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**Neonatologists' judgments regarding medical treatment for
disabled newborns with life-threatening conditions**

Chalnick, Marla Kappen, Ph.D.

The University of North Carolina at Greensboro, 1990

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NEONATOLOGISTS' JUDGMENTS REGARDING MEDICAL
TREATMENT FOR DISABLED NEWBORNS WITH
LIFE-THREATENING CONDITIONS

by

Marla Kappen Chalnick

A Dissertation Submitted to
the Faculty of the Graduate School at
The University of North Carolina at Greensboro
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of the Requirements for the Degree
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Approved by



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APPROVAL PAGE

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CHALNICK, MARLA KAPPEN, Ph.D. Neonatologists' Judgments Regarding Medical Treatment for Disabled Newborns With Life-Threatening Conditions. (1990)
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During the period between 1982 and 1985, the United States government developed a policy that placed stricter limits on physicians' and parents' decisions about when they could withhold medical treatment for disabled newborns with life-threatening conditions. This study investigated neonatologists' judgments regarding treatment for disabled newborns with life-threatening conditions in the context of this policy. Two hundred sixty neonatologists responded to a nationwide mailed survey that included a series of vignettes to describe five disabled newborns. Neonatologists were asked to choose their treatment recommendations under three conditions: (1) the treatments that would be best for the infant; (2) the treatments that would be required by federal policy; and (3) the treatments that they would recommend in actual practice. Results of the repeated measures ANOVA indicated that the seriousness of the infant's medical condition was significant and that the more serious the infant's medical condition the less aggressive the treatments recommended by neonatologists under all conditions. Neonatologists also perceived that the federal policy required more aggressive treatments for disabled infants with life-threatening conditions than they would personally recommend. The relationships between neonatologists' treatment recommendations and their age, religiosity, hospital affiliation were also investigated. Neonatologists with high religiosity scores personally recommended more aggressive medical treatments

for disabled newborns than their less religious colleagues. Age and hospital affiliation had no significant relationship to neonatologists' treatment recommendations.

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CHAPTER I
INTRODUCTION

Background

During the period between the spring of 1982 and the spring of 1985, the United States government developed a policy regarding medical treatment for disabled infants with life-threatening conditions. This policy was promoted by the federal government in response to the circumstances of two specific infants known in the popular press as Babies Doe. In both cases the parents of handicapped newborns refused summary and aggressive medical treatment for their children. While the attending physicians agreed with the parents' decisions, at least one member of each medical team did not and pressed for court involvement to order more aggressive medical treatment for these infants. In both cases, the judicial efforts were unsuccessful. Conservative elements within the Reagan administration and several powerful lobbying groups sought to insure that all handicapped newborns, regardless of the extent of their disabilities, would receive aggressive medical care. Strongly defending the handicapped newborn's right to maximum medical intervention seemed consistent with the "right to life" position on abortion already taken by the administration.

After several years of federal government activity through the issuing of rules to govern medical treatment for newborn infants with

handicaps, and judicial activity to strike down these federal rule-making efforts, a compromise took place. The Child Abuse Prevention and Treatment Act, originally enacted in 1974, was extended by amendments to cover the withholding of medically indicated treatment from significantly handicapped infants. As a condition of receiving state grants (federal funding for certain child abuse programs) under the Child Abuse Prevention and Treatment Act, states had to establish a program within the state's child protective service system to respond to reports of medical neglect. Medical neglect was defined to include the withholding of medical treatment for disabled infants with life-threatening conditions. Withholding of medically indicated treatment means the failure to respond to an infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's reasonable medical judgment, would most likely be effective in ameliorating or correcting all such conditions.

The Act also encourages the establishment of Infant Care Review Committees to assist hospital personnel in making decisions regarding the withholding or withdrawing of medical treatment from disabled infants. These committees are to educate physicians regarding the regulatory rules, establish a link between the local office of the Division of Social Services and the local hospital, and provide a forum for specific case discussion. By design, the Infant Care Review Committee is not to make decisions to withhold or to provide treatment,

but to counsel and advise the medical professionals and the family regarding the options available.

This study is designed to answer research questions about physicians' judgments regarding treatment for disabled infants with life-threatening conditions in the context of the Child Abuse Amendments of 1984. It appears that the Child Abuse Amendments of 1984 have played to mixed reviews. Lund (1985), promoting a sanctity of life position, positively reviews the legislation. Murray (1985) is somewhat positive, acknowledging that the Baby Doe rule is a compromise among physicians, right-to-life groups, and groups representing the disabled, and he believes that the rule can work. Gostin (1985) reviews the legislation negatively, suggesting that the Child Abuse Amendments of 1984 are not "mild" but rather "vitalist" in nature. He argues that such robust vitalism fails to account for people whose disabilities are so grave, functioning so limited, and pain and suffering so unendurable that life is not worth aggressively defending. Kopelman, Irons, and Kopelman (1988) negatively review the Child Abuse Amendments of 1984 and report that many neonatologists believe that the legislation does not serve the best interests of infants.

Diversity of beliefs is common not only among scholars but among physicians and hospitals; this diversity may be reflected in treatment decisions for disabled infants. While many scholars have written position papers about medical treatment for handicapped newborns, empirical research on how the policy is being implemented and its effects on families and children would be even more beneficial.

In the spring of 1983, Levin (1985) conducted a survey about treatment decisions for catastrophically ill (handicapped) infants. Respondents were health care professionals concerned with the fate of catastrophically ill newborns, and they were sampled at a conference and at a major medical center. The first portion of the survey presented four hypothetical vignettes of cases of newborns with four different critical conditions. Respondents were asked to indicate, from a list of possible treatments, which treatments they would give or withhold. In comparing responses across cases, Levin (1985) found that there are clear differences in the levels of treatments that respondents would recommend.

This is illustrated by the fact that many more respondents would recommend each particular treatment for the baby with Down Syndrome and duodenal atresia than would recommend those same treatments for the baby with trisomy-13 and a cleft palate. (p. 180)

It is important to recognize that Levin's research took place prior to the completion of a federal policy concerning medical treatment for disabled infants with life-threatening conditions. The results were published in 1985. This proposed research study will answer questions regarding policy implementation since the enactment of the 1984 policy.

Objectives of the Study

The purpose of this research is to investigate how the federal policy translates into practice with regard to medical treatment for disabled infants with life-threatening conditions. This study will

sample neonatologists nationwide with a survey instrument with includes five hypothetical vignettes describing handicapped newborns with life-threatening conditions. Given current policy, this study will consider the relationship between an infant's medical condition, the characteristics of the neonatologist (age, religiosity, sex), the type of hospital the neonatologist is associated with (teaching vs. private), and the level of aggressiveness of the treatment recommended for a particular newborn. The study will consider individual neonatologist decisions, as well as patterns of decisions found among neonatologists at specific types of hospitals. It will also compare neonatologists' case specific decisions regarding what is best for a particular newborn with their perceptions of the policy requirements for the same case and their actual practice recommendations.

This study will answer the following research questions:

- (1) Are there institutional (type of hospital) differences in medical decisions recommended for disabled infants with life-threatening conditions?
- (2) Are individual physician differences (age, sex, religiosity) related to medical decisions recommended for disabled infants with life-threatening conditions?
- (3) Are specific medical characteristics of infants related to treatment choices?
- (4) Are there differences among neonatologists' treatment decisions regarding what is best for a disabled infant,

their perceptions of the treatment required by federal policy, and their actual treatment choices?

Limitations of the Study

This study was designed as a nationwide survey of the attitudes of neonatologists regarding the Child Abuse Amendments of 1984 and the Amendments' impact on medical decision-making and practice. The survey was mailed to a randomly selected sample of 600 neonatologists from a total population list of 3,000 neonatologists. While surveys are a widely used technique in the social sciences for the collection of data, surveys are not without their risks (Isaac & Michael, 1981). It is possible that surveys only tap respondents who are accessible and cooperative. Surveys may arouse response sets and are vulnerable to over-rater or under-rater bias (the tendency of respondents to give consistently high or low ratings). Poor response rates may require the researcher to plan follow-ups to improve the response rate.

Definitions of Terms and Major Constructs

"Disabled infants with life-threatening conditions" is the policy language used in the Child Abuse Amendments of 1984 to describe the group of infants of interest in this research. The literature has referred to these infants as imperiled infants, catastrophically ill infants, significantly handicapped infants, and Babies Doe. The various terms can be used interchangeably. The terms all describe a class or group of newborns with severe physical and mental disabilities.

Within the Child Abuse Amendments of 1984 the term "medical neglect" is defined as the failure to provide adequate medical care. Medical neglect includes, but is not limited to, the withholding of medically indicated treatment from disabled infants with life-threatening conditions (Federal Register, 1985).

The term "withholding medically indicated treatment" is defined within the legislation and includes several important features. First, it establishes the basic principle that all disabled infants with life-threatening conditions must be given medically indicated treatment (including appropriate nutrition, hydration or medication) which in the treating physician's reasonable medical judgment will most likely be effective in ameliorating or correcting all such conditions. Second, the definition spells out three circumstances under which treatment is not considered "medically indicated." These are when, in the treating physician's reasonable medical judgment:

- (1) The infant is chronically and irreversibly comatose;
- (2) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of survival of the infant; or
- (3) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself would be considered inhumane.

A key feature of the definition specifies that even when one of the three exceptions is present, and the failure to provide treatment is

not a "withholding of medically indicated treatment," the infant must be provided with appropriate nutrition, hydration, and medication. The definition's focus on the potential effectiveness of treatment in ameliorating or correcting life-threatening conditions makes clear that it does not sanction decisions based on subjective opinions about the future "quality of life" of a retarded or disabled person. Another feature of the definition is that its operation turns substantially on the "reasonable medical judgment" of the treatment physician. "Reasonable medical judgment" is defined as a medical judgment that is made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved (Federal Register, 1985).

The term "treatment" is intended to include evaluation, consultation, and in its broadest sense, anything that a physician does to promote the health of the infant.

The term "infant" focuses on infants of less than one year. However, the spirit of the definition was not that it be applied so arbitrarily and rigidly that infants over one year old would not receive appropriate attention from the child protective services systems (Federal Register, 1985). It is possible for the standards articulated by the Amendments to be applied to infants over one year of age, especially if they have been continuously hospitalized since birth, were born extremely prematurely, or were born with long-term disabilities.

Implications

This study is designed to answer research questions about the impact of the Child Abuse Amendments of 1984 on medical decision-making in the field of neonatology. The research builds on existing surveys of physicians' attitudes about treating significantly handicapped newborns and will make a contribution to the knowledge about how physicians make medical treatment decisions for these infants in the context of the current legislation. Following a review of the literature, the specific hypotheses of the study will be described.

CHAPTER II

REVIEW OF THE LITERATURE

Background

History of Neonatology

The field of neonatology has a relatively short history. Prior to the turn of this century, the capability of parents to obtain medical care for their disabled newborn was limited by the inadequacies of the medical sciences (Shelp, 1986).

The realization that extremely small infants could survive with adequate temperature regulation led to the design and development of the first incubator during the early years of the twentieth century. These incubators were not found in hospitals, but at fairgrounds and amusement parks where people paid money to view these new inventions housing premature babies (Fleischman, 1985).

Malnutrition among premature infants had been a frequent cause of death. In 1922 the first premature nursery was opened in a Chicago hospital, and concerns shifted from temperature regulation to feeding infants who were small, sick, or too weak to be maintained with normal breast feeding. The development of artificial formulas and new methods to feed infants increased their chances of survival.

The ability to provide an appropriate environment and appropriate nutrition for premature and disabled newborns, coupled with

research and clinical observations, led to the development of newborn intensive units during the 1950s and 1960s (Shelp, 1986). Fleischman (1985) states that "the 1960s and 70s saw the logarithmic growth of neonatal intensive care, bringing the new technology of respirators, careful monitoring, and aggressive intervention to the sick newborn" (p. 17). Gustaitis and Young (1986) suggest that "no field in medicine is so compelling and so confusing, so wondrous and so disturbing, as neonatology, the care, study, and treatment of the newborn" (p. 15). The success stories are exciting, but the failures are dramatic and force medical professionals, philosophers, sociologists, and anthropologists to ask questions about the appropriateness of aggressive medical treatment for all newborns.

Infanticide

The cultural practice of infanticide in many societies was often directed at disabled newborns. The current notion that non-aggressive treatment decisions for disabled newborns are at times appropriate, and are natural extensions of the cultural practice of infanticide, is well documented in the literature (Farland, 1976; Kett, 1985; Kohl, 1978; Levin, 1986; Lyons, 1986; Tooley, 1983; Weir, 1984). The ability to save infants who would have previously died as nature took its course is both the blessing and the curse of neonatology. While physicians argued, some suggesting that all lives could not and should not be preserved, the Reagan administration mandated aggressive medical treatment for all newborns.

The Babies Doe: Evolution of Current Policy

The Bloomington Baby Doe

In the spring of 1982 the tranquility of the town of Bloomington, Illinois was disrupted by a shocking and tragic episode.

A Bloomington couple allowed its infant son to die of a treatable birth defect. The child, who succumbed while surrounded by willing rescuers, became known to the world as Baby Doe Though Baby Doe's whole existence was compressed into a matter of days, it left more of a mark on the nation than lives of far greater duration. The impact of his death was felt in the White House and in virtually every hospital nursery in the United States, and it triggered a nationwide debate which shows no sign of fading. (Lyon, 1985, p. 21)

The brief eventful life of Baby Doe has been extensively documented (Annas, 1983; Gostlin, 1985; Lyon, 1985; Lund, 1985; Martin, 1985; Murray, 1985; Shelp, 1986). Baby Doe was a Down Syndrome infant born with esophageal atresia and a tracheoesophageal fistula. These conditions result in an inability to take in nourishment by mouth. They are correctable with routine surgical procedures. The parents refused surgery. The attending physician drew up medical orders indicating that hospital personnel might feed the child orally if they wished but they should be advised that it would likely result in aspiration and death; intravenous feedings were positively forbidden; and the child should be kept as comfortable as possible with sedation given as needed.

The day after these medical orders were issued the hospital's attorney asked the County's Circuit Court to hear the case. Several physicians testified that the infant should be transferred for

surgery despite the parents' decision to the contrary. The judge refused the transfer request. The judge accepted the position "that a Down Syndrome child would never have a minimally acceptable quality of life" (Shelp, 1986, p. 179). The court further held that parents have the right to choose a medically recommended course of treatment for their child. Subsequent attempts to mandate corrective surgery failed. Six days following his birth, Baby Doe died.

The White House Responds

On May 18, 1982, Betty Lou Dotson, director of the Office of Civil Rights, was instructed by the Department of Health and Human Services and President Reagan to "remind" health care providers that newborn infants with handicaps such as Down Syndrome were protected by Section 504 of the Rehabilitation Act of 1973 (Bowen vs. American Hospital Association, 1986). The directive read, in part,

It is unlawful . . . to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutrition sustenance medically contraindicated. (Lyon, 1985, p. 40)

While the notice was criticized in both medical and legal circles, right-to-life and disability groups continued to support the efforts of the President. They drew assistance from the Surgeon General of the United States, C. Everett Koop.

On March 2, 1983 the Secretary of Health and Human Services issued follow-up regulations known as the Interim Final Rule. This

rule included the posting of notices in delivery, maternity, pediatric, and intensive care nurseries advising that federal law prohibits discriminatory failure to feed and provide medical care for handicapped infants. The notice included a 24-hour hotline number for reporting any violations. In response to hotline calls Health and Human Service officials were given authority to "take immediate action" to protect the infant. Hospitals were required to provide HHS investigators access to both facilities and medical records (Annas, 1983).

Although standard operating procedure called for the publication of the proposed rule to be followed by a 30-day waiting period during which interested parties may comment, Secretary Heckler took the position that the waiting period was unnecessary in this case.

The Judicial Response

The American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and the Children's Hospital National Medical Center brought suit against the Department of Health and Human Services and its secretary, Margaret Heckler, in the United States District Court, District of Columbia, challenging the "Baby Doe" rules. Judge Gesell set aside the regulations in a decision dated April 14, 1983. Judge Gesell concluded that the interim final regulations constituted an arbitrary and capricious agency action. Additionally, the court found that the Secretary had failed to follow procedural requirements in its promulgation (Gostin, 1985).

Following Judge Gesell's ruling the Reagan administration reissued the Baby Doe regulations on July 5, 1983. Health and Human Services dealt with the procedural issues raised by the court ruling, but substantively the regulations were barely changed. The only significant revision required state child protection agencies to establish procedures to investigate reports of medical neglect of handicapped infants. It is important to note that these revised regulations failed to recognize that hospitals and physicians lack authority to perform treatment to which parents have not given their consent (Bowen vs. American Hospital Association, 1986).

The American Academy of Pediatrics commented extensively on the new "proposed rules." The Academy recommended the establishment and involvement of a bioethics review committee, the structure and function to be consistent with a similar recommendation of the President's Commission for the Study of Ethical Problems in Medicine.

The Final Rules were issued on January 12, 1984. These new rules incorporated the suggestion of a committee review process, but failed to mandate their establishment. The rules advised the creation of Infant Care Review Committees to assist the health care provider in the design of procedures, policies and standards for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases (Shelp, 1986). The designation of "medical benefit" as the sole standard by which treatment decisions are to be made clearly minimized the quality of life factors in the decision-making process. An infant's

present or future handicap, availability of community resources, and impact on the family and society are not considered relevant. Where there is doubt concerning benefit, the rules established a presumption in favor of treatment (Shelp, 1986). When parental decisions do not conform to this standard, hospitals are required to report these actions to a state child protection agency.

Baby Jane Doe

Events became more complex with the birth of Baby Jane Doe on October 11, 1983 in Port Jefferson, New York. This infant was born with myelomeningocele, commonly known as spina bifida, a condition in which the spinal cord is exposed; microcephaly, an abnormally small head; and hydrocephalus, a condition characterized by the accumulation of fluid within the cranial cavity. She exhibited several other neurological symptoms which underscored the severity of her birth defects. Initial medical evaluations indicated that this infant's prognosis was probably paralysis of the lower extremities and severe mental retardation (Lyon, 1985; Martin, 1985; Shelp, 1986).

Baby Jane's parents consulted with physicians, clergy, family members, and a social worker, and refused surgeries to close the opening in the spine and drain the fluid from the skull. The parents chose a conservative course of medical treatment which included nutrition, antibiotics, and hygienic care of the spinal lesion. The physicians at University Hospital supported the parents' decision.

Apparently not all members of Baby Jane's health care team concurred. An anonymous member of the hospital staff phoned a Vermont right-to-life attorney, A. Lawrence Washburn, informing him that an infant was being denied surgery. Washburn had, for many years, instigated lawsuits on behalf of fetuses and handicapped babies. "In spite of the fact that he had never seen the baby, talked to the doctors, or met the parents, he filed suit in the New York Courts to compel the surgery" (Lyon, 1985, p. 46).

Following a hearing held in the New York State Supreme Court, Justice Melvin Tanenbaum ruled that the surgery must be performed. This decision was appealed and one day later an appellate panel of the New York Supreme Court reversed the decision and allowed the conservative course of medical treatment requested by the parents. The appeals panel stated the "concerned and loving parents made an informed, intelligent, and reasonable determination based upon and supported by responsible medical authority" (Martin, 1985, p. 53).

The New York State Court of appeals upheld the decision of the appellate court, but on different grounds. It found that because the petitioner, Washburn, had no relationship to the family and because he had not appropriately contacted state welfare authorities to initiate an investigation there was no precedent or authority for the lawsuit.

The federal government became involved with Baby Jane's case. They believed she was being discriminated against and was not receiving life prolonging surgery because of the prognosis of severe mental

retardation. The Justice Department followed this line of reasoning and filed suit in federal district court to obtain Baby Jane Doe's medical records. U.S. District Court Judge Leonard D. Wexler denied the government access to the records and held that University Hospital had not violated Section 504 of the Rehabilitation Act. An appeal was filed in the U.S. Court of Appeals for the Second Circuit. The Court of Appeals upheld Judge Wexler's opinion by a two-to-one vote. The court argued that Section 504 was originally intended to assure the disabled equality in areas such as employment and housing and not to compel medical treatment of handicapped newborns.

Supreme Court Actions

Lyon (1985) suggests that the judicial actions taken in the Baby Jane Doe case "dealt an apparent death blow to the revised Baby Doe regulations" (p. 53). Lawsuits challenging the legality of the regulations were filed by the American Medical Association, the American Hospital Association, and several other medical societies. Following continuing judicial activity, the Supreme Court agreed to decide whether the federal government had the authority under Section 504 of the Rehabilitation Act to intervene in the care of severely impaired newborns.

Bowen vs. American Hospital Association was argued before the Supreme Court on January 15, 1986 and decided on June 9, 1986. The decision on the validity of the regulations split the court five-three with Chief Justice Burger concurring only in judgment and Justice

Rehnquist not participating. Justice Stevens joined by Justices Marshall, Blackmun and Powell wrote for the four member plurality. Justice Stevens defined the case as limited to whether or not the four mandatory provisions of the Baby Doe regulations (notice posting, mandatory reporting, access to medical records, expedited action to effect compliance) are authorized by Section 504. The plurality concluded that the regulations are not authorized by Section 504. Justice Stevens stated further that Section 504 does not authorize the Secretary of Health and Human Services to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children.

Finally, the decision suggests that while the Secretary's basis for federal intervention is the perceived discrimination against handicapped infants in violation of Section 504, no evidence of such discrimination has been documented. The administrative record does not contain the reasoning and evidence necessary to sustain federal intervention into a historically state-administered decision process that appears to be functioning in full compliance with Section 504. Nothing in Section 504 authorizes the Secretary to dispense with the law's focus on discrimination and instead employ federal resources to save the lives of handicapped newborns, without regard to whether or not they are victims of discrimination by recipients of federal funds.

In reviewing this Supreme Court decision and reflecting on four years of discussion about Baby Doe regulations, Annas (1986) states:

First, the Reagan administration has been concerned with right-to-life politics, and not with enforcing the law as set forth in Section 504. Second, child neglect based on parental treatment refusal has always been a matter of state law. It still is. The Court does not hold that parents have the right to refuse treatment for their handicapped children. The holding is that review of such decisions is a matter for the states. Third, Section 504 was never explicitly or implicitly meant to apply to individual medical treatment decisions in which the handicap itself influences the possible benefit that can be derived from treatment. (p. 30)

Legislative Actions

On another front policy making initiatives were undertaken by both the Senate and House through the Child Abuse Amendments of 1984. The Child Abuse Prevention and Treatment Act, originally enacted in 1974, was the first piece of federal legislation focusing on child abuse and neglect. The 1984 Amendments extend the Act to cover the withholding of medically indicated treatment from handicapped infants. Gostin (1985), Murray (1985), and Lund (1985) acknowledge that these amendments reflect the compromise achieved between the principal congressional sponsors and a diverse coalition of medical, pro-life, and disability organizations. Shelp (1986) suggests that the Act reflects a bias for treatment. Under these guidelines both Baby Does would have been treated.

Physician Attitudes Before and After Baby Doe

Crane (1975) recognized that modern medical technology placed physicians in the midst of a moral and ethical dilemma; the new techniques capable of preserving and restoring patients' lives often resulted in prolonging their pain and suffering. In an extensive study of 3,000 physicians, over a five-year period, Crane asked questions about the best interests of patients and families in relation to the prolongation of life. Her research was grounded in the belief that as "the physician's capacity to treat illness and control the timing of death has increased, the traditional norms that have guided medical practice have become more difficult to apply" (Crane, 1975, p. 1). She reports the results of her inquiry into doctors' attitudes toward the prolongation and termination of life. The results suggest that physicians evaluate the chronically or terminally ill patient not only in terms of the medical aspects of the illness but also in terms of the extent to which the patient is capable of interacting with others. This model suggests that the patient's capacity to perform social roles is an important factor in determining how actively the patient is treated. A portion of this large study specifically looked at the issues central to handicapped newborns.

The data collection for Crane's research included exploratory interviews, case histories (vignettes) followed by precise descriptions of possible medical treatments, attitude questions, and social and professional background questions. Separate questionnaires were

prepared for pediatricians, internists, oncologists, neurosurgeons, pediatric heart surgeons, pediatric cardiologists, and urologists. The questionnaire for physicians in pediatrics asked about the treatment of infants born with congenital anomalies and severe birth defects. Vignettes described infants with anencephaly, spina bifida, Down Syndrome, severe prematurity, and birth defects due to rubella. The questionnaire for pediatric heart surgeons described infants with Down Syndrome and birth defects due to rubella. Background information gathered from the participating doctors included information about the hospital where they were practicing, marital status, number of children, sex, race, religious denomination, religiosity, and father's occupation.

The sampling procedures in Crane's study were modeled after strategies used by Kendall (1963) in her study of learning environments of hospitals. A sample of hospitals was drawn from the American Medical Association's Directory of Approved Internships and Residencies. This Directory classifies hospitals into four categories: (1) those which are major units in a medical school's teaching program; (2) those which have limited roles in such a program; (3) those which are used for graduate training only; and (4) those which have no affiliation with a medical school. The hospitals were asked to provide lists of their physicians in the specialty areas of interest and these physicians were then sampled.

Based on earlier studies (Kendall, 1963; Mumford, 1970) Crane (1975) hypothesized that hospital environment is an important

influence on the behavior of physicians. Staffs of hospitals which are closely connected with medical schools and regarded as more prestigious are more likely to treat patients more actively than staffs of community hospitals. Crane (1975) also recognized the potential effects of the particular departmental policy on medical decision-making. Even in the early 1970s controversy existed among pediatric departments in different hospitals regarding medical treatment for handicapped newborns. During an interview one pediatric informant said: "There's no policy. The individual decisions are made by the house officers. Sometimes there are very heated debates about whether or not a child should have been resuscitated." Another pediatrician indicated that in his hospital the department head was very vigorous, but this point of view was not held by all the staff.

The chairman of the department is very vigorous. His attitude would be to resuscitate every child regardless of the situation. However, this view is not held by a vast majority of the house staff and they would not do it. (Crane, 1975, p. 129)

Crane (1975) found that religious affiliation was more strongly related to decisions to resuscitate a patient and less strongly related to decisions to treat. Catholics and Jews seemed more concerned with the preservation of life and more likely to treat the patient actively regardless of the medical profile than liberal Protestants. Crane (1975) suggests that the correlates of activism (aggressiveness) of treatment are not for the most part organizational variables but are deepseated attitudes concerning the value of life

under different conditions. Religious and cultural background appears to play a role in shaping these attitudes. "Since physicians . . . perceive these issues in various ways, it appears unlikely that controversies regarding appropriate policies for the treatment of critically ill patients will speedily be resolved" (p. 203).

Shaw, Randolph, and Manard (1977) conducted a nationwide survey of the attitudes and practices of pediatric surgeons and pediatricians with respect to some of the different ethical choices confronting them in their treatment of handicapped infants. Questionnaires were sent to members of the Surgical Section of the American Academy of Pediatrics and the responses comprised the "Surgical Group." Questionnaires were also sent to all chairpersons of teaching departments of pediatrics in the United States, chiefs of divisions of neonatology, and chiefs of divisions of genetics in departments of pediatrics. Those returning their questionnaires formed the "Pediatric Group." The results of the study found broad support for the following propositions.

1. Physicians need not attempt to maintain the life of every severely impaired newborn infant, simply because they have the technology and skill to do so.
2. Parents and physicians (in that order) should carry the ultimate responsibility for deciding whether or not to withhold treatment from severely impaired newborns.
3. Such decisions should be made on the basis of the best medical predictions concerning longevity and quality of life.
4. Decisions to treat or not to treat defective newborns are best made on a case-by-case basis.
(Shaw et al., 1977, p. 599)

In an attempt to identify the factors that influence the resolution of ethical dilemmas among pediatricians Todres, Krane, Howell, and Shannon (1977) surveyed Massachusetts pediatricians. Two vignettes were included in this questionnaire along with questions regarding age, sex, religion, religiosity, and type of practice. Vignette 1 described a Down Syndrome infant with duodenal atresia. Vignette 2 described an infant with severe meningomyelocele. Findings of the survey indicated that the resolution of ethical problems affecting the lives of critically ill handicapped newborns varied according to the religious activity, religious persuasion, age, sex, and type of practice of the Massachusetts pediatricians. Using chi-square analysis, they report the following findings:

1. The degree of religious activity rather than the specific religious persuasion was the only factor that was found to be a significant predictor in recommending surgery for both infants.
2. Religious affiliation was found to be a significant predictor of decision-making in the Down Syndrome infant. Catholic physicians recommended surgery significantly more often than Jewish physicians.
3. Younger physicians were more in favor of surgery for the infant with meningomyelocele, perhaps because of greater awareness of surgical techniques developed over the past 15 to 20 years.
4. Female physicians were less likely than male physicians to recommend surgery for the Down Syndrome infant, but as likely as the male physicians to recommend surgery for the infant with severe meningomyelocele.
5. Pediatricians were clearly influenced by the parents' wishes regarding surgery, and viewed parents as final decision makers. (Todres et al., 1977, p. 201)

Levin (1985) explored the continuing controversy in medical decision-making for catastrophically ill newborns using methodology modeled after Crane's 1975 study. In 1983, Levin sampled health care professionals in the field of neonatology. Using four vignettes, she asked the subjects to indicate, given several choices, the specific treatments they would recommend. She also asked if the treatments recommended were required by the then current federal Baby Doe directives. The vignettes presented cases of newborns with four critical conditions--Down Syndrome, anencephaly, trisomy-13, and extreme prematurity. In addition to the vignettes, Levin asked a second set of questions concerning the establishment of guidelines for decision-making and gathered background information on the survey respondents.

Responses to the vignettes were conceptualized to represent a level of aggressiveness of treatment scores for each participant. Levin found that across vignettes there was a high degree of consensus concerning the advisability of recommending the least aggressive treatments. The most aggressive treatments were more likely to be withheld. However, for other treatment choices, there was no clear consensus. Likewise, in interpreting the Baby Doe directives, there was consensus that some treatments were required, but for other treatments no consensus could be found. Most respondents felt that many of the treatments required by the directives would not be in the best interests of the infants. Survey participants agreed strongly that there should not be any federal guidelines for medical decision-making for handicapped infants.

Levin (1985) found differences in level of aggressiveness of treatment across professional disciplines and religious groups. Catholic respondents tended to have higher aggressiveness scores than Protestant or Jewish respondents. Neonatal nurses were found to be significantly more aggressive in their treatment recommendations than neonatologists. Age was found to be a significant variable; older respondents were less aggressive in their treatment recommendations than younger respondents.

Levin (1985) concluded that while advances in medical technology may provide new treatments and improve the prognosis for some newborns, there will continue to be questions about which treatments are best for particular infants.

This point of view is supported in the recent research of Kopelman, Irons, and Lopelman (1988). These researchers argue that the federal regulations now in effect governing the treatment of severely handicapped newborns (Child Abuse Amendments of 1984) require that, except under certain specified conditions, all newborns receive maximal life prolonging treatment. The researchers mailed questionnaires containing vignettes of three hypothetical cases of severely handicapped newborns to 1007 members of the Perinatal Pediatrics Section of the American Academy of Pediatrics. The researchers assumed that the respondents were neonatologists, when in fact a physician need only have an interest in perinatal medicine and pay the required fee to join that section. This assumption has implications

for the results of the study because it is probable that all respondents were not necessarily neonatologists. Nevertheless, the researchers report that almost half (49%) of the "neonatologists" sampled responded to the survey. No follow-ups were planned or carried out. The vignettes presented brief information about a trisomy-13 infant, a severely premature infant, and an infant who is born with hydrocephalus and is blind. Respondents were asked questions about specific treatment decisions, the influence of parents' wishes, the requirements of the federal guidelines, and the possible change in their approach to the hypothetical case because of the federal policy.

Most respondents indicated that they felt the current federal regulations were problematic and resulted in overtreatment of infants. Reacting to the vignettes, the respondents agreed on what decisions were best and agreed that comfort care was sometimes better than maximal life-sustaining treatment in these cases. There was little agreement about what the federal regulations required in the specific cases.

The overwhelming majority of respondents (77% to 87%, depending on the case) wanted to consider the parents' wishes, but 22% to 47% thought the federal regulations required them to treat maximally. Many (22% to 33%) agreed that as a result of the regulations they had changed their practice in caring for such infants.
(p. 630)

In summary, Kopelman, Irons, and Kopelman (1988) found that many participants believe that the new regulations do not serve the best interests of infants.

John V. Hartline, M.D. (Personal communication, August 1989) conducted an informal survey of physician attitudes concerning current federal policy and handicapped newborns at the Southeastern Regional meeting of Neonatologists, held April 6-9, 1989. The sample included 22 board certified neonatologists and seven board eligible neonatologists. Dr. Hartline has no plans to publish these findings, using them primarily as an educational tool, but he was willing to share his results. In a group of questions designed to capture differences in treatments a physician would recommend (taking into account all external forces which apply to decision-making such as current legislation) and should recommend (taking into account what is right for the infant), respondents consistently reported that more aggressive treatment was required by the current policy than they would recommend based on the needs of the infant. Twenty-four of the 29 respondents agreed with the statement, "legal pressures often make physicians initiate or offer treatment which is not indicated." Twenty-five of the 29 respondents also agreed with the statement, "I see a lot of testing done to treat the chart (defensive medicine)." Seven of the 29 respondents also agreed "I think I'll go to law school!"

Statement of the Problem

The objectives for this study and the review of literature lead to the following specific research hypotheses:

1. The more serious the infant's medical condition, the less aggressive will be the best possible treatment

recommendations of neonatologists.

2. The more serious the infant's medical condition the less aggressive will be neonatologists' interpretation of the federal policy requirements.
3. The more serious the infant's medical condition the less aggressive will be neonatologists' actual treatment recommendation.
4. Neonatologists practicing in teaching hospitals are more aggressive in recommending treatment for disabled infants with life-threatening conditions than neonatologists practicing in nonteaching hospitals.
5. Younger neonatologists are more aggressive in recommending treatment than older neonatologists.
6. More religious neonatologists are more aggressive in recommending treatment than less religious neonatologists.
7. Neonatologists will perceive that the federal policy requires more aggressive treatment of disabled infants with life-threatening conditions than they would personally recommend.

CHAPTER III
METHODS AND PROCEDURES

Research Design

This study uses a repeated measures design to answer the research questions and test hypotheses. In a repeated measures design, participants are exposed to all treatments and the dependent variable is measured after the administration of each of them (Pedhazur, 1982). The use of this design results in the following advantages: (a) better sampling of the construct under consideration and, therefore, better measurement; (b) increased statistical power resulting from the increased sample size available since subjects are counted repeatedly; and (c) more precise statistical analysis since each subject acts as his/her own control, which reduces the error term in the analysis.

Pedhazur (1982) suggests there are several problems that could adversely affect the internal and external validity of repeated measures designs. Carry-over effects of treatments from one to another, practice effects, fatigue, and sensitization are among them. These particular threats to validity were not operative in this study. The researcher controlled for these threats via data collection techniques. Five vignettes are the treatments and provided the repeated measure of the dependent variable--level of aggressiveness

of treatment. All five vignettes were randomly ordered and presented to the subjects in a mailed survey. Obtaining data under somewhat controlled conditions, at a given point in time, should deal with carry-over effects, practice effects, and sensitization. The time required for the data collection was approximately 30 minutes.

Sample Selection

This study samples neonatologists in the United States. Given the research questions and hypotheses of this study, neonatologists are in the best position to respond. This group of professionals make real judgments about disabled infants with life-threatening conditions on a daily basis. A random sample of 600 neonatologists was drawn from a comprehensive list of 3,000 neonatologists compiled by Ross Laboratories, Columbus, Ohio. Ross Laboratories is a major producer of infant formula. Their mailing list is generated and updated by their sales staff through on-site, personal contacts. While the Ross Laboratories' mailing list contains many physicians of a variety of specialties, their computer operations can sort the list by specialties and produce a comprehensive nationwide listing of neonatologists. Ross Laboratories' computer operations also randomly selected the sample of 600 neonatologists for this study. The Ross Laboratories' mailing list was chosen over the membership list of the American Academy of Pediatrics, Perinatal Medicine section, for two reasons. First, membership in the Perinatal section is open to all interested

Academy members who choose to pay the section fee and their mailing list is, therefore, not restricted to neonatologists. Second, after a six-month process of negotiation to gain official access to the Perinatal Medicine section list, the Academy ultimately refused to share the list because they erroneously believed this research to be similar to the Kopelman (1988) study.

Methods and Procedures of Data Collection

The treatments used in this repeated measures design are hypothetical vignettes. Previous research on professional judgments and decision-making has demonstrated the feasibility of using vignettes in experimental designs (Otten, 1985). Crane (1975) used case histories followed by precise descriptions of possible medical treatments in her study of physicians' treatment of critically ill patients. Crane (1975) notes that:

One justification for the use of case histories to assess physicians' attitudes toward these issues is that the technique resembles to some extent the tests which physicians take in order to become board certified. These examinations also present typical cases and ask the physician to indicate what treatments he would use. (p. 23)

Building on the work of Crane, Levin (1985) also used vignettes in her study of health care professionals' treatment judgments for catastrophically ill newborns.

Five vignettes were presented to all subjects. These vignettes describe the medical conditions of five newborns. The

newborns' conditions reflect differences in assumed levels of mental and physical impairment, and in prognosis. Subjects responded to questions regarding the specific treatments they would or would not recommend based on what they believe to be best for the infant. Responses provided scores for the "Best Level of Aggressiveness of Treatment" (dependent variable) for the particular vignette. A second question based on the vignette repeats the treatment options, and asks the subjects which treatments would be required based on their interpretation of the Child Abuse Amendments of 1984. Responses provided scores for the "Policy Level of Aggressiveness of Treatment" (dependent variable) for the particular vignette. The third question based on the vignette repeats the treatment options, and asks the subjects which treatments they would actually recommend. Responses provided scores for the "Actual Level of Aggressiveness of Treatment" (dependent variable) for the vignette. In addition to the vignettes, the subjects completed questions about their religious preference, the importance of religion in their lives, their age and sex, the type of hospital environment they practice in, and their professional role. Space was provided for subjects to add additional comments. All questionnaires maintained the respondent's confidentiality.

Data were collected through a mailed survey instrument. Bailey (1987) suggests that mailed surveys offer the researcher certain advantages which must be balanced against a number of disadvantages. Advantages of mailed surveys include a savings of time and

potentially money, assurance of anonymity to the respondent, lack of interviewer bias, and accessibility. Disadvantages include a possible low response rate, capability of gathering information only on reported behavior, and lack of control over the research setting.

The initial mailing included a cover letter and a letter of endorsement from Dr. Jerry Berkowitz, Medical Director, Hemby Intensive Care Nursery, Presbyterian Hospital, Charlotte, North Carolina. Four weeks later a reminder letter was sent. A third mailing, sampling 60 nonrespondents, was sent four weeks after the reminder mailing. The 60 randomly selected nonrespondents received the entire package, including another survey instrument, cover letter, and letter of endorsement.

The Instrument

The independent variables of interest in this study are age and sex of respondent, religion, religiosity, hospital affiliation, nature of their professional role (clinical or administrative, full-time or part-time), and the seriousness of the baby's condition as described by the vignettes.

The dependent variable in this study is called "level of aggressiveness of treatment." Level of aggressiveness of treatment is meant to measure the neonatologist's treatment choices along a continuum of possible treatments from the most basic (nutrition and hydration) to the most invasive (complex surgery). The following

passage contains Levin's (1985) definition of level of aggressiveness of treatment:

Rather than a global choice between giving all treatments to preserve life, and withholding all treatments, the clinicians caring for newborns make decisions concerning specific treatments, among alternate courses of treatment available, for a specific baby . . . one way that clinicians conceptualize the difference between treatments is in terms of their aggressiveness. Treatments that have such attributes as a large physiological effect, that are experimental, invasive, or involve the use of high technology, and/or that are costly in terms of staff time or monetary costs, such as the use of a respirator or neurosurgery, are considered more aggressive than other treatments, such as tube feedings and antibiotics that do not have such attributes. (p. 172)

The dependent variables are Best Level of Aggressiveness of Treatment (BLAT), the Policy Level of Aggressiveness of Treatment (PLAT), and the Actual Level of Aggressiveness of Treatment (ALAT).

Information about background characteristics of the neonatologist such as age, sex, and religious affiliation were collected using a simple data sheet. Age is used as an independent variable in the analysis and is analyzed as a continuous variable. Data regarding religious affiliation and sex, categorical variables, are included in the data analysis.

Hospital affiliation is measured as a categorical variable with four mutually exclusive categories: university based teaching hospital; community based teaching hospital; community based public hospital; community based private hospital.

Religiosity is measured as a continuous, interval level variable using a single forced choice question. Respondents are asked

about the role of religion in their life. Responses are scored from (1) not important to (4) very important. Higher scores suggest a more religious person, while lower scores indicate a person who attaches less importance to the role of religion.

The independent variable labeled "baby seriousness" reflects assumptions regarding the infant's level of mental and physical impairment, as well as the infant's prognosis. This variable is represented by the five hypothetical vignettes. The five vignettes represent baby seriousness as an ordinal variable with five levels. Ranking the vignettes from least serious to most serious would produce the following order:

- | | |
|---------------------------------|-------------------|
| Vignette 4 - Premature Baby | (1) Least Serious |
| Vignette 1 - Down Syndrome Baby | (2) |
| Vignette 5 - Spina Bifida Baby | (3) |
| Vignette 3 - Trisomy-13 Baby | (4) |
| Vignette 2 - Anencephalic Baby | (5) Most Serious |

These rankings represent the clinical opinion of the researcher and are supported in the medical literature. The vignettes have been evaluated by a panel of judges to test construct validity. These judges included a developmental pediatrician specializing in the treatment of developmentally disabled youth, and two neonatal intensive care nurses. The judges found the vignettes to be clinically accurate and appropriate to the research questions. When presented to the subjects, the vignettes were randomly ordered to control for any spillover effects.

Responses to the vignette questions provide the repeated measurement of the dependent variables--Best Level of Aggressiveness of Treatment (BLAT), Policy Level of Aggressiveness of Treatment (PLAT), and Actual Level of Aggressiveness of Treatment (ALAT). The BLAT reflects the physician's treatment recommendations based on what he/she perceives as best for the baby. The PLAT reflects the physician's opinion of the treatments that would be required based on his/her perception of federal policy. The ALAT reflects the physician's ideas about the treatments that actually would be recommended in day-to-day practice.

Each vignette is followed by a series of treatment options. Using a Likert format, respondents were asked to indicate whether or not they would choose this treatment option on a scale of 1 to 4, with 1 being "Definitely No" and 4 being "Definitely Yes." Based on this coding strategy, the higher the score the more aggressive the treatment recommendations, and the lower the score the less aggressive the treatment recommendations. The respondents were asked to consider the treatment options a second time in light of what they believe the policy to require. Finally, the respondents were asked to consider the treatment options for a third time and record the responses they actually would recommend. The coding remains the same for the responses to these questions. The complete questionnaire, cover letter, and letter of endorsement is found in Appendix A.

In summary, each vignette yields three scores--the BLAT, the PLAT, and the ALAT--each of which measures a different dependent

variable. The potential range of BLAT, PLAT, and ALAT scores is as follows:

		Highest	Lowest
Vignette 1	BLAT	20	5
	PLAT	20	5
	ALAT	20	5
Vignette 2	BLAT	24	6
	PLAT	24	6
	ALAT	24	6
Vignette 3	BLAT	20	5
	PLAT	20	5
	ALAT	20	5
Vignette 4	BLAT	20	5
	PLAT	20	5
	ALAT	20	5
Vignette 5	BLAT	20	5
	PLAT	20	5
	ALAT	20	5

The use of scales to obtain scores describing the neonatologists' opinions, perceptions, and attitudes, raises questions about level of measurement and use of statistical techniques. Isaac and Michaels (1983) state that Likert-type or Summated Rating Scales contain a set of items, all of which are considered approximately equal in attitude. A person's response indicates the degree of intensity on a scale ranging between extremes. With this definition in mind, Likert-type scales may be considered interval data for the purposes of satisfying statistical assumptions. Hays (1988) acknowledges that the problem of measurement, especially attaining interval scales, is an extremely serious one for social scientists.

Hays (1988) suggests that obtaining numbers or scores is not the problem, but that the challenge is interpreting the numbers back into statements about the real world. The interpretation of scales, therefore, is approached in this research with caution.

The instrument was pilot tested before the study began. In addition to the panel of judges who reviewed the instrument to assess its validity, reliability was tested. Forty pediatricians in Mecklenburg County, North Carolina, responded to the survey. A reliability coefficient (Cronbach's alpha) of .963 was found for the five vignettes. Vignettes were also tested separately and the following reliability coefficients were found:

Vignette 1 - Down Syndrome Baby	Alpha = .9113
Vignette 2 - Anencephalic Baby	Alpha = .9157
Vignette 3 - Trisomy-13 Baby	Alpha = .8201
Vignette 4 - Premature Baby	Alpha = .9664
Vignette 5 - Spina Bifida Baby	Alpha = .9633

Data Analysis

Several hypotheses were tested using repeated measures analysis of variance. Norusis (1985) suggests that the goals of this statistical procedure are to test hypotheses about the relationship between the dependent variable and the conditions under which it is measured when the same dependent variable is measured on more than one occasion for each subject; and to identify the variables that

contribute to differences between treatment conditions. This type of data analysis requires that each case (subject) have multiple measurements of the same dependent variable for various within-subject factors. Discrete values for the classification variables for between-subjects factors are also included.

Three separate ANOVAs were used in this study to test the following hypotheses:

1. The more serious the infant's medical condition the less aggressive will be the best possible treatment recommendations of neonatologists.
2. The more serious the infant's medical condition the less aggressive will be neonatologists' interpretation of the federal policy requirements.
3. The more serious the infant's medical condition the less aggressive will be neonatologists' actual treatment recommendation.
4. Neonatologists practicing in teaching hospitals are more aggressive in recommending treatment for disabled infants with life-threatening conditions than neonatologists practicing in nonteaching hospitals.
5. Younger neonatologists are more aggressive in recommending treatment than older neonatologists.
6. More religious neonatologists are more aggressive in recommending treatment than less religious neonatologists.

The first analysis of variance was used to test the significance of the main effect of Baby Seriousness on the Best Level of Aggressiveness of Treatment (BLAT). Due to the expected influence of the independent variables on the outcome measure, age, religiosity, nature of professional role, and hospital affiliation were treated as covariates in the analysis. The second and third analysis of variance were used to test the significance of the main effect of Baby Seriousness on the Policy Level of Aggressiveness of Treatment (PLAT) and on the Actual Level of Aggressiveness of Treatment (ALAT).

Following the analyses of variance, multiple regression was used for further explanation. Pedhazur (1982) suggests that multiple regression is a versatile and useful technique where information from independent variables is used to attempt to explain variability in a dependent variable. In this study, information from the independent variables age, sex, religious affiliation, religiosity, hospital affiliation, nature of professional role, and baby seriousness were entered in multiple regression equations for the BLAT, PLAT, and ALAT dependent variables. The use of multiple regression in this design was for descriptive and explanatory purposes.

Following the multiple regression, total BLAT, PLAT, and ALAT scores were compared to determine if what the neonatologist believes is best for an infant is congruous with what the neonatologist believes the federal policy requires and what the neonatologist believes he/she would actually do in everyday practice. The

hypothesis that neonatologists will perceive that the federal policy requires more aggressive treatment of disabled infants with life-threatening conditions than they would personally recommend was tested using the Kendall Coefficient of Concordance. This technique allows the researcher to compare any two (PLAT and BLAT, PLAT and ALAT, ALAT and BLAT) sample distributions to determine if there are significant differences between them.

CHAPTER IV

RESULTS

Using a mailing list of neonatologists provided by Ross Laboratories, 600 subjects were randomly selected from an available list of 3,000 neonatologists. Two hundred sixty-two subjects responded to the first and second mailings of the questionnaire on "Medical Treatment for Disabled Newborns With Life-Threatening Conditions: A Policy Analysis" from the original mailing of 600. One subject had to be dropped from the sample due to incomplete responses. Another respondent identified herself as a child development specialist and a nurse and was not included. This reduced the total number of participants to 260.

Two hundred forty-three neonatologists responded to the first survey mailing and reminder letter. In an attempt to increase the response rate, 60 nonrespondents were randomly selected and sent a third complete mailing including a new survey booklet. Eighteen of the 60 responded to this request. For the purpose of determining if there was any bias created due to this sampling, responses were grouped by early and late responders. In the repeated measures ANOVAs the between-subjects factor "mail group" divided the sample into two discrete subgroups. Results of the statistical analysis showed that there was no significant difference between the two

groups. Therefore, it was decided to aggregate the data for statistical analysis. A description of the characteristics of the responding neonatologists is summarized in Table 1.

The majority (78%) of neonatologists responding to this study were between 30 and 46 years of age. The mean was 42 years, the mode was 38 years, and the median 40 years of age. This degree of homogeneity is not surprising given that neonatology is a relatively new specialty in the field of pediatrics. Seventy-three percent of the respondents were male. The majority of respondents were Catholic (26.7%), Jewish (16.8%), or Protestant (12.2%). Nineteen percent were Baptist (6.1%), Hindu (6.5%), and Presbyterian (6.5%). The remaining religious denominations (Lutheran, Methodist, Muslim, Quaker, Protestant, Unitarian, and No Denomination) each accounted for less than 5% of the sample. Twenty-one percent reported that the role of religion was very important in their lives, 30% reported that religion was important, 23% reported that religion was somewhat important, and 22% reported that religion was not important. A majority (69.5%) of responding neonatologists practiced in teaching hospitals. Seventy-three percent of all respondents were practicing with full-time clinical responsibilities. Twelve respondents (4.6%) reported that they were not neonatologists and listed their specialty as perinatology. Perinatology is concerned with the anatomy, physiology, and diagnosis and treatment of disorders of the mother and fetus or newborn child during late pregnancy, childbirth, and the period just after childbirth. These respondents were included in the study.

Table 1

Characteristics of the Sample of Neonatologists

Description	Percentage	n
<u>Age</u>		
30-35 years	20	52
36-40	33	86
41-45	33	86
46-50	10	26
51+	4	10
<u>Sex</u>		
Male	73	180
Female	27	65
<u>Religious Denomination</u>		
Catholic	26.7	70
Jewish	16.8	44
Protestant	12.2	32
Presbyterian	6.5	17
Hindu	6.5	17
Baptist	6.1	16
Other denominations ¹	25.2	64
<u>Role of Religion</u>		
Very important	21	56
Important	30	78
Somewhat important	23	61
Not important	22	57
No response	4	8
<u>Hospital Type</u>		
Teaching hospitals	69.5	171
Nonteaching hospitals	20.6	54
Other	9.9	26
<u>Professional Role</u>		
Full-time clinical	72.9	191
Part-time clinical	15.6	41
Nonclinical	11.5	22

¹Lutheran, Methodist, Muslim, Quaker, Protestant, Unitarian,
No Denomination

Aggressiveness of Treatment by
Seriousness of Condition

Hypothesis 1

The first hypothesis stated that the more serious an infant's medical condition the less aggressive the best possible treatment recommendations of neonatologists. This was investigated with a repeated measures ANOVA controlling for the effects of hospital type, age, and religiosity. Examination of the means and standard deviations of the neonatologists' best treatment recommendations in Table 2 show an inverse relationship between the infant's medical condition and the level of aggressiveness of treatment recommended. That is, the more severe the infant's medical condition, the less aggressive the treatment recommended. Results of the repeated measures ANOVA found that "seriousness" had a significant main effect ($p < .001$), and that neonatologists' best treatment recommendations differed according to the severity of the infant's medical condition. The mean in Table 2 suggest that the best treatment for the anencephalic baby and the Trisomy-13 baby cluster together with physicians recommending the least aggressive treatments for these two conditions; and the means for the Down Syndrome and premature babies cluster together for these conditions. Multiple comparison statistical procedures indicate that all differences among the treatment means for the five infant conditions are significant using the Tukey method (Honest Significant Difference = .1800). These statistical findings support the first hypothesis.

Table 2

Neonatologists' Best Treatment Recommendations¹

Seriousness	Vignette	Mean	SD
<u>Means and Standard Deviations</u>			
1 (Most	Anencephalic	1.812	.533
2	Trisomy-13	2.149	.545
3	Spina Bifida	3.201	.636
4	Down Syndrome	3.835	.242
5 (Least)	Prematurity	3.909	.217
Source	<u>F</u>	Significance of <u>F</u>	Significance of <u>t</u>
<u>Repeated Measures ANOVA Results</u>			
Main Effect			
Seriousness	384.55	.000	
Covariates			
Hospital type			.526
Age			.790
Religiosity			2.218

¹n = 197Hypothesis 2

The second hypothesis stated that the more serious the infant's medical condition the less aggressive neonatologists' interpretation of the federal policy requirements. Using the same methods as described in Hypothesis 1, similar results were found. Inspection of the means showed that neonatologists' interpretation of the policy requirements were inversely related to the infant's medical condition. That is, the more severe an infant's medical condition, the less

aggressive the policy requirements, but it is interesting to note that generally the treatment required by policy is more aggressive than the treatment the neonatologist thought was best for the infant. The means found in Table 3 describing the treatment required by policy are higher than the means found in Table 2 describing the best treatment recommendations. Results of the repeated measures ANOVA showed that "seriousness" had a significant main effect ($P < .001$), and that neonatologists' interpretation of the federal policy requirements differed according to the severity of the infant's medical condition. The means of policy treatment scores suggest that the policy recommendations for the anencephalic baby and the Trisomy-13 baby cluster together with physicians recommending the least aggressive treatments for these two conditions and the Spina Bifida, Down Syndrome, and premature babies cluster together with physicians recommending the most aggressive treatments for these conditions. Multiple comparison procedures using the Tukey method indicate that all the means are significantly different except for the Down Syndrome and premature babies (Honest Critical Difference = .2079). The statistical findings support this hypothesis.

Hypothesis 3

The third hypothesis stated that the more serious the infant's medical condition the less aggressive neonatologists' actual treatment recommendations. Inspection of the means for actual level of aggressiveness scores, found in Table 4, again showed that neonatologists'

Table 3

Neonatologists' Policy Treatment Recommendations¹

Seriousness	Vignette	Mean	SD	
<u>Means and Standard Deviations</u>				
1 (Most)	Anencephalic	2.025	.683	
2	Trisomy-13	2.354	.669	
3	Spina Bifida	3.552	.541	
4	Down Syndrome	3.854	.302	
5 (Least)	Prematurity	3.912	.269	
Source	<u>F</u>	Significance of <u>F</u>	<u>t</u>	Significance of <u>t</u>
<u>Repeated Measures ANOVA Results</u>				
Main Effect				
Seriousness	235.75	.000		
Covariates				
Hospital type			.027	.979
Age			1.298	.196
Religiosity			.866	.387

¹
n = 196

level of aggressiveness was inversely related to the seriousness of the infant's medical condition. The repeated measures ANOVA found that the main effect "seriousness" was significant ($p < .001$), and that the neonatologists' actual treatment recommendations differed according to the severity of the infant's medical condition. Inspection of the actual treatment means suggest that the actual treatment recommendations for the anencephalic and Trisomy-13 babies cluster

Table 4

Neonatologists' Actual Treatment Recommendations¹

Seriousness	Vignette	Mean	SD
<u>Means and Standard Deviations</u>			
1 (Most	Anencephalic	1.791	.528
2	Trisomy-13	2.115	.545
3	Spina Bifida	3.345	.560
4	Down Syndrome	3.825	.282
5 (Least)	Prematurity	3.902	.214
Source	<u>F</u>	Significance of <u>F</u>	Significance of <u>t</u>
<u>Repeated Measures ANOVA Results</u>			
Main Effect			
Seriousness	420.85	.000	
Covariates			
Hospital type			-.310 .757
Age			-.680 .497
Religiosity			3.930 .000

¹
n = 201

together with physicians recommending the least aggressive treatments for these two conditions and the Spina Bifida, Down Syndrome, and premature babies cluster together with physicians recommending the most aggressive treatments. Multiple comparison procedures indicate that all differences are significant using Tukey's multiple comparison procedure (Honest Significant Difference = .1590). The statistical findings support this hypothesis.

Predictors of Aggressiveness of Treatment

Hypotheses 4, 5, and 6

Hypotheses 4, 5, and 6 stated that neonatologists practicing in teaching hospitals would be more aggressive in their treatment recommendations than neonatologists practicing in nonteaching hospitals, that younger neonatologists would be more aggressive in their treatment recommendations than older neonatologists, and that more religious neonatologists would be more aggressive in recommending treatment than less religious neonatologists. The correlations between the three dependent measures and hospital type, age, and religiosity are found in Table 5. Significant correlations ($p < .001$) between religiosity and the dependent measures were found for best treatment recommendations and the Trisomy-13 baby, and for actual treatment recommendations and the Trisomy-13 and Spina Bifida babies. The variables hospital type, age, and religiosity were used as covariates in the three repeated measures ANOVA. Hospital type and age were not significant (see Tables 2, 3, and 4). Religiosity was significant ($p < .05$) in analyzing the best treatment recommendations and the actual treatment recommendations (see Tables 2 and 4). Religiosity was not significant when used as a covariate in the policy recommendations analysis (see Table 3). The statistical findings did not support the hypotheses that neonatologists practicing in teaching hospitals would be more aggressive in their treatment recommendations than neonatologists practicing in nonteaching hospitals and that

Table 5

Pearson Correlation Coefficients

Vignette	Religiosity	Age	Hospital Type
<u>Best Treatment Recommendation</u>			
Anencephalic	.0843	.0165	-.0592
	$p = .092$	$p = .399$	$p = .181$
Trisomy-13	.2019*	.0113	.0185
	$p = .001$	$p = .430$	$p = .388$
Spina Bifida	.1206	.0029	.0864
	$p = .034$	$p = .483$	$p = .101$
Down Syndrome	.1312	-.0125	.0673
	$p = .020$	$p = .424$	$p = .152$
Prematurity	.1395	.1077	-.0975
	$p = .014$	$p = .048$	$p = .067$
<u>Policy Treatment Recommendation</u>			
Anencephalic	.0427	.0986	-.0549
	$p = .253$	$p = .064$	$p = .201$
Trisomy-13	.1092	.0681	.0199
	$p = .043$	$p = .147$	$p = .381$
Spina Bifida	.0156	-.0167	.1217
	$p = .407$	$p = .402$	$p = .035$
Down Syndrome	.0344	.0859	.0835
	$p = .296$	$p = .094$	$p = .102$
Prematurity	.0143	.0749	-.0368
	$p = .411$	$p = .124$	$p = .287$
<u>Actual Treatment Recommendation</u>			
Anencephalic	.1139	-.0351	-.0694
	$p = .036$	$p = .293$	$p = .143$
Trisomy-13	.2106*	-.0032	-.0157
	$p = .000$	$p = .480$	$p = .405$
Spina Bifida	.1965*	-.0957	.0328
	$p = .001$	$p = .077$	$p = .314$
Down Syndrome	.1352	-.1155	.0610
	$p = .017$	$p = .037$	$p = .176$
Prematurity	.0982	.0606	-.1093
	$p = .061$	$p = .174$	$p = .046$

younger neonatologists would be more aggressive in their treatment recommendations than older neonatologists. Statistical findings showed limited support for the hypothesis that more religious neonatologists would be more aggressive in their treatment recommendations than less religious neonatologists.

Hypothesis 7

The seventh hypothesis stated that neonatologists perceive that the federal policy requires more aggressive treatment of disabled infants than they would personally recommend. This hypothesis was examined using the Kendall's Tau or the Kendall Coefficient of Concordance. Results showed a significant difference between the means of best treatment recommendations and policy recommendations (Chi-Square = 47.0784, probability = .0000). A significant difference was also found between the means of actual treatment recommendations and policy recommendations (Chi-Square = 37.9799, probability = .0000). No difference was found between best and actual treatment recommendations (Chi-Square = .0898, probability = .7644). Inspection of the means found Tables 2, 3, and 4 show that the policy treatment recommendations were more aggressive than either the best or actual treatment recommendations and the Kendall's Tau shows that there is a significant difference between the policy recommendations and both the best and actual treatment recommendations.

Multiple Regression Analysis

Multiple regression analysis was performed in an attempt to further explain the relationships between several of the independent variables and the dependent variables. The independent variables ("Age," "Sex," "Religiosity," and "Hospital Type") were entered into multiple regression equations to determine their possible relationships to the dependent variables. Three equations were used. The first multiple regression equation used the best level of aggressiveness of treatment scores across all vignettes as the dependent variable and the five independent variables. The second multiple regression equation used the policy level of aggressiveness of treatment scores across all vignettes as the dependent variable and the five independent variables. The third multiple regression equation used the actual level of aggressiveness of treatment scores across all vignettes as the dependent variable and the five independent variables. Results of the multiple regression analysis indicated that these five independent variables accounted for relatively little variance in the best, policy, and actual treatment scores, and are not shown.

In order to determine the relative contribution of religious affiliation to the level of aggressiveness scores, 13 religious denominations were used as independent variables in another set of multiple regression equations. "Baptist," "Roman Catholic," "Hindu," "Jewish," "Lutheran," "Methodist," "Muslim," "Quaker," "Presbyterian,"

"Protestant" (other, "Unitarian," "None," and "Other" were entered in three equations using best level of aggressiveness scores, policy level of aggressiveness scores, and actual level of aggressiveness scores as the respective dependent variables. Multiple regression results indicated that religious denomination accounted for relatively little variance in the best, policy, and actual treatment scores.

The multiple regression findings suggest that the subject variables are not significant in explaining neonatologists' judgments regarding medical treatment for disabled newborns, and lend support to the repeated measures ANOVA findings that the seriousness of the baby's condition is most important in determining the best, policy, and actual levels of aggressiveness of treatment scores.

CHAPTER V
DISCUSSION

Summary of Results

This study was designed to answer questions about neonatologists' judgments regarding treatment for disabled newborns with life-threatening conditions in the context of the Child Abuse Amendments of 1984. Relationships between the seriousness of a newborn's medical condition and a neonatologist's treatment recommendations and perceptions of the treatment required by policy were explored using a nationwide mailed survey. Two hundred sixty usable responses from neonatologists were obtained. Five different infant medical conditions, varying in terms of seriousness, were presented in a series of vignettes. The vignettes provided brief descriptions of newborns with the following medical conditions: Anencephaly, Trisomy-13, Spina Bifida, Down Syndrome, and prematurity. Subjects were presented with a list of possible treatments for each newborn and asked to identify the treatments they believed to be best for the infant, the treatment they believed to be required by policy (the Child Abuse Amendments of 1984), and the treatment they would actually recommend. Answers to these questions provided scores for the three dependent variables: best level of aggressiveness of treatment, policy level of aggressiveness of treatment, and actual level of aggressiveness of treatment.

Each vignette yielded scores on these three dependent variables and the total survey provided five repeated measures of each of the dependent variables. The possibility that variables such as the neonatologist's age, religious denomination, religiosity, professional role, and hospital affiliation could contribute to an explanation of the neonatologist's treatment recommendations were also considered.

Using repeated measures ANOVA, the data derived from the surveys were used to test three hypotheses. It was hypothesized that the more serious the infant's medical condition the less aggressive will be the best treatment recommendations, the perceptions of treatment required by policy, and the actual treatment recommendations of neonatologists. Support for each of these three hypotheses was significant at the .001 level.

Using age, religiosity, and hospital affiliation as covariates in the repeated measures ANOVAs, three hypotheses were tested. It was hypothesized that neonatologists practicing in teaching hospitals are more aggressive in recommending treatment for disabled newborns with life-threatening conditions than neonatologists practicing in non-teaching hospitals. There was no statistical support for this hypothesis. It was hypothesized that younger neonatologists are more aggressive in recommending treatment than older neonatologists. There was no statistical support for this hypothesis. It was hypothesized that more religious neonatologists are more aggressive in recommending treatment than less religious neonatologists. There was partial statistical support for this hypothesis. Religiosity was a significant

covariate in the analysis of neonatologists' best treatment recommendations at the .005 level, and in the analysis of neonatologists' actual treatment recommendations at the .001 level. Significant Pearson correlation coefficients between religiosity and the infant's medical condition for best and actual treatment recommendations lend further statistical support. Religiosity did not approach significance when used as a covariate in the analysis of neonatologists' policy treatment recommendations.

The Kendall's Coefficient of Concordance was used to examine the seventh hypothesis. It was hypothesized that neonatologists perceive that the federal policy requires more aggressive treatment of disabled infants with life-threatening conditions than they would personally recommend. The means of best and actual treatment recommendations were significantly different from the means of policy recommendations. Support for this hypothesis was significant at the .001 level.

Discussion of Results

Data from this study support the hypotheses that the seriousness of the newborn's medical condition affects neonatologists' best, policy, and actual treatment recommendations. For all infants under all conditions "baby seriousness" was a significant main effect. Seriousness was inversely related to aggressiveness of treatment.

It is interesting to note that the Down Syndrome baby had high aggressiveness scores, second only to the premature baby. The Baby

Doe issue began with the refusal of routine surgery for a Down Syndrome baby. High aggressiveness scores for this vignette may be suggesting a change in perception, at least among neonatologists, about the future and quality of life of Down Syndrome persons. In the earlier research of Todres et al. (1977) 46% of the pediatricians surveyed responded that they would not perform surgery on a Down Syndrome baby with duodenal atresia. Shaw et al. (1977) found that 49.5% of pediatricians responding to their questionnaire would not perform surgery on a Down Syndrome baby with duodenal atresia if the baby's parents refused consent. In this study 92.4% of the neonatologists responding to the survey indicated strong agreement with surgery for a Down Syndrome baby with duodenal atresia as a best possible course of treatment. The change in medical professionals' decision-making regarding Down Syndrome infants suggests that these infants are regarded more positively than they were prior to the controversy about the 1982 Baby Doe case.

Among the infant conditions, prematurity and Down Syndrome babies consistently had the most aggressive treatment scores. The other infant conditions (Spina Bifida, Trisomy-13, Anencephaly) had less aggressive treatment scores. This clustering of scores along the "seriousness" continuum may suggest that the federal policy is appropriately applied to less severe conditions to insure maximum treatment for those infants with the best prognosis, but is inappropriate for those infants whose outcomes do not warrant the most aggressive treatments available. Findings of Kopelman et al. (1988) suggest

that the federal policy results in overtreatment of all infants. They did not investigate the relationship between the infant's medical condition and the medical professional's treatment recommendations.

There was no support for the hypothesis that younger neonatologists are more aggressive in their treatment recommendations than older neonatologists. The thinking behind this hypothesis was that neonatologists who had been most recently trained in the most current technology would be more apt to prescribe these treatments than older neonatologists whose training did not include the most current therapies. It is possible that this hypothesis was not supported because neonatology is such a new field that the age group practicing in this specialty is relatively homogeneous and that there is little variation in treatment recommendations that is attributable to differences in age of the respondents.

There was no support for the hypothesis that neonatologists practicing in teaching hospitals would be more aggressive in recommending treatment than neonatologists practicing in nonteaching hospitals. Again, the thinking behind this hypothesis was that physicians practicing in teaching hospitals would be exposed more routinely to the newest, most aggressive medical technologies available for use with disabled newborns with life-threatening conditions. Crane (1975), in her study of physicians' treatment of critically ill patients, found that "among pediatric residents, hospital setting was the most important influence upon decisions to treat patients" (p. 203). In prestigious settings such as university-based teaching

hospitals more aggressive treatments were used. In correspondence with Dr. Robert Dillard, Associate Professor of Pediatrics, The Bowman Gray School of Medicine, he suggested that it might be difficult to elicit "hospital" policies or preferences. "Because of the diversity of organization of the institutions in which your respondents practice there is likely to be no specific institutional or department policy." It appears that the approach taken in various hospitals regarding the interpretation of federal policy and the aggressiveness of treatment of significantly handicapped newborns is more informal in nature and cannot be categorized by the "type" of hospital. It is possible that groups of neonatologists working together in a given hospital discuss their points of view and come to a consensus about how they will go about treating these infants. Perhaps the best way for a researcher to explore this issue would be through participant observation in a variety of neonatal intensive care units to experience how everyday treatment decisions are made.

The issue of treatment philosophy in various neonatal intensive care units and in various "types" of hospitals is magnified by difficulties in interpreting the federal policy as described in the Child Abuse Amendments of 1984. One neonatologist said, "I believe the passage 'in the physician's best medical judgment' should be interpreted to place the responsibility with the physician and not with the courts." Another responded:

I think the Child Abuse Amendments of 1984 allow the family/clinician to make decisions around what is merely prolonging life. Thus, there is room for different choices to be made within its guidelines.

Other neonatologists remarked that they had difficulty making sense of the language of the policy. One neonatologist suggested, "I believe decision by doctors and parents cannot be legislated." Another stated that "the wording (of the policy) is too vague which leaves room for too many interpretations."

There was partial support for the hypothesis that more religious neonatologists would be more aggressive in recommending treatment than less religious neonatologists. The findings of this study support this hypothesis when applied to the neonatologists' recommendations for treatment thought to be best for a disabled newborn, and when applied to the neonatologists' actual treatment recommendations. In these cases, the more religious the neonatologist the more aggressive the treatment recommendations. The findings did not support this hypothesis when applied to the neonatologists' perception of the treatment required by policy. Perhaps the policy requirements are sufficiently clear in calling for maximally aggressive treatment that there is less room for clinical judgments about treatment to be influenced by factors such as religiosity.

There was statistical support for the hypothesis that neonatologists would perceive that the federal policy requires more aggressive treatment than they would personally recommend. Although 57% of the neonatologists surveyed responded that they strongly agreed or agreed with the guidelines for treating disabled infants with life-threatening conditions as set forth in the Child Abuse Amendments of 1984, their responses to the vignettes showed a difference between the

treatment they would personally recommend and the treatment the policy required. It is possible that while agreeing in principle with the policy, neonatologists may find the policy more restrictive than they would actually prefer. It is also possible that respondents might indicate agreement with the policy because it is law but interpret the policy in a way that is acceptable to their personal belief system and medical practice. One respondent indicated he disagreed with the guidelines established by the Child Abuse Amendments and wrote: "Child Abuse Act is restrictive. [It] does not include quality of life considerations and impact on family." Another respondent indicated agreement with the Child Abuse Amendments and wrote:

I have learned from this questionnaire that there is not a great deal of disparity between what I think the Child Abuse Statutes demand, what I consider to be in the baby's best interest, and what I advise.

Another respondent indicated strong agreement with the policy and shared the following personal thoughts:

- (1) Neonatologists should not play at being God
- (2) In cases of questionable outcome thought must be given to any potential that might exist in infant
- (3) Where infant status is bleak, infant's care should be
 - a) humane
 - b) painless
 - c) not unnecessarily extended by technology

It is questionable whether this neonatologist's personal thoughts are as much in harmony with the Child Abuse Amendments of 1984 as he believes.

Suggestions for Future Research

One of the major problems identified by the responding neonatologists is the lack of consideration of parents' wishes in the Child Abuse Amendments of 1984. Among the written anecdotal comments of the respondents, the need to consult with parents and families was a common theme. The following statements represent a sample of the neonatologists' comments.

Female respondent, 45 years old: Family consideration becomes important - an abandoned, cocaine exposed black infant (with Downs Syndrome) of a known prostitute probably is better off if nature has her way.

Female respondent, 40 years old: None of these decisions are valid without the participation of the family.

Male respondent, 39 years old: To make decisions, we can't disregard parent's opinion.

Female respondent, 36 years old: The family and health care team must all participate to reach the most compassionate and ethical decision.

Male respondent, 55 years old: The issue should not be solely what is best for the baby but what is best for the combination of baby and family.

The lack of regard for the family's wishes is problematic not only to many of the neonatologists participating in this study, but to many scholars writing on this issue. Shelp (1986) suggests that

labeling parents as unfit, abusive, or neglectful because their reasonable medical-moral judgments do not coincide with others in positions to enforce their view may unjustly stigmatize parents psychologically and socially. (p. 198)

Additional research is needed to explore neonatologists' attitudes regarding the role for parents in medical decision-making. This study

did not consider the question of parental input in decision-making, but it is clear that this issue needs to be addressed. The research question might ask: What role is there for parents of disabled newborns in medical decision-making in the context of the Child Abuse Amendments of 1984?

Future research also needs to address the relationships between family variables and treatment decisions for disabled newborns with life-threatening conditions. As suggested by one neonatologist, family considerations may alter a physician's opinion of appropriate treatment for an infant. Family variables such as socioeconomic status and education might be used in a study utilizing vignettes. Given the findings of this research indicating that the seriousness of a newborn's medical condition affects the treatment recommendations, a researcher could hold the medical condition constant and vary the family's circumstances to determine the possible effects of family factors on medical decision-making. The research question is: Do family variables such as socioeconomic status and education influence a neonatologist's medical decision-making for a disabled newborn with life-threatening conditions? A second research question might ask: Do parents' intelligence, verbal abilities, and level of cooperation influence a neonatologist's medical decision-making for a disabled newborn with life-threatening conditions?

Soliciting information from parents of disabled newborns would add another dimension to future research. Asking parents questions such as: What was your role in medical decision-making for your

child? Did you feel comfortable and well informed about the choices and alternatives regarding treatment for your child?, would elicit new and important data. Survey research would not be appropriate to answer these questions. A qualitative approach using structured interviews seems more conducive to obtaining this sensitive information.

Conclusions

This study has shown that there are specific medical characteristics of disabled newborns related to neonatologists' treatment choices. In addition, there are differences between neonatologists' perceptions of the treatments required by federal policy and the treatments they think best and would actually recommend for a disabled newborn. The results of this research suggests that the federal policy stated in the Child Abuse Amendments of 1984 may not be effective in meeting the needs of infants, parents, and health care professionals. The guidelines provided for medical decision-making are controversial and subject to interpretation by the neonatologist whose practice is governed by them. For those neonatologists who take the position that providing less than the most aggressive treatment can rarely, if ever, be justified, the current policy is acceptable. For those neonatologists who take the position that treatment choices are made based on the seriousness of the disabled infant's medical condition, the current policy raises definitional and interpretative problems. When many individuals with diverse moral

convictions face a series of decisions about similar cases, there must be a way to accommodate the diversity of private beliefs with some degree of agreement about how such cases should be managed. It is up to professionals in the fields of medicine, law, medical ethics, and related specialties to continue efforts to explore the problems inherent in treating disabled newborns with life-threatening conditions and to define the role of federal policy in making sensitive medical decisions.

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APPENDIX A
QUESTIONNAIRE ON MEDICAL TREATMENT FOR DISABLED
NEWBORNS WITH LIFE-THREATENING CONDITIONS
AND ACCOMPANYING LETTERS

2022 Knickerbocker Drive
Charlotte, NC 28212
August 12, 1989

Dear Neonatologist:

I am writing to request your participation in the data collection for my research on Medical Treatment for Disabled Newborns with Life-Threatening Conditions. This research is being conducted on a nationwide basis and will be used to complete my doctoral dissertation at the University of North Carolina at Greensboro, Department of Child Development and Family Relations.

It is my hope that you will take fifteen minutes from your hectic schedules and complete this survey. The results should provide interesting information about how the Child Abuse Amendments of 1984 have affected medical decision-making for disabled newborns. I have enclosed a postcard with your packet. Please drop the postcard in the mail when you complete the survey. This will be my way of knowing who did participate, and I will not contact you further with reminders. Your survey instrument remains confidential. Also, the postcard will ask if you are interested in receiving the results of the study.

It will be appreciated if you will complete this questionnaire prior to September 11 and return it in the stamped envelope enclosed. Other phases of this research cannot be completed until the questionnaire data are analyzed. Your comments concerning the issues addressed in this research are welcomed. I am thanking you in advance for your cooperation, support, and prompt response.

Sincerely yours,

Marla Kappen Chalnick

200 Hawthorne Lane
 Post Office Box 33549
 Charlotte NC 28233-3549
 704/ 371-4944

Hemby Intensive Care Nursery
 Neonatology Department

Vijay G Dhande MD
 Gerald P Berkowitz, MD
 Joseph L. Brady, Jr. MD
 Margaret J. Donovan, MD



Presbyterian Hospital

July 24, 1989

Dear Fellow Neonatologists:

I hope you will take some time to read and complete the enclosed survey being sent to you by Marla Chalnack. Ms. Chalnack will be using the results of this survey to complete her doctoral dissertation at the University of North Carolina at Greensboro.

I have had the pleasure of knowing Ms. Chalnack only a short period of time, but I can assure you that she is a thoroughly dedicated and professional individual. She has worked for many years at one of our local developmental centers evaluating infants with special needs. She has been involved full-time over the last year working toward her doctoral degree.

Although there have been a number of other surveys done concerning the issue of treatment for disabled newborns, I believe that this survey addresses some areas that have not previously been explored. I would hope that a careful analysis of the results of this survey could add to our understanding of how we make decisions in this difficult area.

On behalf of Ms. Chalnack, I would really appreciate you taking the time to complete this survey.

Sincerely,

Gerald P. Berkowitz, M.D.
 Medical Director
 Hemby Intensive Care Nursery

GPB/dn63/28

Enclosure

2022 Knickerbocker Drive
Charlotte, NC 28212
September 10, 1989

Dear Neonatologist:

A few weeks ago I mailed you a questionnaire entitled Medical Treatment for Disabled Newborns with Life-Threatening Conditions. I hope that you will participate with other neonatologists across the country and complete this survey. The data collected with this instrument will be used to complete my doctoral dissertation at the University of North Carolina at Greensboro, Department of Child Development and Family Relations.

The survey will take approximately fifteen minutes to complete. The results should provide interesting information about how the Child Abuse Amendments of 1984 have affected medical decision-making for disabled newborns. If you are unable to locate your survey packet I will be glad to send you a replacement. I have enclosed a postcard with the packet. Please drop the postcard in the mail when you complete the survey. This will be my way of knowing who did participate, and I will not contact you with further reminders. Your survey instrument remains confidential. Also, the postcard will ask if you are interested in receiving the results of the study.

Please join with your colleagues and complete this questionnaire by October 5, 1989. Other phases of this research cannot be completed until the questionnaire data are analyzed. Your comments concerning the issues addressed in this research are welcomed. I am thanking you in advance for your cooperation, support, and response.

Sincerely yours,

Marla Kappen Chalnick

2022 Knickerbocker Drive
Charlotte, NC 28212
October 10, 1989

Dear Neonatologist:

I am writing to you about my study of neonatologists' opinions regarding medical treatment for disabled newborns with life-threatening conditions. I have not received your completed questionnaire.

The large number of questionnaires returned is very encouraging. But, whether I will be able to describe accurately how neonatologists feel about the Child Abuse Amendments of 1984 and their affect of medical decision-making for disabled infants depends upon you and others who have not yet responded. This is because past experiences suggest that those of you who have not yet sent in your questionnaire may feel differently than those who have.

In the event that your questionnaire has been misplaced, a replacement is enclosed. I will be happy to send you a copy of the survey results if you want to have them. Simply put your name, address, and "copy of results requested" on the back of the return envelope. I expect to have the results ready to send this spring.

Please join with your colleagues and complete this questionnaire as quickly as possible. Take a break, enjoy the candy, and spend a few minutes filling out the survey. Your contribution to the success of this study will be appreciated greatly.

Most sincerely,

Marla Kappen Chalnack

Medical Treatment for Disabled Newborns With Life-
Threatening Conditions: A Policy Analysis

Phase II

1989 Survey

Marla Kappen Chalnick, Researcher

Doctoral Candidate at The University
of North Carolina at Greensboro

2022 Knickerbocker Drive
Charlotte, NC 28212

Passage from the Child Abuse Amendments of 1984

[The withholding of medically indicated treatment is] 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 most likely be effective in ameliorating or correcting all such conditions, except that 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 any of the following circumstances apply: (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) 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.

In my opinion, the Child Abuse Amendments of 1984 provide appropriate guidelines for treating disabled infants with life-threatening conditions. (please circle one response)

Strongly Agree

Agree

Disagree

Strongly Disagree

Please read the following five vignettes. For each one assume that the parents' views are the same as yours. Assume that you are involved in the treatment decisions for each baby.

Please circle the response which most closely represents your opinion for EACH treatment.

Baby "A"

Baby "A" is born with Down Syndrome. Soon after birth the baby is also found to have a surgically correctable duodenal atresia. The baby cannot take nutrition by mouth. LEAVING ASIDE ALL OTHER CONSIDERATIONS, WHAT TREATMENTS DO YOU THINK ARE BEST FOR THE BABY?

Intravenous feedings

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Surgery to correct the intestinal defect

Definitely Yes Probably Yes Probably No Definitely No

Suppose the baby was also suspected to have a life-threatening, but potentially correctable, heart defect.

Diagnostic cardiac testing (ultrasound)

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Regardless of your judgment about the treatments that are best for Baby "A," WHICH OF THE FOLLOWING TREATMENTS WOULD BE INDICATED BASED ON YOUR INTERPRETATION OF THE CHILD ABUSE AMENDMENTS OF 1984?

Intravenous feedings

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Surgery to correct the intestinal defect

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing (ultrasound)

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

IN ACTUAL PRACTICE, WHAT TREATMENTS WOULD YOU MOST LIKELY RECOMMEND?

Intravenous feedings

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Surgery to correct the intestinal defect

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing (ultrasound)

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Baby "B"

At birth Baby "B" is found to be anencephalic. LEAVING ASIDE ALL OTHER CONSIDERATIONS, WHAT TREATMENTS DO YOU THINK ARE BEST FOR THE BABY?

Resuscitation, if necessary, in the delivery room

Definitely Yes Probably Yes Probably No Definitely No

Feeding by mouth if the baby can suck

Definitely Yes Probably Yes Probably No Definitely No

Tube feeding if the baby cannot suck

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Suppose the baby was also suspected to have a life-threatening, but potentially correctable, heart defect.

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Regardless of your judgment about the treatments that are best for Baby "B," WHICH OF THE FOLLOWING TREATMENTS WOULD BE INDICATED BASED ON YOUR INTERPRETATION OF THE CHILD ABUSE AMENDMENTS OF 1984?

Resuscitation in the delivery room

Definitely Yes Probably Yes Probably No Definitely No

Feedings by mouth if the baby can suck

Definitely Yes Probably Yes Probably No Definitely No

Tube feeding if the baby cannot suck

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

IN ACTUAL PRACTICE, WHAT TREATMENTS WOULD YOU MOST LIKELY RECOMMEND?

Resuscitation, if necessary, in the delivery room

Definitely Yes Probably Yes Probably No Definitely No

Feeding by mouth if the baby can suck

Definitely Yes Probably Yes Probably No Definitely No

Tube feeding if the baby cannot suck

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Baby "C"

Baby "C" was born with multiple congenital anomalies including low set ears, skin folds around the neck, a cleft palate, and possible cardiac anomalies. Chromosomal analysis indicates that Baby "C" has Trisomy-13. The baby is expected to be severely mentally retarded and to die within the first year of life. LEAVING ASIDE ALL OTHER CONSIDERATIONS, WHAT TREATMENTS DO YOU THINK ARE BEST FOR THE BABY?

Nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Putting the baby on a respirator

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Regardless of your judgment about the treatments that are best for Baby "C," WHICH OF THE FOLLOWING TREATMENTS WOULD BE INDICATED BASED ON YOUR INTERPRETATION OF THE CHILD ABUSE AMENDMENTS OF 1984?

Nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Putting the baby on a respirator

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

IN ACTUAL PRACTICE, WHAT TREATMENTS WOULD YOU MOST LIKELY RECOMMEND?

Nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Putting the baby on a respirator

Definitely Yes Probably Yes Probably No Definitely No

Diagnostic cardiac testing

Definitely Yes Probably Yes Probably No Definitely No

Open heart surgery

Definitely Yes Probably Yes Probably No Definitely No

Baby "D"

Baby "D" was born prematurely. The baby has a 50% chance of survival. If Baby "D" should survive, there is a 50% chance of normal physical, neurological, and/or cognitive development. LEAVING ASIDE ALL OTHER CONSIDERATIONS, WHAT TREATMENTS DO YOU THINK ARE BEST FOR THE BABY?

Nutrition and fluids

Definitely Yes	Probably Yes	Probably No	Definitely No
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Suctioning to remove excess fluids from airways

Definitely Yes	Probably Yes	Probably No	Definitely No
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Drugs to maintain blood pressure

Definitely Yes	Probably Yes	Probably No	Definitely No
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Putting the baby on a respirator

Definitely Yes	Probably Yes	Probably No	Definitely No
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Cardiac resuscitation in the event of an arrest

Definitely Yes	Probably Yes	Probably No	Definitely No
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Regardless of your judgment about the treatments that are best for Baby "D," WHICH OF THE FOLLOWING TREATMENTS WOULD BE INDICATED BASED ON YOUR INTERPRETATION OF THE CHILD ABUSE AMENDMENTS OF 1984?

Nutrition and fluids

Definitely Yes	Probably Yes	Probably No	Definitely No
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Suctioning to remove excess fluids from airways

Definitely Yes	Probably Yes	Probably No	Definitely No
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Drugs to maintain blood pressure

Definitely Yes	Probably Yes	Probably No	Definitely No
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Putting the baby on a respirator

Definitely Yes	Probably Yes	Probably No	Definitely No
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Cardiac resuscitation in the event of an arrest

Definitely Yes	Probably Yes	Probably No	Definitely No
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IN ACTUAL PRACTICE, WHAT TREATMENTS WOULD YOU MOST LIKELY RECOMMEND?

Nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Suctioning to remove excess fluids from airways

Definitely Yes Probably Yes Probably No Definitely No

Drugs to maintain blood pressure

Definitely Yes Probably Yes Probably No Definitely No

Putting the baby on a respirator

Definitely Yes Probably Yes Probably No Definitely No

Cardiac resuscitation in the event of an arrest

Definitely Yes Probably Yes Probably No Definitely No

Baby "E"

Baby "E" was born with the following disorders: Microcephaly, paraplegia and hydrocephaly. LEAVING ASIDE ALL OTHER CONSIDERATIONS, WHAT TREATMENTS DO YOU THINK ARE BEST FOR THE BABY?

Oral nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Intravenous feedings if necessary

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Shunting the hydrocephalus

Definitely Yes Probably Yes Probably No Definitely No

Surgical repair of the spinal lesion

Definitely Yes Probably Yes Probably No Definitely No

Regardless of your judgment about the treatments that are best for Baby "E," WHICH OF THE FOLLOWING TREATMENTS WOULD BE INDICATED BASED ON YOUR INTERPRETATION OF THE CHILD ABUSE AMENDMENTS OF 1984?

Oral nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Intravenous feedings if necessary

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Shunting the hydrocephalus

Definitely Yes Probably Yes Probably No Definitely No

Surgical repair of the spinal lesion

Definitely Yes Probably Yes Probably No Definitely No

IN ACTUAL PRACTICE, WHAT TREATMENTS WOULD YOU MOST LIKELY RECOMMEND?

Oral nutrition and fluids

Definitely Yes Probably Yes Probably No Definitely No

Intravenous feedings if necessary

Definitely Yes Probably Yes Probably No Definitely No

Antibiotics if the baby has an infection

Definitely Yes Probably Yes Probably No Definitely No

Shunting the hydrocephalus

Definitely Yes Probably Yes Probably No Definitely No

Surgical repair of the spinal lesion

Definitely Yes Probably Yes Probably No Definitely No

DATA SHEET

Age _____ Sex _____

In what religious denomination were you raised? (please check one of the following)

Baptist _____
 Roman Catholic _____
 Hindu _____
 Jewish _____
 Lutheran _____
 Methodist _____
 Muslim _____
 Quaker _____
 Presbyterian _____
 Protestant (not otherwise listed) _____
 Unitarian _____
 None _____
 Other (please specify) _____

If you have changed your religion, please indicate your new faith.

The role of religion in my life is: (please circle one response)

very important	important	somewhat important	not important
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What type of hospital do you practice in: (please check the appropriate description)

University based Teaching Hospital _____
 Community based Teaching Hospital _____
 Community based Public Hospital _____
 Community based Private Hospital _____
 Other (please describe) _____

What is the nature of your professional role: (please check the appropriate description)

Neonatologist - full-time clinical practice _____

Neonatologist - part-time clinical practice _____

Neonatologist - not performing clinical duties _____

(please specify your current professional role)

I am not a neonatologist _____

(please specify your current professional role)

Thank you for completing this survey. If you have any additional comments please feel free to use this space. Your remarks are important.