration is not possible anyways because roughly 30% of risk pregnancies cannot be identified by current medical knowledge: see A Regionalized System for Reproductive Medical Care in Ontario: Report of the Advisory Committee on Reproductive Medical Care to the Minister of Health for Ontario 49 (1979). Nevertheless, Ontario's policy means that a very high proportion of seriously ill children must be referred to a neonatal centre after birth: 1,898 of 2,600 admissions to tertiary care centres in Ontario were referred as newborns for the 1976 year.

In Ontario, the units were an important factor in successfully attacking newborn mortality. The death rate per thousand live births at age 0-6 days fell dramatically, from 19 in 1950, to 7.6 in 1976: see A Regionalized System for Reproductive Medical Care in Ontario, Report of the Advisory Committee on Reproductive Medical Care to the Minister of Health for Ontario 3 (1979).

For example, at McMaster University Medical Centre (25 beds) in 1978, the intensive care unit had 735 admissions. Of these, 394 (53.6%) were under 2,500 grams; 158 (21.5%) were under 1,500 grams. In Ontario as a whole, the incidence of low birth weight infants (less than 2,500 grams) was 7.1% of live births in 1968: Ontario Council of Health, Perinatal Problems 12 (1971).


Chance, supra note 1.
The ethics and legality of passive euthanasia of defective newborns will not be discussed. As previously mentioned, all Canadian units engage in selective treatment. Although, in one case, under the Ontario Child Welfare Act, 1978, a Canadian court compelled treatment, it is notable that, based on the defence of standard medical practice, Canadian law tolerates passive euthanasia in most cases. In some provinces, deputy attorneys-general have suppressed prosecutions commenced by junior prosecutorial staff. Similarly, on the ethical front, while some have spoken out against selective treatment—most notably the Canadian Psychiatric Association—there is a distinct absence of outrage or clamour for public attention on the part of most interested Canadians.

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8 S.O. 1978, c. 85.
9 Court Saves Mongoloid Baby. The Toronto Star, 21 Jan. 1977, at p. 1. Moreover, threats of legal action have compelled treatment where an initial decision for no intervention was made. In one case, pressure from nursing staff forced a doctor to operate after active treatment had been withheld for six weeks: Guttman. On Withholding Treatment, 111 CAN. MED. ASSN. J. 520 (1974). In another case, threats of legal action by a psychiatrist-administrator of a child welfare organization resulted in the reversal of the medical decision: id. Similar cases have occurred in the United States: see In re Phillip B., 156 Cal. Rptr. 48 (Ct. App. 1979); In re Hofbauer, 411 N.Y.S. 2d 416 (App. Div. 1978); Maine Medical Center v. Houle, (unreported, Me. S.C., 19 Feb. 1974) (Roberts J.).

10 See generally Linden. The Negligent Doctor, 11 OSGOODE HALL L.J. 31, at 32 (1972): "If a physician's conduct complies with the customary practices of his profession he is virtually assured of being exonerated when something goes wrong.''

11 It is sufficient to base the proposition on the fact that there has been no successful criminal prosecution or civil liability against any Canadian doctor for passive euthanasia of defective newborns, despite wide publicity of the practice. Criminal prosecutions have been commenced in British Columbia, but the Deputy Minister ultimately instructed the local prosecutor to discontinue the cases. The cases came to the attention of the Crown's office through the Vancouver police who received a complaint from a nurse working at the hospital: see The Globe and Mail (Toronto), 16 Aug. 1978, at 11. There have been Children's Aid proceedings brought in Canada, as in the United States, to compel lifesaving treatment: see supra note 9. However, these cases only illustrate the breadth of the principle that a substituted consent to refuse lifesaving medical treatment may be given by a properly authorized person: see Superintendent of Belchertown State School v. Saikewicz, 370 N.E. 2d. 417 (Mass. 1977); In re Quinlan, 355 A. 2d. 647 (N.J. 1976). The cases do not defeat the principle of substituted consent on behalf of incompetents to refuse medical treatment. This view is unlikely to satisfy the academic purist, as evidenced by the lengthy literature found in law journals: see, e.g., Robertson. Involuntary Euthanasia of Defective Newborns: A Legal Analysis, 27 STANFORD L. REV. 213 (1975); Skegg. The Termination of Life-Support Measures and the Law of Murder, 41 MODERN L. REV. 423 (1978); Swadron & Himel. Legal Opinion on Position Paper: Withholding Treatment, 24 CAN. J. PSYCHIATRY 81 (1979). However, administration of the law in the United States and Great Britain does not support the wide view of a prohibition on withholding treatment in appropriate cases.

12 Supra note 11.


14 The Canadian Medical Association has officially endorsed withholding treatment from seriously defective newborns. In 1974, the governing body passed a
A fruitful line of inquiry lies in probing the process of selection for treatment. Legal and medical policy can more effectively be formulated if research concentrates on difficulties relating to who is the proper decision-maker, what is the proper procedure of decision, what paramedical data properly figures in the decisional formula, what is the proper role of the parents, and what is the proper interim case.

Canadian doctors face these difficult questions in neonatal intensive care every day. In practice, Canadian neonatologists have developed standards of acceptable medical conduct to cope with such dilemmas. The standards are articulated in medical practice; nowhere are they written down or otherwise formally codified. These practices condition the behaviour of staff, including new staff, in the units. A neonatology resident, for example, will observe, absorb, and be instructed in approved routines. Such routines — which, of course, can be documented empirically — constitute a code of ethics professionally established in the system of institutional medical life. These routines are practical ethics in the sense that this is what doctors actually do and feel pressured to do, even if not certain that what they are doing is right.

It follows that nothing worthwhile can be said about passive euthanasia until the facts are established. In pursuit of this objective, interviews were conducted with over 200 neonatologists, pediatric specialists, nurses, residents and parents in all Canadian neonatal intensive care centres. What follows are certain observations and conclusions emanating from that research.

The first important issue is identifying the proper authority as between parents, courts, variously constituted committees and doctors to make decisions for passive euthanasia of defective newborns. The research leaves no doubt whatsoever that, in Canada, a professional medical consensus exists on this issue. Where doctors conclude that treatment is improper, they retain decisional authority. Even if parents

-resolution recognizing the ethical acceptability of entering a “no resuscitation” order on a patient’s file in some conditions of “ill-health.” This term was used in contrast to “impending inevitable death” and thus implies conditions of ill-health where death is not inevitable: see Canadian Medical Association, Council on Community Health, General Council 84 (1974). Recognizing that legal liability could attach to a doctor giving effect to this resolution, the C.M.A. sought the advice of a joint C.M.A./C.B.A. Committee and of the Medical Protective Association. These sources advised the withdrawal of the resolution for legal reasons. The Council ignored this advice and reaffirmed its position the following year. A representative of the C.M.A. summed up the Association’s attitude: “The law be damned.”

15 The proposition derived from the research is consistent with views expressed by doctors in the American and British literature: see Forrester, Ethical and Social Aspects of Treatment of Spina Bifida, 295 The Lancet 1033 (1968) (letter to the editor); Ingelfinger, Bedside Ethics for the Hopeless Case, 289 New Eng. J. Med. 914 (1973); Lorber, Ethical Problems in the Management of Myelomeningocele and Hydrocephalus, 10 J. Roy. Coll. Physic. 47, at 56 (1975):

Who should make the decision to treat or not to treat? . . . One cannot leave it to the parents because they are hardly ever sufficiently informed and because they are under severe emotional strain at the time. Further, whatever
specifically demand surgery, doctors may refuse. "The decision is ours," a chief neonatologist stated, "but we take the parents' wishes into every consideration." As one neurosurgeon said with great emphasis:

I don't let the parents make the decision. I don't think it's fair letting the parents make the decision. I think we are the responsible ones to make the decision . . . anyway, they should not be able to make a decision. They can't make a decision. Therefore, we make the decision for them after discussion back and forth with them.

Although the parents' views about treatment are important to the medical team and figure significantly in the decision-making formula, sharp disagreements about medical protocol result. Three mechanisms are employed by the doctors when asserting their authority: first, doctors use their control over the flow of medical information given to the parents to shape the parents' views; secondly, co-ordinated interchanges between neonatal staff and the parents influence the parents; thirdly, doctors refuse outright to treat, advising the parents to seek care elsewhere. If a problem occurs because the parents refuse to consent to treatment deemed medically necessary, medical authority is asserted by the same means. In addition, however, the hospital compels treatment by application under the child protection statutes for court-ordered substituted consent.¹⁶

The established consensus that doctors are the proper decision-makers results in certain disquieting phenomena. The most obvious is a failure to inform parents, adequately and objectively, of available medical alternatives. Associated with this is a failure to inform parents of actual medical decisions which have been taken about their child and which will result in its death. Parents are not usually told that, for example, a decision was made to withhold ventilation from their child or to turn the ventilator off. Parents may not be told about available

¹⁶ In Ontario, for example, The Child Welfare Act, S.O. 1978, c. 85, s. 19(1)(b)(ix) defines "child in need of protection" as, inter alia a child where the person in whose charge the child is neglects or refuses to provide or obtain proper medical, surgical or other recognized remedial care or treatment necessary for the child's health or well-being, or refuses to permit such care or treatment to be supplied to the child when it is recommended by a legally qualified medical practitioner . . .

Under s. 21(1) various officials may seize a child in need of protection without warrant or secure an order to bring the child before the court. Under s. 29, if a court finds a child is in need of protection, a medical assessment of the child can be ordered to assist the court in deciding on a proper order. Similar procedures are provided for in Quebec under the Youth Protection Act. S.Q. 1977, c. 20.
transplantation if the doctors opt for passive euthanasia. In many instances doctors by-pass established hospital committees — such as the transplant committee — after having made a decision not to treat a particular newborn. As well, in numerous cases doctors initiate treatment without parental, court or committee consent.

Existing Canadian law as to informed consent\textsuperscript{17} is inadequate to meet the challenge of these cases. The speed required for decisions in the intensive care nursery precludes long explanation and court or committee proceedings. Medical opinion in these cases, being interdisciplinary, frequently resists easy, non-technical summation in the form of "yes" or "no" options. Parents are often overwrought when confronted by a severely damaged newborn. It is unrealistic to expect in these circumstances a cold, rational calculation of risks by the parents.

Legal control by the familiar adversarial process of civil and criminal litigation is inappropriate and unproductive to govern such abuses as described above. Is it not worth considering whether a more appropriate assertion of legal authority would be accomplished through internal administrative control by the hospital's medical agencies? An internal unit could develop standards and guidelines, continuously revised, in light of mandatory research, for the contentious cases that repeatedly occur in the intensive care nursery. Greater strength could be given to the process by powers of internal discipline. The disciplinary machinery could be engaged by internal or external complaint. This form of control would have the benefit of improving the quality of medicine through a continuous program of review and research, and of generating standards having the sanction of those in an informed position. Of course, if the hospital were negligent in its review and supervision of the process, for example, by articulating indefensible standards, or failing to initiate continuing review and research, civil liability would follow in the ordinary way.

Is it not worth considering also whether existing ethical precepts require redefinition in light of these cases? Are not the models of

self-determination and privacy grossly artificial when applied to newborns? Even the language of "substituted consent" reeks of unreality. Discerning ethical analysis is needed of the smaller issues involved, such as the proper decision-maker or decisional process. Abstract generalities about the larger issues of passive euthanasia and infanticide are insufficient.

A second dilemma relates to the procedure by which decisions to withhold treatment are made. Assuming that doctors are the decision-makers, which doctors should decide, and, if more than one, what procedures should govern the decision-making process? Established Canadian routines reveal that a professional consensus exists on that issue. While the neonatologist retains formal responsibility for the decision, established procedure requires that his formal authority be tempered by the necessities of an interdisciplinary specialty. Institutional practices require the neonatologist to initiate appropriate consultation with pediatric colleagues.

The interdisciplinary approach to serious neonatal cases is a key rationale for the neonatal unit. Meningomylocele, for example, produces deficiencies in urological, neurological and orthopedic functioning. A urologist would not be competent to treat meningomylocele, but, as a member of the neonatal team, he could tell other doctors whether the urological system was repairable, and describe the expected quality of the child's life from a urological point of view. Neurological and orthopedic data would be separately assessed by pediatric neurologists and orthopods. The neonatologist collates, assembles, and discusses all the data with participating members. Decision-making follows a team approach.

The interviews revealed that the interdisciplinary approach is vulnerable. Where one system anomaly is pronounced, the specialist evaluating that system becomes the key. Not uncommonly, that doctor regards the patient as his patient. This may affect his willingness to consult with or accept the advice of pediatric colleagues.

In neurosurgical cases, this problem is conspicuous. Neurosurgeons jealously guard their perceived prerogative to decide whether to operate. Consultation withers. The interdisciplinary approach shatters.

One chief neonatologist, angrily describing the typical decision-making process with respect to spina bifida in his hospital, stated:

A. They don't consult very much. Some people don't consult. These neurosurgeon doctors don't consult very much.
Q. Do you feel that's a problem?
A. It is a problem! It's so much of a problem you don't know exactly what could be done.

The problem is that a one-man approach usurps the interdisciplinary _raison d'être_ for neonatal intensive care and undercuts the demonstrated strength of its team approach to medicine. An ultra-sophisticated facility metamorphoses into a neurosurgical satellite.
What has Canadian law contributed to resolving these difficulties? Some hospital regulatory statutes stipulate a duty to consult in serious cases. However, enforcement is through the torts system; it thus depends on patient-initiated complaints to the courts. This has never happened. The Canadian Medical Association’s Code of Ethics requires consultation acceptable to the patient when diagnosis or treatment is difficult or obscure. Again, the problem is enforcement through the torts system or by externally-initiated action by the College of Physicians and Surgeons. This is unlikely to happen. More successful is the requirement of consultation imposed on medical staff by the by-laws of many hospitals. The by-laws are enforceable by informal, internal administrative discipline. Is it not worth considering whether, if refined, this might prove useful? Continuing review and research could illuminate decision-making procedures which could be articulated as standards by the hospital’s medical agencies. The standards could be enforced by inspection. Disciplinary machinery, triggered by internal or external complaint, could strengthen the process. Court control would be used only if the hospital were negligent in establishing a research, review, and inspection program.

A third problem area concerns the information which must be developed prior to deciding to withhold treatment. Neonatologists are generally agreed that the child’s anticipated quality of life must be determined by extensive medical assessments of the child’s separate body systems. “Quality of life” refers to the child’s potential for physical and mental development, and environmental factors which bear on the potential for development. Where the anticipated quality of life

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19 Yepremian v. Scarborough Gen. Hosp., 6 C.C.L.T. 81 (1979), rev’d on other grounds, 28 O.R. (2d) 494, 13 C.C.L.T. 105 (C.A. 1980). Additional enforcement is provided by the power of the department head to remove the attending physician from the case. This is unlikely as the chief neonatologist is usually the attending physician.


21 See The Health Disciplines Act, 1974, S.O. 1974, c. 47, s. 60(3)(c) which allows a member of the College of Physicians and Surgeons to be found guilty of professional misconduct as defined in the regulations. According to O.Reg. 577/75, ss. 26.20, 26.31, professional misconduct is defined as “failure to maintain the standard of practice of the profession” and “conduct . . . that . . . would reasonably be regarded by members as disgraceful, dishonourable or unprofessional.” These sanctions must be taken to incorporate the C.M.A. Code of Ethics adopted by resolution of the Council of the College. Proceedings under this section may be initiated by a complaint of a member of the public or of the College to the Complaints Committee under s. 58 of the Act.

22 See, e.g., By-Law Ottawa Civic Hospital, s. 10.2.24 (1973).

23 Breach of a rule is subject to discipline by the department head under s. 22 of the By-Law, id. There is a right to a hearing by the Hospital Appeal Board if a doctor is so disciplined.
does not decisively indicate whether treatment should be initiated, the parents' wishes are ascertained, and figure as a separate factor in the decision whether to treat.

The use of socio-economic and personal data in medical decision-making is a special problem. Most Canadian neonatal centres take initiative in developing paramedical facts to weigh in the decision-making process.\(^{24}\)

Many units employ social workers as paramedical fact-gatherers. They are charged with the responsibility for interviewing the family and preparing reports containing paramedical data. The reports are attached directly to the child's medical chart.

The following is a list of the paramedical data repeatedly emphasized as relevant: the marital status of the baby's parents; the quality of the parents, including such things as intelligence and psychological adaptation; the effect a deformed child would have on the family; the economic position of the baby's family; the ability of the parents to have additional children; and the presence of mental retardation.

The reason why such factors are considered important is because, as a chief neonatologist has stated:

There is no use in sending a baby back who requires complicated management and care to a mother who is unmarried, who has an I.Q. of 70 and quite unable to deal with it. She may have part-time work or something like that, or six other kids in the family. We know it's not going to work . . . .

"You have to consider," said a cardiologist, " . . . if you are dealing with a [poor] psychological situation . . . if you fix this child surgically, is he going to make it in the post surgery? . . . It's a very big part of pediatrics."

Canadian law has little to contribute to the debate about the use of paramedical data in medical decision-making. The Canadian Medical Association's Code of Ethics, enforceable through the torts system and external disciplinary machinery of the College of Physicians and Surgeons,\(^{25}\) requires doctors to consider as paramount the patient's well-being.\(^{26}\) It is unlikely that this constitutes any legal guide to data

\(^{24}\) See, e.g., Shurtleff, Hayden, Loeser & Kronmal, *Myelodysplasia Decision for Death or Disability*, 291 N. ENG. J. MED. 1005 (1974): "For an initial decision to offer maximum therapy the following points were considered: . . . a family (i.e. natural parents) with economic and intellectual resources living within reach of appropriate medical facilities . . . ."; Lorber, *Results of Treatment of Myelomeningocele*, 13 DEV. MED. CHILD NEUROL. 279 (1971). Diane Crane's, *THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS* (1975), leaves no doubt that non-medical socio-economic and personal information regularly influences decisions whether to treat. Professor Crane administered questionnaires to large numbers of doctors describing roughly identical cases with certain non-medical factors varied. The resulting variation in answers as to whether the child would be treated is convincing proof that these factors are highly germane.

\(^{25}\) *Supra* note 21.

selection or quality control. Again, is it not worth considering whether appropriate legal intervention could come from an internal disciplinary body supported by continuous review, research, and standard setting? If all units researched the use of paramedical data and methods of quality control, would not medical practice improve? Clearly that must be a major objective of legal control.

A final dilemma concerns the care to be provided to a child whom the doctors decide not to treat actively. There is general agreement that the child should be fed, kept warm, and have his fluids managed. A consensus exists that nothing further should be done for him. No antibiotics should be administered. No minor surgery should be performed. No resuscitation should be attempted.27 If all units researched the use of paramedical data and methods of quality control, would not medical practice improve? Clearly that must be a major objective of legal control.

If anything, Canadian law relating to interim care has had a deleterious effect on medical practice. The nineteenth-century common law cases hold that any omission to provide life-saving necessaries in a hospital context, including medical treatment, is sufficient to engage the manslaughter and murder sections of the Criminal Code.28 As previously mentioned, prosecutions have been started, but subsequently discontinued, on this theory. Additionally, the Canadian Criminal Code imposes special duties on physicians, once treatment is commenced, to continue, if failure to treat would be dangerous to life.29 These provisions, general in their application, need reconsideration as applied to the intensive care nursery. It would be most unfortunate if a widely publicized prosecution were commenced, for it would cast a chill over the entire development of neonatal practice. Would it not be preferable to

27 The research finding is consistent with views expressed by certain British doctors in the literature. See also Lorber, The Doctor’s Duty to Patients and Parents in Profoundly Handicapping Conditions, in Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children 9, at 21 (D. Roy ed. 1978):

It is essential at this point to state clearly that one hopes that those who are not treated should not live long. It is imperative that non-treatment should really be non-treatment, not just no operation. Nothing should be done to prolong life; no incubators; no tube feeding; no antibiotic drugs and most certainly no resuscitation.


29 S. 199.
assert legal control through an internal, administrative organ, based on a sound program of research and review? In this way, the twin goals of developing the quality of medicine, and providing machinery to settle disputes swiftly, certainly, and with justice, could be harmonized.