

### ***2.2.4 Treatment Decisions for Seriously Ill Newborns***

Making treatment decisions for seriously ill newborns is emotionally and ethically challenging for both parents and health care professionals. Decisions must take into account the newborn's medical needs; the interests, needs, and resources of the family; and available treatment options. Decision makers must also assess whether the choice made for the newborn will abrogate a choice the future individual would want to make for him- or herself, i.e., whether the choice will undermine the child's right to an "open future." Providing information and other resources to support parents or guardians when they must make decisions about their child's care and future is a key responsibility for physicians and other health care professionals.

Decisions not to initiate care or to discontinue an intervention can be emotionally wrenching in any circumstance, but may be particularly so for a seriously ill newborn. Physicians are in a position to help parents, families, and fellow professionals understand that there is no ethical difference between withholding and withdrawing treatment—when an intervention no longer helps to achieve the goals of care or promote the quality of life desired for the patient, it is ethically appropriate to withdraw it.

To help parents formulate goals for their newborn's care and make decisions about life-sustaining treatment on their child's behalf, physicians should:

- (a) Inform the parents about available therapeutic options, the nature of available interventions, and their child's expected prognosis with and without treatment.
- (b) Help the parents formulate goals for care that will promote their child's best interests in light of:
  - (i) the chance that the intervention will achieve the intended clinical benefit;
  - (ii) the risks involved with treatment and nontreatment;
  - (iii) the degree to which treatment can be expected to extend life;
  - (iv) the pain and discomfort associated with the intervention;
  - (v) the quality of life the child can be expected to have with and without treatment.
- (c) Discuss the option of initiating an intervention with the intention of evaluating its clinical effectiveness after a given amount of time to determine whether the intervention has led to improvement. Confirm that if the intervention has not achieved agreed-on goals, it may be withdrawn. Physicians should recognize, and help parents appreciate, that it is not necessary to have prognostic certainty to withdraw life-sustaining treatment, since prognostic certainty is often unattainable and may unnecessarily prolong the infant's suffering.
- (d) Initiate life-sustaining and life-enhancing treatment when the child's prognosis is largely uncertain.
- (e) Adhere to good clinical practice for palliative care when life-sustaining treatment is withheld or withdrawn.
- (f) Provide access to counseling services or other resources to facilitate decision making and to enable parents opportunity to talk with others who have had to make similar decisions.

- (g) Seek consultation through an ethics committee or other institutional resource when disagreement about the appropriate course of action persists.

*AMA Principles of Medical Ethics: I,III,IV,V*

*Background report(s):*

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report I-A-2 Treatment decisions for seriously ill newborns

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## CEJA Report I – A-92 Treatment Decisions for Seriously Ill Newborns

### HISTORY

In April 1982, in Bloomington Indiana, Baby Doe was born with Down's syndrome (trisomy 21) and a life-threatening esophageal defect (esophageal atresia with tracheo-esophageal fistula).<sup>1(p.118)</sup> Baby Doe's parents refused consent for the surgical repair of the esophageal defect. The infant's physicians requested a court order to perform the corrective surgery. The Indiana state courts upheld the parents' decision and the infant died.<sup>1(p.118)</sup> This case brought national attention to the issue of decisions to withhold life-saving treatment from disabled newborns.

In response, the Department of Health and Human Services issued a notice to hospitals warning them that the nontreatment of seriously ill newborns constitutes discrimination on the basis of handicap.<sup>2</sup> The Department based its warning on Section 504 of the Rehabilitation Act of 1973 which states:

No otherwise qualified handicapped individual in the United States...shall, solely by reason of his handicap, be excluded from participation in, or be denied the benefits of, or be subjected to discrimination under any program of activity receiving Federal financial assistance.<sup>3</sup>

Shortly thereafter, the DHHS issued an interim final rule<sup>4</sup> that, in addition to reiterating the prohibition of nontreatment of handicapped newborns, required hospitals to post a large sign in every nursery that stated "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law."<sup>4</sup> These signs were required to include a toll free hotline number to encourage anonymous reports of nontreatment. The rule also authorized DHHS personnel to immediately investigate any reports of alleged discriminatory nontreatment. Such investigatory teams acquired the name "Baby Doe Squads" and were highly criticized for their intrusiveness and insensitivity to parents and hospital personnel.<sup>2,5,6</sup>

This first Baby Doe rule was invalidated by a federal district court on two grounds.<sup>7</sup> First, the court found that the DHHS had acted arbitrarily and capriciously and without adequate consideration of the relevant issues. Second, DHHS failed to observe certain procedural requirements, including the required 30-day period for public comment before the rule was to take effect.

The DHHS subsequently issued a proposed regulation, which provided the required notice and comment period. The final rule was issued in January of 1984.<sup>8</sup> A number of modifications were made in this new rule. The required signs could be smaller and placed so that they were only visible to the hospital staff. The requirement to treat handicapped newborns was modified so that clearly futile therapies "which would merely prolong an infant's process of dying" were exempted. Furthermore, the new rule stated that "reasonable medical judgment" would be respected regarding the choice of a treatment plan. The DHHS also encouraged hospitals to establish infant care review committees to review treatment decisions for handicapped newborns.

The first challenge to the second Baby Doe Regulation occurred with the case Baby Jane Doe. In October 1983, Baby Jane Doe was born with spina bifida and associated meningocele (protruding sac filled with cerebrospinal fluid and containing a defective spinal cord), hydrocephalus and microcephaly.<sup>1(pp.121-2)</sup> The patient's physicians at University Hospital at Stony Brook, New York, estimated that she might live for several weeks to two years without surgery.

Surgery could extend her life for 20 years during which time she would experience paralysis, epilepsy, severe mental retardation and a likelihood of bladder and urinary tract infections.<sup>1(p.121)</sup>

Baby Jane Doe's parents chose to forgo surgery but to maintain antibiotic therapy. An unrelated party tried to sue to have surgery performed.<sup>1(p.121)</sup><sup>9</sup> The New York Supreme Court concluded that surgery was necessary and ordered it to be performed. The Court of Appeals reversed, determining that the parents were acting in the best interests of the child. The New York Court of Appeals, New York's highest court, affirmed the appellate court's ruling, but based its decision on procedural grounds.<sup>29</sup> During this time, the DHHS attempted to make its own investigation of the case. University Hospital refused to relinquish Baby Jane Doe's medical records and the Justice Department filed suit in federal court to obtain the records. The Second Circuit Court of Appeals ruled that Section 504 of the Rehabilitation Act did not give the DHHS authority to investigate the case. According to the court, Congress never intended to have Section 504 apply to treatment decisions involving seriously ill newborns.

The second Baby Doe rule was eventually invalidated in June of 1986 by the United States Supreme Court when the American Medical Association, the American Hospital Association and the American College of Obstetricians and Gynecologists challenged DHHS's final rule in *Bowen v. American Hospital Association, et al.*<sup>11</sup> The Court held that Section 504 of the Rehabilitation Act does not apply to situations where the parents of a handicapped infant refuse to consent to life-saving treatment of their child.

In the meantime, in 1984 Congress passed an amendment to the Child Abuse Prevention and Treatment Act that defined withholding medically indicated treatment from disabled infants as medical neglect.<sup>2</sup> The amendment further stated that:

[T]he term "Withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.<sup>12</sup>

It is important to note that Congress did not make this new rule binding on states. Instead, the law mandates that in order for states to receive federal grants through the Child Abuse Protection and Treatment Act, the rule must be incorporated into the state's own law.<sup>13</sup> Participation in the grant program is voluntary, and the funds are minimal.<sup>3</sup> However, almost every state has enacted the rule in some form, usually through the rules of its child abuse prevention agency.<sup>13</sup>

## ETHICAL ANALYSIS AT TREATMENT DECISIONS FOR SERIOUSLY ILL NEWBORNS

In previous reports, the Council examined the issues of withdrawing and withholding life-sustaining treatment from competent patients upon their request,<sup>14</sup> and from incompetent patients upon the request of a surrogate decisionmaker.<sup>15</sup> The Council concluded that competent patients have a right to refuse medical treatment, even if the patient will die as a result of nontreatment,<sup>14</sup>

and that the right to forgo life-sustaining treatment persists when a patient is incompetent.<sup>15</sup>

### *Best Interests of the Infant*

In Report D (A-91) the Council concluded that when a patient has never been competent, decisions regarding life-sustaining treatment should be guided by the best interest standard-i.e., what course of action best promotes the patient's well-being.<sup>15</sup> The best interest standard is grounded in the bioethical principles of beneficence and nonmaleficence.

The best interest standard requires a weighing of the benefits and burdens of treatment options including nontreatment as objectively as possible.<sup>15(p.162)</sup> Factors that should be considered when making decisions about life-sustaining or life-saving treatment for a seriously ill newborn include: 1) the chance the therapy will succeed, 2) the risks involved with treatment and nontreatment, 3) the degree to which the therapy if successful will extend life, 4) the pain and discomfort associated with the therapy and 5) the anticipated quality of life for the newborn with and without treatment.<sup>17(p.135)</sup>

### Quality of life considerations

Appropriate considerations about an infant's "Quality of life" do not include any form of assessment of the patient's social worth or value to other persons, such as the infant's parents.<sup>15,16(p.158)</sup> An infant's quality of life must be evaluated from the infant's perspective.<sup>17(p.219)</sup> Individual decisionmakers must avoid making decisions for the infant based on what they would want for themselves. This task can be more difficult than it may appear at first. Competent, generally healthy, adults must try to imagine what quality of life would be valuable to a seriously ill newborn. Though difficult, this approach is ethically required.

There has been much controversy surrounding the use of quality of life considerations. Some commentators argue that all life must be preserved regardless of the degree of disability.<sup>19</sup> However, while many persons with disabilities can live fulfilling lives, there are a number of disorders that promise for an infant a life of pain and discomfort with little hope of experiencing pleasure. When the burdens of a life are so severe and extensive that they overwhelm the potential for experiencing the joys of life, it is reasonable to conclude that the prolongation of such a life would not be in the interests of the individual infant.<sup>16(p.161),17(p.218)</sup> For example, the Council believes that physicians may ethically withhold or withdraw life-sustaining treatment from a newborn with Tay-Sachs disease whose parents request nontreatment.<sup>16(p.160)</sup> A child born with Tay-Sachs disease has a life expectancy of four or five years, during which time he or she will develop paralysis, spasticity, deafness, blindness and convulsions, leaving the child virtually vegetative by the age of two or three. Such infants will also experience recurrent infections which may often necessitate artificial respiration, resuscitation, or aggressive antibiotic therapy.

Occasionally, an infant may suffer extreme neurological damage, and is consequently not capable of experiencing either suffering or joy. Extending the life for such newborns will not enable the child to possess any of the capacities which give life meaning, such as the ability to form personal relationships, to will one's actions, to interact in a meaningful way with one's environment, and to give and experience love.<sup>18</sup> For these newborns, decisions may be made to withhold or withdraw life-sustaining treatment upon the request of the parents. This analysis is consistent with the Council's previously enunciated position regarding decisions to withdraw life-sustaining treatment from permanently unconscious patients.<sup>15</sup>

### The problem of uncertainty

There are often situations when the prognosis of a seriously ill newborn is largely uncertain.<sup>20</sup> This is especially the case for infants who are born at extremely low birth weights (less than 750g).<sup>21</sup> There is frequently no way of knowing whether a particular low birth weight infant will survive to leave the hospital.<sup>21</sup> Furthermore, it is often impossible to predict how impaired such a child will be if he or she survives.<sup>21</sup> This high degree of uncertainty presents an especially difficult dilemma for those who must make treatment decisions for the infant. The decisionmaker is caught between subjecting an infant who may not survive to futile treatment or prolonging a life that may be marked by overwhelming suffering, and letting an infant die who may survive with a disability that is not unduly burdensome.

In situations when an infant's prognosis is largely uncertain, treatment to keep the infant alive should be provided.<sup>22</sup> The patient's condition should be continually assessed. Eventually, the infant's prognosis should become more clear over time, and decisions about continuing lifesustaining treatment should be reevaluated.<sup>21,22</sup> It is not necessary to wait for absolute or near absolute prognostic certainty before making a decision to withhold or withdraw treatment.<sup>21,22</sup> Such certainty or near certainty may never be attainable. In addition, waiting for prognostic certainty risks overtreating the infant and subjecting him or her to a great amount of pain and suffering with only a faint hope of surviving reasonably intact.<sup>21,22</sup>

### *Who Should Decide*

In Report D (A-91) the Council concluded that when decisions must be made for an incompetent patient, the patient's family should be given the authority to make treatment decisions.<sup>15</sup> In the case of seriously ill newborns, the parents should be responsible for making treatment decisions for their child based on the child's best interests. Due to the love that parents have for their children, they are most likely to make decisions that promote their children's best interests.<sup>23</sup> Parents are more likely to treat if their child was a person rather than a symbol of a cause.<sup>24</sup> In addition, society has recognized the importance of family autonomy and privacy from outside intervention.<sup>17(pp.215-7)</sup> <sup>23</sup> Only when it is demonstrated that a parent's decision for his or her child seriously jeopardize the welfare of the child, has the state seen fit to override parental authority.<sup>23</sup> For example, parents may not refuse a life-saving transfusion for their child based on their own religious beliefs.<sup>17(p.215)</sup>

There are a number of factors that can impinge upon the ability of parents to make treatment decisions for their seriously ill newborns. Parents may be so emotionally distressed and overwhelmed by the condition of their child that their judgment is clouded.<sup>17(pp.215-7)</sup> In addition, parents are likely to be unaware of the relevant medical facts as well as the prospects for their child.<sup>17(pp.215-7)</sup> All of these factors must be addressed so that parents can competently make treatment decisions. Physicians must provide full information to parents of seriously ill newborns regarding the nature of treatments, therapeutic options and expected prognosis with and without therapy, so that parents can make informed decisions for their children.<sup>17(pp.215-7)</sup> Counseling services and an opportunity to talk with persons who have had to make similar decisions should be available to parents.<sup>17(pp.215-7)</sup> Ethics committees or infant review committees should also be utilized to facilitate parental decisionmaking for these decisions. These committees should help mediate resolutions of conflicts that may arise among parents, physicians and others involved in the care of the infant.

Ethics committees or infant care review committees should also be responsible for referring cases to the appropriate public agencies when it is concluded that the parents' decision is not a decision

that could reasonably be judged to be in the best interests of the infant.<sup>17(p.227)</sup> In this way the standard for state intervention for parental decisionmaking for seriously ill newborns is consistent with the standard for child abuse and neglect in general. Parents are presumed to act on behalf of their child's welfare, unless it is demonstrated otherwise. In cases where parents act in a way that is detrimental to the welfare of their child, the state intervenes through its child protection services to protect the interests of the child and assist the family.

## ETHICAL CRITIQUE OF BABY DOE RULE

A survey of neonatologists indicates that there is serious discontent with the current Baby Doe rule among physicians who are involved in the care of seriously ill newborns.<sup>25</sup> The survey found that 76% of the neonatologists that responded to the survey believed the regulations were not necessary to protect the rights of handicapped infants. Sixty-six percent believed that the rule interfered with parents' right to make treatment decisions that are in the best interests of their children. Sixty percent believed that the regulations did not allow adequate consideration of the infants' suffering. In three vignettes presented in the survey, up to 32% felt that maximal treatment was not in the best interests of the children described, but such treatment was required by the Baby Doe regulations.

Based on ethical principles, the Council has similar objections to the current rule.

### *Range of Situations Where Treatment Is Not Required Is Too Narrow*

The current Baby Doe Rule lists a number of exceptions where failure to provide medically indicated treatment is not considered medical neglect: 1) if the infant is chronically and irreversibly comatose, 2) the treatment will prolong dying, 3) the treatment is futile "in terms of survival of the infant", and 4) the treatment is virtually futile and the treatment itself would be inhumane.<sup>2</sup> These exceptions, however, fail to encompass many of the situations in which the ethical guidelines above do permit physicians to respect parents' decisions to forgo life-sustaining treatment for their newborns.

The exception for a newborn who is chronically and irreversibly comatose is too narrow. First, technically, an irreversible coma is a terminal condition, and therefore cannot be chronic.<sup>26</sup> Second, a coma is a neurological condition distinct from a persistent vegetative state.<sup>26</sup> Both are states of permanent unconsciousness. However, a coma is a sleeplike unarousability, while a persistent vegetative state is a state of unconsciousness where the patient exhibits sleep-wake cycles and other responses controlled by the brain stem.<sup>26</sup> Therefore, a strict interpretation of the Baby Doe rule would require that a newborn who is in a persistent vegetative state always be treated. Although one court has ruled that an infant who was in a persistent vegetative state met the rule's exception even though it was not comatose,<sup>25</sup> there still exists much confusion over how broadly the exception should be interpreted. The Council believes life-sustaining treatment may be ethically withheld or withdrawn from any newborn who is so neurologically damaged such that he or she will never possess any of the capabilities that give life meaning.

The rule also requires that nutrition, hydration and medication always be provided. The Council concluded in Report B and D (A-91) that artificial nutrition and hydration as well as medication, are forms of lifesustaining treatment that may be forgone if their provision is not in the best interests of a patient that has never been competent.<sup>14,15</sup> Although life-sustaining treatment, including artificial nutrition, hydration and medication, may ethically be withheld or withdrawn, comfort care must not be discontinued.

### *Rejects Use of Quality of Life Considerations*

The Amendment to the Child Abuse Prevention Act noticeably omits reference to quality of life considerations. Furthermore, in its nonbinding interpretive guidelines for the Amendment, the DHHS explicitly rejects the legitimacy of quality of life considerations.<sup>27</sup> The Council, however, believes that it is important to consider the quality of life the infant will likely have with and without treatment from the infant's perspective.

### *Undermines Parental Decisionmaking*

The DHHS' discussion accompanying its nonbinding interpretive guidelines states that in most cases the parents should have the authority to make treatment decisions for their infant.<sup>27</sup> However, the discretion that parents have is considerably limited by the rule itself.<sup>13</sup> In particular parents cannot decide to refuse consent for a medically indicated treatment because they believe that the life their child will have if treated will be so overwhelmed by suffering that it is in the best interests of the infant not to have his or her life prolonged.

Circumstances where decisions about whether to provide lifesustaining treatment to seriously ill newborns can be extremely complicated. While there must be every effort made to be objective, the values of the decisionmaker will occasionally unavoidably enter into these decisions. Reasonable persons may disagree as to whether a particular infant's life holds enough promise for benefit to the infant that treatment should be provided despite the suffering that the child will also have to experience.

The President's Commission recognized a gray area of situations for which treatment decisions must be made for seriously ill newborns.<sup>17</sup>(PP21722&28) In such cases the Commission concludes, parents should have the authority to make decisions for their newborn including a decision for nontreatment.<sup>17</sup>(P218) This framework is helpful and better represents the complex nature of these decisions than does the current Baby Doe Rule. The Baby Doe Rule does not recognize this gray area of decision making, primarily because it rejects the use of quality of life considerations.

## RECOMMENDATIONS

The Council recommends that physicians should play an active role in advocating for changes in the Child Abuse Prevention Act as well as state laws that require physicians to violate the following ethical guidelines:

1. The primary consideration for decisions regarding life-sustaining treatment for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are: 1) the chance that therapy will succeed, 2) the risks involved with treatment and nontreatment, 3) the degree to which the therapy, if successful, will extend life, 4) the pain and discomfort associated with the therapy, and 5) the anticipated quality of life for the newborn with and without treatment.
2. Care must be taken to evaluate the newborn's expected quality of life from the child's perspective. Life-sustaining treatment may be withheld or withdrawn from a newborn upon the parents' request when the pain and suffering expected to be endured by the child will overwhelm any potential for joy during his or her life. When an infant suffers extreme neurological damage, and is consequently not capable of experiencing either suffering or joy a decision may be made to withhold or withdraw life-sustaining treatment upon the parents' request. When life-sustaining treatment is withheld or withdrawn, comfort care must not be discontinued.

3. When an infant's prognosis is largely uncertain, as is often the case with extremely premature newborns, all life-sustaining and life-enhancing treatment should be initiated. Decisions about life-sustaining treatment should be made once the prognosis becomes more certain. It is not necessary to attain absolute or near absolute prognostic certainty before life-sustaining treatment is withdrawn, since this goal is often unattainable and risks unnecessarily prolonging the infant's suffering.

4. Physicians must provide full information to parents of seriously ill newborns regarding the nature of treatments, therapeutic options and expected prognosis with and without therapy, so that parents can make informed decisions for their children about life-sustaining treatment. Counseling services and an opportunity to talk with persons who have had to make similar decisions should be available to parents. Ethics committees or infant review committees should also be utilized to facilitate parental decision making for these decisions. These committees should help mediate resolutions of conflicts that may arise among parents, physicians and others involved in the care of the infant. These committees should also be responsible for referring cases to the appropriate public agencies when it is concluded that the parents' decision is not a decision that could reasonably be judged to be in the best interests of the infant.

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