The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children

I. INTRODUCTION

Artificial respirators, artificial cardiac pacemakers, kidney dialysis machines, amniocentesis,1 and reproductive engineering2 have become common medical terms, known and used widely today. However, with these rapid advancements in medicine, concomitant ethical, legal, and medical dilemmas come about, the resolution of which often lags considerably behind the medical breakthroughs. The parental decision to withhold medical treatment from a child is strained additionally by the new medical technology. Some of these decisions are viewed with skepticism by society, with irony by the media, and with caution by the courts. An additional complication is that currently there are no clear-cut medical or legal criteria to guide parents, doctors, and courts in resolving the human problems presented by life-saving, life-preserving, and death-precipitating issues. Opinions differ on whether parents must take advantage of all the medical advancements and preserve life at all costs, regardless of their child’s underlying condition and possibilities for a meaningful existence.

The types of medical, legal, and moral decisions facing parents today are vast and complex. For example, should a life-sustaining system be disconnected so that a child, who is in an irreversible vegetative state, is allowed to live or die naturally?3 Should an operation be performed on a newborn infant to cure a physical defect, leaving untouched a severe physical handicap and possible mental retardation?4 Should parents withhold their consent from the performance of a risky operation that may cure the heart defect of their otherwise dying Down’s Syndrome child?5 Should they decline to follow a conventional but very painful treatment for their child that provides only a slim chance of cure, in favor of a new and unproven but painless method of treatment?6

This Note will review the present state of the law regarding the legal limits on parental autonomy in the area of withholding treatment from chil-

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1. Amniocentesis is a minor surgical procedure that involves the aspiration of amniotic fluid from the uterus. It is used to detect genetic diseases, such as Down’s Syndrome, during the third or fourth month of pregnancy. DOWN’S SYNDROME (MONGOLISM): RESEARCH, PREVENTION, AND MANAGEMENT 49, 72 (R. Koch & F. del la Cruz eds. 1975). “This new and exciting technology, coupled with the continuing evolution in social and ethical attitudes of our society, opens new doors for medical science—but these are doors which must be opened with great care and concern.” Id. at 52.

2. Reproductive engineering is a way of “[i]nterfering with the natural process of fertility and childbearing . . . . Methods include all types of contraception or family planning, abortion, sterilization, artificial insemination by husband or other donor, and in vitro fertilization.” Omenn, SCIENTIFIC MANIPULATION OF THE UNBORN, 1975 NATIONAL MEDICOLEGAL SYMPOSIUM 15.


dren. The state’s power to intervene and order treatment against the parents’ decision will be examined. Also, the views on this matter within the medical profession will be briefly stated. Finally, differing points of view within legal and medical circles about the proper resolution of this matter will be presented.

II. THE DOCTRINE OF PARENTAL AUTONOMY

The doctrine of parental autonomy had its beginnings as an issue of constitutional stature in a series of United States Supreme Court decisions dealing with parents’ rights to direct their children’s education. In 1923 in Meyer v. Nebraska,7 the Court struck down a Nebraska statute that made it a criminal offense to teach a foreign language to children who had not yet completed the eighth grade. The Court stated that the liberty guaranteed by the fourteenth amendment encompassed “the right of the individual to . . . acquire useful knowledge, to marry, establish a home and bring up children.”8 Two years later, in Pierce v. Society of Sisters,9 referring to an Oregon compulsory education act that required children to attend the state’s public schools, the Court stated that the act “unreasonably interferes with the liberty of parents and guardians to direct the upbringing and education of children under their control.”10

In 1944 the Supreme Court rendered the landmark decision of Prince v. Massachusetts.11 While affirming unswerving support for Meyer and Pierce, the Court announced that parental rights were not without limitation: “The right . . . does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death.”12 The custodian of a nine-year-old child who had been selling religious pamphlets in violation of the state’s child labor laws claimed that the conviction violated her freedom of religion and her rights as a parent. In upholding her conviction, the Court retreated somewhat from its prior broad rulings. However, the case stands for the proposition, quoted in many subsequent decisions, that “the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder.”13

Finally, in Wisconsin v. Yoder14 the Supreme Court held that Amish parents could not be convicted of violating Wisconsin’s compulsory school attendance law for preventing their minor children from attending the last two grades of high school. Although the case arose in a first amendment freedom

7. 262 U.S. 390 (1923).
8. Id. at 399.
10. Id. at 534–35.
12. Id. at 166–67.
13. Id. at 166.
of religion context, the Court shed some light on the limits of parental autonomy in the area of medical care: "[T]he power of the parent, even when linked to a free exercise claim, may be subject to limitation under *Prince* if it appears that parental decisions will jeopardize the health or safety of the child."

So far, however, the Supreme Court has not explicitly stated what protection should be accorded the parental decision to withhold medical treatment from their child. The only law on the subject is a product of state court decisions, often in conflict even within a specific jurisdiction. The guidelines that have emerged are helpful mainly in situations in which the child is in imminent danger of death. The most serious questions arise when the child’s life is not immediately in danger, and the treatment either is strongly recommended by the medical profession or is of some value to the child, and the parents refuse to give their consent.

### III. Limitations on Parental Autonomy

The state acquires authority to intrude in the parental decision making process from its police power, its *parens patriae* power, and its statutory power, either through penal or child neglect statutes. Under its police powers, the state may enact legislation for the protection and welfare of the population at large, which, of course, includes children. Thus, in the exercise of its police powers, the state legitimately may provide for compulsory vaccination over parental religious or other objections.

The state may legislate for the protection of children under the doctrine of *parens patriae*. The concept originated in the courts of equity and, since then, has been invoked as a legal ground to enact child neglect, abuse, and dependency statutes. In *People ex rel. Wallace v. Labrenz*, the Illinois Supreme Court stated that a court’s jurisdiction in a parental neglect situation is not only conferred by statutory language, but also by the fact that it is "the responsibility of government, in its character as *parens patriae*, to care for infants within its jurisdiction and to protect them from neglect, abuse, and fraud." Thus, even if a state had not enacted an appropriate statute specifically conferring jurisdiction on the court, or even if the statutory definition of

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15. *Id.* at 233–34.
17. E.g., *People ex rel. Durham Realty Corp. v. LaFeta*, 230 N.Y. 429, 130 N.E. 601 (1921).
23. *Id.* at 623–24, 104 N.E.2d at 773.
neglect did not encompass the wrong suffered by the child, the state could still use its parens patriae power as a jurisdictional basis to intervene.24

Child neglect statutes25 were enacted after the penal laws26 and supplemented the penal sanctions with civil remedies. Although they coexist today, it is a rare case in which parents are convicted for neglecting the medical needs of their children.27 The most common procedure used today when parents fail to provide a child with necessary medical treatment is court appointment of a provisional guardian for the limited purpose of consenting to the needed treatment or for court declaration of wardship for the limited purpose of securing the treatment.28

While parental autonomy may be limited by the state’s power to intervene on behalf of the child, it may also be limited by the individual rights of the child. The United States Supreme Court has held that, “Minors, as well as adults, are protected by the Constitution and possess constitutional rights.”29 Though parents are presumed to act in the child’s best interests,30 there is judicial recognition that this is not always the case.31 In recent cases the child’s independent decision to forego or undergo treatment without parental consent has been recognized on the theory that the child, like an adult, has a right of privacy. For example, in a series of Supreme Court decisions dealing with abortion and contraception,32 the Court recognized “that a state could not lawfully authorize an absolute parental veto over the decision of a minor to terminate her pregnancy.”33 Aside from the Supreme Court’s recognition of a child’s independent right of decision, there is also statutory recognition of the principle. For example, some states have a specific provision for the “mature minor.”34 However, there is truth in the assertion that “[w]hen an apparent conflict between the constitutional rights of a child and his parents does reach the courts, careful analysis . . . may reveal that the degree of conflict is greatly

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27. See generally Areen, Intervention between Parent and Child: A Reappraisal of the State’s Role in Child Neglect and Abuse Cases, 63 GEO. L.J. 887, 896-99 (1975).
34. See, e.g., Illinois Emancipation of Mature Minors Act, ILL. ANN. STAT. ch. 40, § 2203-2 (Smith-Hurd 1980), which states, “‘Mature minor’ means a person 16 years of age or over and under the age of 18 years who has demonstrated the ability and capacity to manage his own affairs and to live wholly or partially independent of his parents or guardian.”
Although children's rights are increasingly recognized today, and although in certain circumstances the desires of parent and child will be in obvious conflict, it is only in the case of a "mature minor" that the child's decision regarding treatment will be given decisive weight.

State courts differ in the amount of weight accorded the minor's stated preference regarding medical treatment. For example, in In re Green, the Pennsylvania Supreme Court remanded the case to the lower court so that the wishes of the sixteen-year-old boy regarding nonemergency treatment could be ascertained. An opposite position was taken by the New York Court of Appeals in In re Sampson. There the court indicated that the fifteen-year-old child's preference regarding nonemergency treatment was neither necessary nor material. The court refused to follow In re Seiferth, decided fifteen years earlier, in which the New York Court of Appeals had ruled that a twelve-year-old child's preference to forego nonemergency surgery should be given great weight, since the post-operative therapy would require full cooperation from the child. In the above three cases the child was old enough to have a preference, and in the last two cases the child's preference was identical to that of the parents. Therefore, there never was a clash between each set of parents and child, but merely between the state and the parents. When the conflict between the parent and child surfaces, the disagreement raises constitutional issues.

IV. THE SCOPE OF PARENTAL AUTONOMY

When parents decide to withhold medical treatment from their children, courts have considered the following factors in deciding whether to intervene in the parental decision: (1) whether the risks of treatment outweigh the benefits; (2) whether there is immediate threat to the child's life; (3) whether the nontreatment decision will have adverse emotional consequences on the child; and, in general, (4) whether the child's life will benefit from the proposed treatment. The approach most commonly used is a balancing of the pertinent factors to ascertain whether there is a sufficient basis for state intervention. However, it is difficult to reconcile the developing law in different jurisdictions, mostly because of the emphasis placed on the facts of the particular case, and the great amount of deference granted to the trial court's determination of facts, especially in juvenile court proceedings. Also, in many cases resolution of the problem is a matter of statutory interpretation of the

40. See, e.g., In re Hudson, 13 Wash. 2d 673, 126 P.2d 765 (1942).
42. See, e.g., In re Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955).
43. See, e.g., In re Karwath, 199 N.W.2d 147 (Iowa 1972).
pertinent child neglect, abuse, and dependency statute. Since state statutes vary widely, their interpretation will also vary, as will their applicability to specific parental acts or omissions constituting abuse or neglect in different jurisdictions.\footnote{44}

A. In General

The broad guidelines that have emerged from state court decisions are as follows. In most cases in which the child's life is in imminent danger, parents have no choice and must consent to the necessary treatment.\footnote{45} The rationale is that the child's interest in the preservation of his or her own life is paramount and overrides any parental decision to the contrary, even in light of religious objections.\footnote{46} In situations that are not imminently life-threatening, courts generally give parents great discretion and uphold their decisions as long as they are in the child's best interests and not arbitrary.\footnote{47} In some cases, courts have ordered treatment over parental objections, even in circumstances that were not immediately life-threatening.\footnote{48}

The courts that have ordered treatment over parental objections in situations in which the child's life was not immediately threatened have expressed concern for the child's physical as well as emotional well-being. In re Rotkowitz\footnote{49} concerned a ten-year-old girl who needed surgery on her foot in order to arrest further deterioration of a leg deformity. Although only one parent was opposed to the surgical procedure, the court stated that it would have ordered treatment even if both parents were opposed to it, adding, “A child who is deprived of the use of its limb which becomes progressively worse cannot have a sense of security.”\footnote{50}

A great number of cases have dealt with parental religious objections to blood transfusions needed by their children, either in connection with surgery

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\item\footnote{47} In re Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955); In re Green, 448 Pa. 338, 292 A.2d 387 (1972); In re Frink, 41 Wash. 2d 294, 248 P.2d 553 (1952); In re Hudson, 13 Wash. 2d 673, 126 P.2d 765 (1942). See also Annot., 97 A.L.R.3d 421 (1980); Annot., 52 A.L.R.3d 1118 (1973).
\item\footnote{49} 175 Misc. 948, 25 N.Y.S.2d 624 (1941).
\item\footnote{50} Id. at 950, 25 N.Y.S.2d at 626.\end{itemize}}
entailing substantial blood loss or in connection with an Rh blood condition. In *People ex rel. Wallace v. Labrenz* the Illinois Supreme Court upheld an order to appoint a guardian for an eight-day-old infant girl whose parents refused to give their consent to a transfusion. The child had erythroblastosis fetalis and would have died or been mentally impaired without the transfusion. Most jurisdictions are in accord with the court decision in *Labrenz*, especially when the consequences of deferring to the parents’ wishes would bring death or grave harm to the child. In *Hoener v. Bertinato* a New Jersey court went even further and ordered that custody of an unborn child be given to the welfare department after its birth. In order to live, the child would require blood transfusions to which the parents objected.

By way of contrast, “a competent adult generally has a right to refuse medical treatment, even when such treatment is necessary to save his life.” On the other hand, incompetent adults, even though legally unable to choose to receive or decline life-saving treatment in their own best interest, may do so through their legal guardian or through the proper court, by way of the substituted judgment mechanism.

The success of needed surgery may depend on blood transfusions being administered during the operation. Although some parents consent to the operation, their refusal to consent to the concomitant blood transfusions represents in effect a bar to the operation itself since physicians may refuse to perform the operation if opportunity to transfuse is denied. In this situation courts are split, but the weight of authority is in favor of ordering the transfusion when the child’s life is in danger. Some courts will not appoint a

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53. Id.

54. Erythroblastosis fetalis is defined as follows:

[A] hemolytic disease of the newborn; a grave hemolytic anemia that, in most instances, results from development in the mother of anti-Rh antibody in response to the Rh factor in the (Rh-positive) fetal blood; it is characterized by many erythroblasts in the circulation, and often generalized edema . . . and enlargement of the liver and spleen.

STEDMAN’S MEDICAL DICTIONARY ILLUSTRATED 482 (23d ed. 1976).

55. See cases cited in notes 45 and 46 supra.


59. When a court applies the substituted judgment rule, [T]he goal is to determine with as much accuracy as possible the wants and needs of the individual involved.

60. *See* cases cited in note 46 supra.
guardian if the child’s life is not in immediate danger.\textsuperscript{61} And in other jurisdictions, transfusions have been ordered even in non-life-threatening circumstances. For example, in a case in which the child’s life was not endangered, surgery was very risky and only offered partial correction of a malformed cheek, and the operation would be less risky if delayed for a few years, the court in \textit{In re Sampson}\textsuperscript{62} ordered a fifteen-year-old boy to undergo the dangerous surgical procedure over parental religious objections to the blood transfusions that would probably be required during surgery.

The cases discussed above are in irreconcilable conflict and illustrate the disharmony in the present state of the law, as well as the need for clear and definite guidelines to help avoid seemingly capricious ad hoc judgments by state courts. The uncertainty is not limited to those cases that present a conflict between the parental religious beliefs and the state’s intervention powers. For example, in \textit{In re Karwath}\textsuperscript{63} the father of three children refused to authorize surgical removal of his children’s tonsils and adenoids. The Iowa Supreme Court upheld the order for surgery and stated that it was not “required that a medical crisis be shown constituting an immediate threat to life or limb.”\textsuperscript{64} By way of contrast, in \textit{In re Seiferth}\textsuperscript{65} the court refused to order surgery performed on a fifteen-year-old child with a cleft palate and harelip stating that “[h]is condition is not emergent and there is no serious threat to his health or life.”\textsuperscript{66}

\textbf{B. Recent Decisions}

Three cases decided in 1979 starkly present the problems that courts face today in the area of withholding medical treatment from children: \textit{In re Cicero},\textsuperscript{67} \textit{In re Phillip B.},\textsuperscript{68} and \textit{In re Hofbauer}.\textsuperscript{69} \textit{In re Cicero} dealt with withholding medical treatment from a defective newborn, \textit{In re Phillip B.} with withholding treatment from a Down’s Syndrome twelve-year-old boy, and \textit{In re Hofbauer} with withholding conventional cancer treatment from a child in favor of treating him with laetrile, an unorthodox and unproven method of treatment. Among the factors that entered into the courts’ decisions were: (1) the medical opinions, (2) the immediacy of death, (3) the quality of life, (4) the risks and benefits of the treatment.

\textsuperscript{61} In \textit{In re Green}, 448 Pa. 378, 292 A.2d 387 (1972), the parents of a fifteen-year-old boy would have allowed spinal surgery but would not allow necessary transfusions. The Pennsylvania Supreme Court refused to uphold an order to appoint a guardian, indicating that the physical condition of the child did not immediately endanger his life.


\textsuperscript{63} 199 N.W.2d 147 (Iowa 1972).

\textsuperscript{64} \textit{Id.} at 150.

\textsuperscript{65} 309 N.Y. 80, 127 N.E.2d 820 (1955).

\textsuperscript{66} \textit{Id.} at 85, 127 N.E.2d at 822.

\textsuperscript{67} 101 Misc. 2d 699, 421 N.Y.S.2d 965 (1979).


\textsuperscript{69} 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 783 (1979).
1. In Re Cicero

The problem of the seriously defective newborn, which was raised in *In re Cicero*, has become a hotly debated issue in legal circles.\(^{70}\) Abundant literature on the subject is available within the medical arena.\(^{71}\) This is not surprising since the decision to withhold medical treatment from a defective newborn is made in the special care nursery, usually by the physician in conjunction with the parents, without legal sanctions or intervention or even knowledge on the part of the state. In *In re Cicero*, however, the physician disagreed with the parents and sought a court order to appoint a guardian for the limited purpose of consenting to the needed surgery. The case involved a baby girl born with spina bifida, a spinal disorder\(^{72}\) that required immediate surgery. The court ordered that life-saving surgery be performed on the child, who, if successfully treated, would be able to walk with short braces, but would still lack sphincter control of the bladder and bowels and would run the risk of mental retardation. If treatment had not been ordered, the infant probably would not have lived longer than six months.\(^{73}\)

Although some believe that withholding treatment from defective newborns is a new practice, it has been prevalent for centuries, though not widely publicized until recently.\(^{74}\) A study\(^{75}\) undertaken by Duff and Campbell in the special care nursery of the Yale-New Haven Hospital indicated that of 299 consecutive deaths occurring there, forty-three deaths or fourteen percent were the result of withholding medical treatment pursuant to the combined decision of parents and physicians, and seven of the infants had the condition for which the baby girl in *In re Cicero* was treated.

A widely publicized case\(^{76}\) reveals the cruelty of the practice of withhold-
ing treatment from defective newborns. At Johns Hopkins University Hospital, a premature boy was born with Down's Syndrome and an intestinal blockage. Surgery was needed to correct the blockage in order for the child to take nourishment. The parents of the infant, a nurse and a lawyer, refused to consent to the life-saving surgery, and neither the hospital staff nor the physicians sought a court order to perform the operation. The child died of starvation eleven days later.

When situations such as these reach the courts, court resolution in favor of treatment may seem to be an unbearable imposition on the parents, who already may be overwhelmed by the birth of an unhealthy child. The problem is aggravated by the obviously disparate legal treatment such parents receive, as compared with the treatment accorded to those parents whose family doctors favor their decision to withhold medical care. Absent specific and well defined laws, most parents could avoid the court encounter and litigation of the matter by choosing well ahead of their child's birth a physician who agrees with them about these delicate life and death matters. Commentators have espoused total nonintervention by the state in the parental decision to withhold treatment from a severely defective newborn,77 and medical compliance with court ordered deference to the parental decision to withhold treatment.78 Court intervention severely limits parental autonomy and runs the risk of imposing the court's morality and judgment on the affected parents and children.

In In re Cicero the court declared that it was neither infringing on valid parental rights nor overstepping the bounds beyond which a court is empowered to intervene. The New York Supreme Court stated, "Where, as here, a child has a reasonable chance to live a useful, fulfilled life, the court will not permit parental inaction to deny that chance."79 When other courts have been confronted with similar situations, they also have opted to save defective lives.80

Since the practice of withholding medical treatment from defective newborns is prevalent and not likely to be eradicated by anything less than a full-blown societal movement culminating in the enactment of stringent laws, it is interesting to note briefly some suggestions being made by persons in different occupations regarding the proper resolution of this problem. Before the Best Interests of the Child81 represents the combined effort of a physician, a psychoanalyst, and a lawyer to delineate guidelines for the propriety of state intrusion in family matters. Generally, the authors advocate minimal state intrusion, arguing that state intervention should be permitted only if three

80. For example, in Maine Medical Center v. Houle, Civil No. 74-145 (Me. Super. Ct. Feb. 14, 1974), the court ordered surgery to correct a condition afflicting the feeding and respiration of a child who was born with multiple physical defects, and who had suffered brain damage.
factors are present: (1) the medical profession must agree that the nonexperimental treatment should be given to the child; (2) the child will die without treatment; and (3) if the treatment is successful, the child will then have a "life worth living"—as judged by societal standards. The authors believe that since societal consensus exists in only a few narrowly defined situations, in most cases there will be no consensus in the determination of whether a child's life is a "life worth living." As a result, the state would intervene in only a few cases. They assert that the state should not intervene in the parental decision to reject life-saving treatment for a severely defective newborn unless the state can provide an adequate parental substitute for the child and the financing required to meet the special needs of the child. Had these principles been applied in In re Cicero, the case would never have reached the court since there is no medical consensus that treatment should be administered in that situation, nor societal consensus that the infant would have a "life worth living."

At the other end of the spectrum is the position taken by the Canadian Psychiatric Association. Its recommendations are as follows: (1) treatment should never be withheld from defective newborns, such as those afflicted with Down's Syndrome or spina bifida, if the treatment would not be withheld from "normal" infants; (2) the act of withholding treatment should be considered a legal and not a medical matter, requiring a court order to implement it; and (3) the medical profession should take steps to inform the parents fully concerning the factors to be considered in a decision to withhold treatment. The Association bases its recommendations on the belief that there is a very real possibility of finding a cure for genetic defects, such as those causing Down's Syndrome. It also asserts that it is within the medical expertise to save lives, and that this expertise does not carry over to terminating lives or to placing a value on those lives. The Association points out that Down's Syndrome children are "warm-hearted, effervescent, usually happy and [a] warmly responsive group of people." As another commentator has suggested, "Just as the sacrifice of newborn infants with Down's Syndrome is the logical extension of the abortion of viable infants with Down's Syndrome, the rationalization of withholding care for newborns establishes a precedent for neglecting older children with Down's Syndrome." This happened in the case considered below.

82. Id. But see Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 754, 370 N.E.2d 417, 432 (1977), in which the court rejected the "quality of life" argument as a determinative factor in the decision to withhold medical treatment from an incompetent adult with an IQ of ten and a mental age below three years of age.
84. Id. at 76.
2. In re Phillip B.

_In re Phillip B._ concerning a twelve-year-old Down's Syndrome child who needed surgery to correct a congenital heart defect. If left untreated, this defect would cause progressive and irreversible damage to the boy's lungs, and he would be increasingly devitalized to the point of leading a bed-to-chair existence. At best, it was estimated that he would survive twenty more years, but his life would be severely restricted. When Phillip's parents refused to consent to the surgery, the juvenile probation department filed a petition with the juvenile court requesting that Phillip be declared a dependent child of the court for the sole purpose of assuring that he receive the corrective surgery. The court, applying a "clear and convincing evidence" standard of proof, dismissed the petition, and the dismissal was affirmed on appeal. The United States Supreme Court denied certiorari.

The crucial question presented by _In re Phillip B._ is: What are the permissible legal limits of parental autonomy in determining whether to withhold medical treatment from a minor in light of the state's power to intervene to protect such individual's best interests? By its disposition of the case, the court apparently believed that the outer limits of parental autonomy were not exceeded and that the parents had acted properly. However, due to the unique set of facts confronting the court, the decision is rather startling, if not disquieting, for though Phillip did not face imminent death, without the operation a torturous or sudden death would be a daily possibility.

The major difference between the situation faced by the parents of a defective newborn and that faced by the parents of an older child with a defect is that in the latter case it is possible to determine more accurately the extent of the disability and the medical prognosis. In other respects, the situations are comparable. As is true with a defective newborn, successful treatment of a mongoloid child's heart defect would alleviate one medical problem but leave the underlying handicap untouched. Since Phillip was classified as a "high functioning trainable mentally retarded" boy, his underlying handicap was not severe, and the parental decision to withhold medical treatment from him was more questionable. One reason given by Phillip's parents for refusing to consent to the surgical procedure was that Phillip's life, due to his mental retardation, was not a "life worth living." However, time and time again courts have stressed the fact that mental and physical handicaps have no relation to the value placed on life. The "poor" quality of Phillip's life

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87. Baines, _In re Phillip B.: Unequal Protection for the Retarded?_ 4 AMICUS 128 (1979). According to Baines, there was a possibility that Phillip would be able to work in a competitive environment. _Id._ at 128.
88. _Id._
89. _See_, e.g., _In re Spring_, Mass. App. Ct., 399 N.E.2d 493 (1979): "The Saikewicz case recognizes a presumption in favor of the life-saving, life-prolonging treatment decision—a factual presumption, based on common experience, that most persons would elect life over death, regardless of age or level of intelligence." _Id._ at 497 n.5. In _Gleitman v. Cosgrove_, 49 N.J. 22, 227 A.2d 689 (1967), the New Jersey Supreme Court said:
may have entered into the appellate court’s determination that there was substantial evidence to support the trial court’s decision to deny the request for an order of treatment. If so, this case may stand for the unprecedented proposition that the limits of parental autonomy are not surpassed when parents decide to withhold life-preserving medical treatment from their child merely because of his moderate mental handicap.  

The appellate court in In re Phillip B. affirmed the trial court’s decision seemingly on the basis of the risks posed by the surgery, and not on the basis of Phillip’s mental retardation. It is difficult to believe that the parents were concerned about the risks of surgery after Phillip’s father conceded that, in his opinion, “it would be better for everyone, including Phillip, if Phillip were dead now.” The risk consisted of a maximum ten percent chance of death from the surgical procedure. On the other hand, if the surgery successfully corrected the defect, the benefits would be substantial: Phillip would probably live a normal life span instead of less than twenty years, the progressive damage to his lungs would be arrested, and he would be subject to significantly fewer risks of an early and sudden death. Consequently, it is hard to justify the court’s decision on the basis of the risk factor alone, especially in light of the other factors that were considered in making the decision. In any case, there is precedent for the proposition that state intervention will be denied when parents reasonably conclude that the risks of treatment outweigh the benefits.

The controversial decision of the court can be explained on procedural grounds. The trial court determined that the evidence presented by the state in support of the petition was inconclusive. Because of the nature of the issue involved, the state was required to prove its case by clear and convincing evidence, something it failed to do. This factor alone may have tipped the

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[92] The other factors that were to be taken into account are the following: “[T]he seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation for the treatment by the medical profession; . . . and the expressed preferences of the child.” In re Phillip B., 92 Cal. App. 3d 796, 802, 156 Cal. Rptr. 48, 51 (1979), cert. denied, 445 U.S. 949 (1980).

balance in favor of the long-standing presumption that parents act in their child’s best interests.94

One commentator has argued that life-saving and life-prolonging treatment should be withheld by parents, without court or state intervention, only in situations of medical infeasibility.95 A treatment is “infeasible” if the child faces imminent death or irreversible unconsciousness, regardless of treatment or nontreatment. Parental autonomy is unquestionably protected in situations of medical infeasibility. Since Phillip did not face imminent death or irreversible unconsciousness, his situation was not one of medical infeasibility. Thus, this model provides no support for the court’s approval of Phillip’s parents’ refusal to consent to the corrective surgery.

3. In Re Hofbauer

Much controversy surrounds the use of unconventional treatment, such as the administration of laetrile, for cancer patients.96 In re Hofbauer97 involved a parental decision to administer such treatment to a minor. Even though the choice to administer unconventional therapy may be equated with the decision to withhold treatment from a child, the state’s decision to intervene is a greater infringement on family privacy in the former case where parents merely choose one treatment over another. However, courts have viewed the problem as one involving a parental refusal to administer a well-known method of treatment that poses great danger to the child.

In Custody of a Minor,98 a case decided on similar facts prior to Hofbauer, the court reached a different result. Custody of a Minor involved a three-year-old child afflicted with acute lymphocytic leukemia.99 The orthodox treatment of such a disease is chemotherapy, but some physicians believe that “metabolic therapy”100 is useful in the treatment of childhood leukemia or other types of cancer, mainly because of its detoxification and placebo effects.101 After the child was treated with chemotherapy, which had brought

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94. Parham v. J.R., 442 U.S. 584 (1979). “[H]istorically it has been recognized that natural bonds of affection lead parents to act in the best interests of their children.” Id. at 602.
99. Leukemia: Progressive proliferation of abnormal leukocytes found in hemopoietic tissues, other organs, and usually in the blood in increased numbers. L. is classified by the dominant cell type, and by duration from onset to death. This occurs in acute L. within a few months in most cases, and is associated with symptoms that suggest acute infection, with severe anemia, hemorrhages, and slight enlargement of lymph nodes or the spleen. STEDMAN’S MEDICAL DICTIONARY ILLUSTRATED 775 (23d ed. 1976).
100. According to the court, “metabolic therapy” consists of “daily administration of enzymes, large doses of vitamins, and the drug amygaldalin, more popularly known as laetrile.” Custody of a Minor, 393 N.E.2d 836, 839 (1979).
101. Id. at 839. The detoxification effect “improves a patient’s tolerance for chemotherapy and increases his or her appetite, energy level and general sense of wellbeing.” Id. The placebo effect is “a psychogenic response deriving essentially from human susceptibility to the power of positive suggestion.” Id.
the disease into a state of remission, the parents discontinued the treatment and refused to recommence it. The treating physician sought a court order to reinstate the chemotherapy since the child’s leukemia had reappeared. The parents argued that they should be the ones to decide, without state intervention, which course of treatment the child should undergo. The court rejected the argument and ordered the treatment after finding that the child had a substantial chance of cure with chemotherapy, that the usual noxious side effects of chemotherapy were absent or easily controllable, and that the child would die without chemotherapy. The decisive factor was that the medical testimony was uncontradicted in favor of chemotherapy.

At a review and redetermination hearing, the court affirmed its prior order. There, the parents were not contesting the administration of chemotherapy, but merely requesting that metabolic therapy be administered as a supplement to chemotherapy. The court found that metabolic therapy posed a serious threat to the child’s health by way of cyanide poisoning, hypervitaminosis A, and bacterial infection, and that it was dangerous and inadvisable.

*Hofbauer* was decided after the trial court’s decision in *Custody of a Minor*, but before that court’s decision on appeal. The eight-year-old child in *Hofbauer* was suffering from Hodgkin’s disease, a disease usually treated with radiation and chemotherapy. Instead, the parents decided to treat the child with metabolic therapy, and sought the services of a licensed physician who favored that treatment. A neglect proceeding was instituted, but the court ruled in favor of the parents. The court rested its decision on the following facts: (1) numerous licensed physicians had treated the child; (2) the parents justifiably feared the side effects of radiation and chemotherapy; (3) the metabolic therapy was controlling the disease; (4) the parents were willing to administer conventional therapy, if necessary; and (5) the parents were loving and sincerely concerned about the child’s welfare. The court distinguished *Custody of a Minor*: “Nor is this a case where the parents have made a [sic] irreversible decision to deprive their child of a certain mode of treatment.”

There are other ways of factually distinguishing the cases. In *Custody of a Minor* the metabolic therapy was poisoning the child, while in *Hofbauer* there was no evidence of toxicity. In *Hofbauer* the metabolic therapy was arresting the disease, while in *Custody of a Minor* the evidence indicated that, not only did it lack a curative effect, but also the disease had reappeared without the chemotherapy. Finally, in *Custody of a Minor*, the medical evidence was uncontradicted in favor of chemotherapy, while in *Hofbauer* the medical evidence was sharply conflicting.
Although the children in both cases were suffering from a type of cancer, one commentator has noted that it is "absurd to describe a group as a 'class of cancer patients' or measures to treat them as 'conventional approaches to cancer therapy.' Childhood leukemia and cancer of the pancreas are as different as the common cold is from a stomach ache." Therefore, it is not unlikely that leukemia and Hodgkin's disease responded differently to the metabolic therapy simply because they are completely different diseases, requiring different treatments. "If a physician treated them the same way, he would be guilty of malpractice and ignorant of the advances of the past few decades. To group them together deprives the legal system of the enlightenment medicine can provide." This medical fact draws the two cases further apart and highlights the need to resolve cases in this area, not only on the basis of precedent, but also on the basis of informed medical opinions.

The rule that emerges from these two cases is that the parental decision to choose a method of treatment not widely embraced by the medical community will be honored if there is some medical evidence to support the decision. More deference is accorded the parental decision to choose among several alternative treatments than to choose to withhold treatment altogether. Unless there is empirical proof that the method of treatment chosen by the parents is harming the child—like cyanide poisoning in Custody of a Minor—the court will not impose its own subjective judgment.

V. A Final Word

An overview of the present state of the law in the area indicates that there is no easy solution to the problem of setting workable and effective guidelines to determine when or whether to withhold medical treatment from a child. The particular facts of each case are linked inextricably to the final resolution of the case. The evaluation by the medical profession plays a vital role in defining the desirability of treatment, the risks posed by the particular treatment, and the medical prognosis after treatment. The parental decision to withhold medical treatment from a child should not be upheld in the absence of a solid medical basis backing up the parental choice. However, since medicine is not an exact science, the medical evaluation is merely an informed opinion on probabilities at a certain point in time. For example, diseases that could not be treated in the past can be treated successfully today. Therefore, the medical evaluation should not have conclusive effect on the final decision by the court.

105. Marco, Why Chad Green Died in Mexico, LEGAL ASPECTS MED. PRAC. Dec., 1979, at 19, 21.
106. Id.
107. See, e.g., In re C.F.B., 497 S.W.2d 831 (Mo. Ct. App. 1973), in which the parental choice of psychiatric care was upheld over the state's petition that the child be declared a ward of the court for the purpose of ensuring that the child receive "proper" care for her ailment. The court stated, "The mother had a right to choose between different doctors or institutions for the purpose of this type of care. So long as the mother was willing and intended to provide appropriate care in some manner, no finding can stand that she was guilty of neglecting the child." Id. at 835.
Though courts are generally strongly influenced by the parents' wishes under the doctrine of parental autonomy, the deference due the parental decision must be tempered by the "best interests of the child." In the case of the defective newborn, for example, the parents may have a conflict of interest and may not be the best decision makers. They may be concerned with the welfare of the child and also with their own interests, such as their interest in avoiding the financial and emotional strain involved in caring for a child with special needs. An analysis based solely on such cost-benefit considerations is not ultimately in the best interests of the child. Therefore, the court should accord less deference to the parental decision to withhold treatment in a situation in which a conflict of interest exists. The court decision always should be in favor of the best interests of the child.

The decision to withhold medical treatment from a child is not primarily a matter of legal concern. Ethical considerations stand in the foreground. The decision to withhold treatment from a child—especially from a defective newborn—has serious moral implications. For example, if one accepts the validity of withholding treatment from a defective newborn who has serious medical complications, is it less ethical to withhold nourishment from an equally defective child, who does not require medical attention at birth? Is it less ethical to withhold treatment from a defective newborn who develops a common and treatable childhood disease? A line must be drawn. A well-defined standard must be developed in the context of withholding treatment from children, a standard that, at the very least, would have allowed Phillip B. to live a long life.

VI. CONCLUSION

Cases involving the parental decision to withhold medical treatment from a child will continue to be decided on a case-by-case basis until the Supreme Court squarely addresses the issue and carefully defines the outer limits of parental autonomy. Even though it is axiomatic to say that "parents do not and must not have absolute authority over the life and death of their children," in actual practice, such authority is being exercised in many cases. Generally, parents and physicians agree on the course of conduct that will be followed in a particular case, without state intervention. Also, in the infrequent cases where the matter reaches the court—as when the physician disagrees with the parents' choice of treatment—the court, in turn, exercises its own subjective judgment. Meanwhile, many children will suffer the consequences of this lack of definitive guidance. It will continue to be true that "a significant deviation from normal intelligence, coupled with the appropriate parental desire, is sufficient to permit an infant to die." Yolanda V. Vorys

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