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Analysis of the utilization of various ethical paradigms in the bioethical decision-making process for seriously ill neonates with developmental disabilities

Hughes, Ronald Clayton, Ph.D.

The Ohio State University, 1989
ANALYSIS OF THE UTILIZATION OF VARIOUS ETHICAL PARADIGMS
IN THE BIOETHICAL DECISION MAKING PROCESS FOR
SERIOUSLY ILL NEONATES WITH DEVELOPMENTAL DISABILITIES

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate School
of the Ohio State University

By

Ronald C. Hughes, M.Sc.S.A.

The Ohio State University
1989

Dissertation Committee:

Henry Leland, Ph.D.
David Hammer, Ph.D.
Nolan Rindfleisch, Ph.D.

Approved by:

[Signature]
Adviser
Department of Psychology
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VITA

November 19, 1948 ........................................... Born, Wadsworth, Ohio

1970 ........................................................... B.A., Philosophy, College of Wooster, Wooster, Ohio

1970-1975 .................................................. Social Worker, Wayne County Welfare Department, Wooster, Ohio

1975 ........................................................... M.Sc.S.A., Case Western Reserve University, Cleveland, Ohio

1975-1977 .................................................. Social Worker, Franklin County Children Services, Columbus, Ohio

1977-Present ............................................ Director, Institute for Human Services, Columbus, Ohio

PUBLICATIONS


**FIELDS OF STUDY**

**Philosophy**

Studies in ethics with Nels F.S. Ferré and metaphysics with Albury Castell.

**Social Work**

Studies in child welfare and clinical social work.

**Developmental Psychology**

Studies in child development and developmental disabilities with Henry Leland, Ph.D.
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PREFACE

In 1985, the Congress of the United States, through the Child Abuse Amendments (Department of Health and Human Services, 1985) suggested that hospitals develop internal infant bioethics committees to facilitate the process of bioethical decision making, and assigned final responsibility for determining the legitimacy of “treat/no treat” decisions for developmentally disabled neonates with life threatening medical complications to public child welfare agencies. It quickly became clear to many who worked in child welfare that no consensus decision making criteria existed to provide a basis for such determination. The “best interests of the child” criteria, used in the child welfare profession as the decision making criteria in other child welfare assessments, had little utility. There was no consensus regarding what would be in the best interests of children in these situations. No consensus guiding ethical paradigm existed.

By suggesting that bioethics committees should monitor the decisions of parents and physicians, and then suggesting that public children services agencies should monitor the ethics committees, it appeared that the government was attempting to legislate bioethical consistency in the decision making process by standardizing the structures and processes of such decision making, and abdicating
responsibility for the more difficult problem of establishing a consistent guiding ethical paradigm for such decision making. It appeared very possible that without a consensus ethical paradigm guiding this society’s bioethical decision making activities, ethics committees may not be a sufficient means of achieving consistent and just bioethics decisions, and, children service agencies would not be able to monitor these activities to assure conclusions which were “in the child’s best interests.” To my knowledge, no children services agency in this country has challenged a hospital’s “treat/no-treat” decision regarding a developmentally disabled neonate with life threatening medical complications since the inception of the Child Abuse Amendments.

This disturbing and continuing situation prompted this research to evaluate the relationships between ethical paradigms and treatment decisions to “treat/not treat” developmentally disabled neonates with life threatening medical complications.
CHAPTER I

INTRODUCTION AND STATEMENT OF THE PROBLEM

Thousands of developmentally disabled children are born each year with life threatening medical complications (Lyon, 1985; Driscoll, 1982; Todres, 1977). For each of these children, a decision is made to either provide vigorous medical treatment or to withhold treatment. For the vast majority of cases, decisions are quickly and routinely reached to provide rigorous medical treatment (Shaw, 1973; Duff and Campbell, 1973; Lorber, 1971). For a number of cases, however, decisions are made to terminate, or not to begin, rigorous medical treatment. Reasons given for withholding or terminating treatment include: 1) treatment would only prolong the dying process and thus would be inhuman (Kuhse and Singer, 1987; Mahon, 1988); 2) the potential good achievable from treatment would not justify the certain and horrific consequences of treatment (Fleischman, 1986; Brennan, 1986; Mahon, 1988); 3) the post-treatment quality of life achievable by the infant in the best scenario prognosis suggests the beneficent option is not to prolong the life (Keyserlingk, 1987; Fleischman, 1986; Kuhse and Singer, 1987); 4) the limited potential good which the child may receive from initiating treatment would not outweigh the potential harm the child can bring to the integrity of the family (Berkowitz, 1986; Mason and Meyers, 1986; Simms, 1986; Battle, 1987); and, 5) social justice or social utility
would be better served if society's limited resources were utilized in
different ways to more efficiently and effectively save and maintain life
(Lister, 1986; Taft, 1987; Subramanian, 1986).

These decisions are inherently difficult for a number of situational
reasons including; 1) the neonates are often in life-threatening distress
requiring immediate medical decisions (Battle, 1987; Lyon, 1985);
2) treatment efficacies and prognoses are often inherently equivocal (Lyon,
1985; Shelp, 1986); and, 3) parents may be extremely emotionally distraught
at a time in which very rational decisions are needed (Simms, 1986; Davis,
1986; Mahon, 1988). But these decisions are difficult for other more
fundamental reasons as well. Our society has not decided who should make
these decisions, or, what the criteria for decision making should be.
Considerable disagreement exists regarding medical intervention for
developmentally disabled newborns with life threatening medical
complications, with regard to the proper locus of responsibility, and with
respect to the selection of criteria for decision making (Brody, 1981;
Stahlman, 1986; Weil, 1986; Kimura, 1986; Eidelman, 1986; Cranford and
Doudera, 1984; Rosner, 1983; Brennan, 1986; Davis, 1986; Mason and Meyers,

Until very recently, in the vast majority of instances in which such
decisions were made, the locus of responsibility was, de facto, with the
child's parents in private consultation with the attending physicians (Lyon,
1985; Shelp, 1986; Cranford and Doudera, 1984). Parents are sometimes
considered to have special rights which supervene societal goals when family goals are considered, and thus may have the right and responsibility to subordinate a developmentally disabled neonate's interests to the interests of the family (Shoeman, 1985). Parents are often considered the proper locus of decision making authority because of a presumed emotional bond and commitment, between parents and newborns (Battle, 1987; Singer, 1987; Cranford and Doudera, 1984; Taft, 1987). This locus of responsibility is, however, being questioned and challenged by various factions of the medical establishment, the courts, theologians and theological institutions, and within a plethora of political arenas.

Various voices within the theological community representing various religious traditions often have not accepted parents as the locus of responsibility for this decision making process. Often, no secular locus is acceptable. Many theological traditions consider the ethical imperatives regarding matters of life and death as transcendent, and therefore, the parents and all others involved have a moral responsibility to follow sacrosanct guidelines for conduct and behavior (Ashley and O'Rourke, 1978; Francoeur, 1983). These guidelines are generally presented as absolute and categorical, because they are held to be derived from God or other transcendent sources (Rosner, 1983; Beauchamp and Childress, 1983). Problems arise, however, as a result of inconsistencies resulting from attempts to interpret and utilize absolute moral principles as practical guidelines in situations replete with relativistic consideration (Pence, 1980). For example, although all Judeo-Christian traditions place high
value on life, practical differences exist among denominations in their development of guiding rules of conduct (Veatch, 1981). A common fundamental presupposition for many denominations of the Judeo-Christian tradition is the “sanctity of life” (Rosner, 1983). For many groups, adherence to this principle requires that efforts to maintain life must always be attempted, regardless of how heroic and extraordinary the effort, and without consideration of the expected expenditure of resources or consideration of the quality of the life which is perpetuated (Veatch, 1981; Lyon, 1985). Yet, with a different practical implication, the Declaration of Euthanasia of the Catholic Church uses the premise of sanctity of life as a justification for sometimes withholding treatment (Ross, 1986; Harron, Burnside and Beauchamp, 1983). The implication is that life’s sacredness must be protected from the dangers of the humanistic excesses of medical technology (McCormick, 1978). Where there is no hope or benefit for the patient, treatment may be withheld or withdrawn. There can be, therefore, nearly dichotomous interpretations of required normative rules derived from the same absolute principle.

The medical community is equally divided in their opinions and actions regarding the ethical injunctions and the locus of responsibility for decision making. The circumstances of the now famous “Baby Doe” case are a good illustration of this professional disagreement within the medical community. On the evening of April 9, 1982, a child was born in a Bloomington, Indiana hospital, severely hypertonic, blue from lack of oxygen, not breathing, with an erratic heartbeat, and with an Apgar rating of
2. It was clear after the first few moments of birth that the child had Down Syndrome. Further examination revealed the child had a constricted aorta, esophageal atresia, and a tracheo-esophageal fistula. After consultation with the attending physicians, the parents decided it was in the child's best interest not to treat the child for physical and medical problems, a decision which meant imminent death for the newborn. Many similar scenarios have ended shortly thereafter with the death of the child in relative anonymity. With this particular child, though he would die six days later, the legal, theological, political, and medical machinations which ensued would so focus attention on the problems and dilemmas associated with the medical and ethical decisions which must be made concerning treatment of mortally ill developmentally disabled infants, that henceforth, this case would acquire historical significance and notoriety and be known as the "Baby Doe" case (Lyon, 1985). From the very beginning, the medical community was divided with respect to who should make the decision, and, what should be the proper treatment for Baby Doe (Lyon, 1985). There were three attending physicians consulting with the parents of Baby Doe to facilitate their decision making. Two of the physicians recommended immediate and extraordinary medical intervention. The other physician, considering the imminent death of the infant the best possible case outcome, recommended no treatment as the best possible medical approach after taking into consideration the child's and the parents' best interests. Two physicians believed the local protective service agency with the local courts should make the treatment decision. The third physician believed the decision
should remain entirely with the parents. Thus, there was a strong difference of opinion among the attending physicians regarding both the best treatment approach, and who should make the decision (Lyon, 1985).

This case scenario appears to reflect the general situation within the medical community. There is no consensus regarding proper medical approaches toward "Baby Doe" cases and no consensus regarding the locus of responsibility for the decision making process. Siegler (1986) believes that moral deliberation and ethical decision making should remain with the physicians and nurses in the neonatal environment because this is where the "anguish of the moral dilemma" is played out. He believes experiencing this anguish is an essential element for the moral deliberations and therefore believes the attending physicians and nurses are the proper loci of decision making authority. Gustaitis (1988) believes the ethical principle of "Do No Harm", derived from the Hippocratic Oath, requires that physicians make the treatment decisions, and requires that physicians advocate for the patient's best interests when conflicts arise between those interests and the interests of other involved parties, such as the parents. Moskop and Saldanha (1986) agree that the "Do No Harm" principle requires that physicians be the locus of decision making authority. Brennan (1986) agrees, stating that ethicists and jurists are not familiar with the medical and emotional nuances associated with the care of the acutely ill and dying patients, and therefore, the treatment decision should be left to the physicians. Mahon (1988) believes that nurses have no choice but to assume moral responsibility because although the physicians write the treat/no
treat orders, the nurses usually carry out the instructions. Therefore, the nurses are morally culpable. Mahon suggests that nurses always act in the "best interests" of the child.

Other physicians believe the final moral decision making authority should not rest with physicians. Battle (1987) states that in her job as Medical Director of a large pediatric hospital, she sees children "salvaged" because of the "professional challenge" such activities afford the physicians involved, rather than in response to the best interests of children. Some physicians believe that although it was a responsibility in the past, physicians should no longer be the arbitrator of life and death decisions regarding developmentally disabled infants (Weil, 1986). Some feel that physicians, because of their positions of authority, have undue influence over parents in the decision making process and should not be making the decisions (Lister, 1986). Cranford and Roberts (1986) state that a physician's training affords little skill in areas other than medicine, and therefore, a physician should not be construed as possessing special abilities in moral decision making. They also believe that physicians can be in a conflict of interest regarding this ethical decision making. Asch, Cohen, Edgar, & Weisbard (1987) believe that because there is no consensus among physicians regarding treatment policies, and because of the possibility of conflict of interest, there is good reason not to assign medical professionals exclusive authority in bioethical decision making for seriously ill newborns. Wolf (1986) believes the courts, rather than physicians, should be the final forum for review. Victoroff (1986) agrees
that physicians should not make final bioethical decisions regarding
treatment/non-treatment of seriously ill newborns, but he doesn't believe
lawyers or the courts are any better. He believes child welfare protective
service workers are in the best position to make these moral assessments
and decisions.

The medical community appears to be as divided regarding the
criteria for treatment decision making as they are regarding who should
make the bioethical decisions. Differences in opinions are reflected in
published papers which first began to appear in the early 1970's. Dr.
Raymond Duff and Dr. Alexander Campbell published an article in the New
England Journal of Medicine (1973) which revealed that of 299 deaths that
occurred in the intensive care nursery at the Yale-New Haven Hospital from
1970 to 1972, 43 were the result of intentional withdrawal of treatment
from infants with such disorders as myelomeningocele and chromosomal
disorders. Shaw (1973) described similar case situations for eight children
under his medical care. Lorber, (1971) an English specialist in the treatment
of myelomeningocele, published criteria for selection of newborns with
spina bifida for non-treatment. During the same period that these articles
were being published, there were numerous published instances throughout
the United States and England, in which individual doctors and hospital
administrators were seeking and obtaining court orders to permit surgery in
nearly identical case situations (Maine Medical Center, 1974; Application
a poll in the journal Pediatrics, in which surgeons and pediatricians across
the United States were questioned regarding a number of troubling ethical issues in children's medicine. When presented with a hypothetical case nearly identical to the circumstances of the "Baby Doe" case, 85% of the surgeons indicated they would abide by a parental decision to withhold treatment. Sixty-five percent of the pediatricians indicated they would also abide by such a parental decision. Approximately 60% of both groups indicated they would do the same for an infant with myelomeningocele. California pediatricians were asked how they would proceed with an infant with Down Syndrome and an intestinal obstruction if the parents wished to withhold treatment. Sixty-one percent stated they would abide by the parents' decision (Todres, 1977). Forty percent stated they would seek to have the child treated through court intervention. A survey of Massachusetts pediatricians, given nearly identical circumstances, indicated that 50% would abide by the parents' decision and 50% would seek to have the parents' decision set aside by the courts. This apparent lack of consensus among physicians is also apparent among the various professional medical societies and associations. In response to the "Baby Doe" case, the Federal Department of Health and Human Services issued several rounds of regulations which attempted to make it unlawful for hospitals to allow the withholding of treatment for developmentally disabled infants. These regulations "strongly encouraged" the formation of "ethics committees" to "assist the health care providers in the development of standards, policies, and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases," (Lyon, 1985) The American Medical Association and several other medical
societies successfully challenged the legality of these regulations on
grounds that the government was interfering with privacy rights of parents
(U.S. v. University Hospital, 1984). Notably absent from the AMA law suit
was the American Academy of Pediatricians. The Academy had taken a stand
more in line with the Department of Health and Human Services. The
Academy stated that "decisions regarding treatment should be based solely
on medical criteria and not on the child's intellectual or physical potential"
(Lyon, 1985). The American Academy of Pediatricians also agreed with the
Department of Health and Human Services that a ten member ethics
committee should be formulated within hospitals to review all cases in
which parents and attending physicians proposed to forego life support for
an infant (Lyon, 1985). It appears that the actions of individual physicians
within local communities, the divergent actions of the medical societies
and physicians' professional associations, and the results of published
opinion polls of physicians of various specialities across the United States
and England; all indicate that the medical community is strongly divided

regarding the proper guiding ethical principles, the proper decision making
procedures, and the locus of responsibility for decision making, regarding
issues of treatment for severely ill developmentally disabled infants.

Judge Carol Mansmann, United States District Court, echoes current
general legal opinion when she states that the Constitution of the United
States, through its protection of individual privacy rights, gives the
individual the freedom to deny medical treatment where there is no
counterbalancing interests of the State (Mansmann, 1986). The individual may choose what to believe is in one's own best interests, when those interests are the only compelling interests affected by such choice, even if the choice is obviously and eminently a lethal one. Legislation and common law canon are also generally supportive and protective of parental rights and the integrity of the family unit (Garibaldi, 1987). There is also strong legal precedent supporting the rights of privacy and confidentiality in the therapeutic physician-patient relationship (Gustaitis, 1988). These privacy rights, combined with the basic legal tenets regarding the fundamental integrity, rights, and responsibilities of the family unit, provide strong legal support for the philosophical and legal contention that the locus of decision making authority regarding strategies for medical intervention for seriously ill developmentally disabled infants, should generally reside with the infant's parents. However, unlike a situation in which a competent and able adult refuses medical treatment, in a situation in which parents are refusing treatment for a child, the State may have countervailing interests (Sassaman, 1983). The courts have also clearly maintained authority to intervene. Victoroff (1986) states that the U.S. Supreme Court began hearing arguments between medical professionals and parents regarding the treatment of children in the 1980's. He states there is a long standing legal tradition of recognized formal state interest in this decision making process expressed in the doctrine of "parens patriae - the parental role of the state." Countervailing interests of the State begin at the point of viability of the fetus and newborn (Victoroff, 1986). The infant is generally protected by child welfare law from being put in
situations by a parent or caretaker where the child is at risk of harm, either through intentional acts of the parent or caretaker, through inaction, or through inability on the part of the parent or caretaker to protect the child from harm (Victoroff, 1986). These are laws protecting children from abuse and neglect. The courts have consistently ruled that privacy rights or parental rights cannot supercede the State's compelling interest to protect a child from serious harm (Sassaman, 1983; Avery, Janeway, Berenberg, and Medearis, 1978; Curran, 1978; Damme, 1978). While interpretation of evidence may vary from court to court, the United States Court systems' present stance regarding this issue is relatively clear with respect to what criteria may be used to decide such cases, and with respect to the courts' authority to intervene. Presently, the State's compelling interest is not to legally assure adherence to a transcendent value like the categorical sanctity of life. Rather, it is to assure that the caretakers make a decision based upon the child's best interests and with due consideration of the medical evidence and options available (Gustaitis, 1988; Elias and Annas, 1987). Wolf (1986) warns that the rise in authority and utilization of bioethics committees does not dismiss the need for court review. She believes the courts should evaluate disputed bioethics committee determinations on a case by case basis. She further states that bioethics committees' determinations should not be interdictive, and the committees should not be given legal immunity.
National politics have played an increasingly prominent and important role in this issue in the past several years. The process of decision making has been an important issue in the politics of both the executive and legislative branches of government. After the media attention given to the Baby Doe case brought the issue to national attention, using civil rights legislation for its authority, the Reagan Administration strongly endeavored, with regulatory initiative through the Department of Health and Human Services, to effect policy which approached the issue of medical treatment of handicapped infants from a sanctity of life position (Victoroff, 1986). The courts repeatedly found such attempts unlawful and set aside such regulatory efforts. The Administration then promulgated nearly identical rules in the form of child abuse legislation (Victoroff, 1986). The present compromise law governing decision making for seriously ill developmentally disabled neonates is The Child Abuse Amendments, P.L. 98-457 (1985). This law’s ambiguous and indistinct wording and instruction provides little guidance regarding the ethical principles which should guide decision making.

There has been a recent emphasis on the consideration of ethics committees as a locus of decision making authority. Many authors suggest that some form of infant ethics committee is appropriate and needed as a locus of decision making authority (Asch, Cohen, Edgar, & Weisbard, 1987; Cranford and Doudera, 1984; Weil, 1986; Lyon, 1985; Ross, Bayley, Michel, and Pugh 1986; Hosford, 1986; Cranford and Roberts, 1986; Doudera, 1986; Bioethics Committee of the Canadian Paediatric Society, 1986; Victoroff,
1986; Fleishman, 1986; Taft, 1987). Committees formulated to deliberate on bioethical issues are not new. Sterilization review committees were established in the 1950's to protect the rights of individuals with developmental disabilities (Department of Health and Human Services Policy for Protection of Human Subjects). In the 1960's, dialysis committees were established to select the few among many who would benefit from scarce medical resources (Fox and Swazey, 1978). Also at this time, federally mandated review boards were established in efforts to standardize research involving human subjects, and to protect human subjects from the potential abuses of dangerous and/or intrusive science. In the 1970's, we began to see social and legal impetus for the genesis of formal ethics review committees regarding the withholding or termination of medical treatment. The Karen Ann Quinlan case was an important impetus in 1976 in its recommendations that "ethics committees" be established to verify prognoses (In Re Quinlan, 1976). The impetus and support for the establishment of ethics committees continued through the 1980's. In 1983, the "President's Commission for the Study of Ethical Problems" recommended ethics committees as a means of resolving medical ethics dilemmas (The President's Commission for the Study of Ethical Problems, 1983). The American Academy of Pediatricians, in response to the early Baby Doe regulations, in 1983 suggested that infant ethics committees be utilized by institutions providing care to handicapped newborns. In the early 1980's, surveys were conducted to determine how many hospitals utilized bioethics committees. Some surveys suggested as few as 1% of hospitals were utilizing bioethics committees in the early
80's. Others suggested as many as 16% had such committees in the early part of the decade (Hosford, 1986). By 1983, 25% of those hospitals surveyed by the American Hospital Association indicated they utilized hospital ethics committees (Hosford, 1986). The Infant Doe Regulations, also known as the Child Abuse Regulations, whose final issuance was in 1985, strongly encouraged the establishment of Infant Ethics Committees for all hospitals caring for newborns (Child Abuse Amendments, PL 98–457, 1985). By 1985, the American Hospital Association was reporting 60% of respondents as having an institutional ethics committee (Hosford, 1986).

The responsibilities suggested as appropriate for Ethics Committees have been varied. The American Academy of Pediatrics has designated four areas as proper concern of "Infant Care Review Committees": education, policy development, case review for case planning, and retrospective review of cases (American Academy of Pediatrics, 1984). As would be expected, the suggested responsibilities of case review are the most controversial. It is this responsibility which establishes ethics committees as a locus of treatment decision-making authority for seriously ill neonates with developmental disabilities.

The suggestions for the proper membership of ethics committees is also varied. The American Academy of Pediatrics recommends a core membership which includes: a physician specializing in the medical care of children, a nurse, a hospital administrator, a social worker, a disability advocacy group member, a lay community member, and a member of the
hospital's medical staff to serve as the chairperson. Hosford (1986) recommended that in addition to the above, membership should include a philosopher or other specialist who is trained in ethics. The University of Michigan Hospitals in 1984, in their Guidelines for Infant Care Review Committees, suggested a similar core group, but with the addition of the hospital attorney and a child protective services representative (University of Michigan Hospitals, 1984). The Albert Einstein College of Medicine established a core group for an infant bioethical review program which they called "consistent with the recommendations of the American Academy of Pediatrics," but, which in fact included two bioethicists and two attorneys, one attorney representing the hospital serving as a non-voting member (Fleischman, 1986). In 1983 a survey of 101 hospitals in New Jersey indicated that 54 had ethics committees. They reported the following membership: Neurologist/neurosurgeon, 78%; Administrator, 54%; Other physician, 46%; Pediatrician, 43%; Clergy, 35%; Attorney, 31%; Other surgeon, 20%; Nurses, 19%; Anesthesiologists, 11%; Social Workers, 11%; Psychiatrist, 6%; Hospital Trustee, 2% (McIntyre and Buchalter, 1984). Youngner and associates (1984) at Case Western Reserve University examined 17 hospitals and reported the following average committee composition: 5.25 physicians, 1.05 clergy, .58 administrators, .44 nurses, .35 lawyers, .21 social workers, and .15 lay persons (Youngner, Jackson, & Coulton, 1984). In a survey of patient opinion, Youngner (1984) asked who should serve as members of ethics committees. The research subjects chose physicians (96%); nurses (74%); clergy (58%); and social workers (55%); with the most frequency. Forty-two percent felt lawyers should serve as
members. Thirty-two percent felt that lay membership was important. Only 11% specified others, such as ethicists, friends, or family. (Youngner, 1984). Ross, Bayley, Michel, and Pugh (1986) believe that personal qualities such as attitude, temperament, and the capacity for critical thinking are more important than educational field or type of degree. Ross and associates do, however, give the following suggestions regarding the appropriate composition of an ethics committee: 1/3 physicians; 1/3 nurses; and 1/3 others, including social workers, administrators, ethicists, clergy, and lay members. It is noteworthy that despite the important perspectives to ethical decision making that psychologists could bring to bioethics committees' activities, including diagnostic expertise, understanding of intra- and inter-personal developmental dynamics, perspectives on the process of moral reasoning, and, despite the fact that psychologists are probably responsible for the majority of services and case planning provided for individuals with developmental disabilities across their life span, there were almost no suggestions in the literature that psychologists should be represented in ethics committee membership.

Several authors suggest caveats regarding ethics committee membership. Lyon (1985) states that Infant Care Review Boards were founded in the desire for standardization of treatment decision making, but in fact, have done nothing to standardize the treatment decisions for developmentally disabled newborns. There are many reasons suggested for this lack of standardization and potential inconsistency, including the lack of philosophical sophistication of Infant Ethics Committee members (Wolf,
1986; Siegler, 1986); the inherent lack of medical sophistication of Infant Ethics Committee members (Brennan, 1986); the intrinsic inadequacy of such groups in making decisions most appropriately made by primary care physicians (Siegler, 1986; Brennan, 1986) and, the utilization of different philosophical paradigms as guiding principles for decision making by different infant ethics committees (Wolf, 1986). Wolf (1986) suggests that most members of ethics committees are not experts in moral reasoning and have no formal training in ethics. In her opinion, this should make their decisions suspect. It is for this same reason that Ross et.al. (1986) suggested that we should require that all ethics committee members be capable of Kohlberg Stage 5 and 6 moral reasoning. Siegler (1986) states that the usual ethics committee is an unmanageable collection of uninvolved professionals with no special expertise in moral reasoning. For this reason, he believes that interdisciplinary ethics committees should have a principal role only in education, and the resolution of bioethical dilemmas should be left to “advisory committees” (presumably making ethical decisions) composed of specialized nurses and physicians. Brennan (1986) warns that “ethicists...are not familiar with the medical and emotional nuances associated with the care of acutely ill and dying patients” in his argument for physician responsibility. While the above authors warn of problems of subduction or abdication of physicians authority and responsibility and of potential problems with uninformed or incompetent ethical committee members; others warn against physician dominated bioethical decision making committees, and testify to the utility of more diverse committee membership. Victoroff (1986) warns that, in his experience, bioethics
committees dominated by physicians are usually much less effective than those whose membership consists of a majority of other professionals. Fleishman (1986) believes that ethics committee membership and the power to request ethics committee review greatly empower nurses and social workers, both of whom bring important perspectives to the decision making process. Father John Paris (1982) suggests that ethics committee membership include hospital maintenance and housekeeping staff to combat professional elitism in the ethical decision making process.

SUMMARY

There is no consensus in the professions serving individuals with developmental disabilities, or in society at large, regarding the proper locus of decision making authority, or the proper content of decision making criteria, with respect to bioethical decision making for developmentally disabled neonates with life threatening medical problems. While various loci of decision making authority are championed, there has been a recent emphasis on "Infant Ethics Committees" as the proper locus of such decision making authority. Given this state of affairs, certain questions arise. Is a consensus important regarding the locus of decision making authority and regarding the utilization of a specific decision making criterion? Given that there is movement in our society toward bioethics committees as the locus of decision making authority, do bioethics committees have any potential intrinsic superiority over other possible loci of decision making authority? Is it important to have a consensus ethical paradigm to guide
bioethical decision making for developmentally disabled, severely ill neonates? If so, is there an ethical paradigm which is "best"? We can now turn to the literature to obtain some of these answers, and to determine which questions have not been addressed, questions which will structure this research.
CHAPTER II

LITERATURE REVIEW

A search of the published material in this area leads one to conclude that there has been no published research to evaluate any aspect of the decision making process of infant ethics committees. There have been no studies performed to assess the validity of infant ethics committee decisions. There have been no studies to assess the intra-committee or inter-committee reliability of infant ethics committee decisions. There has been no research which addresses the important questions: 1) Will bioethics committees consisting of a number of professionals and laymen make more valid bioethical decisions than a single, trained or untrained person? 2) Will the consistency in process and outcome of decision making be greater for Infant Bioethics Committees than for other potential loci of decision making authority, i.e. parents and physicians, for example? 3) Is there a single, and readily evident and available, set of guiding principles which Infant Ethics Committees could best utilize to make their decisions?

In spite of this lack of reported research, the federal government has made sweeping recommendations that all hospitals should convene and utilize such committees (Child Abuse Amendments, 1986); and, Infant
Ethics Committees have increased their presence in hospitals from a very small minority in the early part of this decade to the vast majority of hospitals in present day (Hosford, 1986).

There has, however, been a considerable amount of written material over the last several years which have begun to question some of these assumptions, and which have begun to argue deductively for varied conclusions. Some authors suggest that it is not inappropriate to have inconsistency in ethical decision making. Cranford and Roberts (1986) suggest that in a pluralistic society the federal government should not set down "a single morality." The ethics committee of any hospital should reflect its community's social mores. They felt, for example, that what might be right in a Jewish hospital may well differ from what is right in a Catholic hospital. Veatch (1981), while stating that universal applicability is so central to ethics that it is often incorporated into the very notion of what ethics is, still concluded that we must accommodate a pluralistic ethic in our society.

Churchill and Siman (1986), though their logic is hard to follow, indicate that strict adherence to principles in ethical decision making is inappropriate because it renders decision making rigid, by focusing on the principle rather than the person as the "end". Ackerman (1980) suggested that we should view bioethical principles as generalizations which
summarize our previous decision making history. They should not be used as moral rules. He would have us derive our ethical views from our intuition about the facts of each case in question.

Some authors indicated that logical consistency and principled analysis were essential for an ethics committee to function as an ethical decision making body, but that we should, or in a practical sense must, allow different ethics committees to utilize different ethical paradigms in their respective activities (Cranford and Roberts, 1986; Veatch, 1984). Veatch believes that the ethical framework within which an ethics committee operates must be generated by a process involving the active participation of community lay persons and professionals. He believes this process will necessitate an inter-committee flexibility with respect to guiding ethical paradigms. Veatch believes the relationship between the ethics committee and the lay population it serves is a covenant, or contract relationship, thus requiring a participatory genesis for any guiding ethical paradigm. Therefore, Veatch suggests that we will not be able to set out one ethical paradigm which will be definitive for all hospital ethics committees. Veatch apparently believes this covenant or contract relationship, and its participatory obligation, supercedes the necessity for inter-committee consistency in decision making.

Most authors, however, strongly indicated that consistency in ethical decision making was important, even essential, to a valid decision making process. (Moskop and Saldanha, 1986). Gibson and Kushner (1986) see an
evolutionary process taking place regarding the nature of decision making in ethics committees. They see an increasingly public and social context within which decisions are made. They perceive a movement away from the more private, idiosyncratic approach, or intuitionism, toward a more rational and reasonable approach guided by discernible and communicable principles. This movement toward a more principled and guided decision making process would, in their opinion, result in a higher degree of consistency as ethics committees evolve. Fost (1981) in response to Churchill and Siman, advocated the utilization of generalized principles in ethical decision making for one singular reason: precisely because it would facilitate consistency. Basson (1983) suggests that traditional deductive ethics insists on logical consistency in moral thinking, else how would we be able to decide among conflicting opinions or intuition. Without the requirement for consistency, Basson wonders how we could deal with a system with no obligatory doctrine requiring similar cases to be treated similarly. If this doctrine is abandoned, he wonders, why not leave the decision up to chance? Beauchamp and Childress (1983) suggest that an ethic system cannot count as an ethical system if it fosters inconsistent decisions, because it would not yield similar results when used by different people, or even by the same people in different but similar circumstances. Brody's (1981) suggestion for assessing decision making processes uses consistency as the criterion for eliminating inadequate moral systems. He suggests that no one can claim ethical validity for a statement, no decision can be "correct", unless a rigorous and rational analysis proves its logical consistency. Wolf (1986) uses the test of consistency as the criterion to
evaluate the legal legitimacy of bioethical decision making bodies. Wolf states that it is inappropriate to defer to ethics committees regarding questions of withholding treatment, because their decisions are inconsistent due to a lack of any uniform set of rules to guide their decision making activities, and because there is a lack of any formal accountability.

If the argument for the necessity of consistency in bioethical decision making is accepted, then it becomes necessary to establish a guiding set of principles which will inform our decision making processes. We must look to the philosophical discipline of Ethics for such a set of principles (Popkin and Stroll, 1956.) Ethics as a discipline can be simply described. It is the study of deliberate action in an attempt to determine which actions are "right or wrong" and/or, "good or bad". An Infant Bioethics Committee is, therefore, charged with the responsibility of making treatment decisions for newborns which are "right" and "good". Existing literature on bioethics and medical ethical decision making suggests that there are two Western philosophical paradigms of normative ethics which are the culmination of ethical thinking in Western cultures, and, which are used, and should be used, in medical ethical decision making. These two paradigms are the Utilitarian and the Deontological. (Candee and Puka, 1984; Harron, Burnside, and Beauchamp, 1983; Beauchamp and Childress, 1983; Francoeur, 1983; Barry, 1982).

Francoeur (1983) states that all our ethical decisions and moral beliefs grow out of a person's "world view." One group can be clustered
under the title of duty oriented ethical systems. The most common label, Francoeur tells us, for this group is "Deontological," from deon, the Greek word for "duty, and logos, the Greek word for "discourse." Under the Deontological label, Francoeur lists many ethical systems which dictate the ideal moral life as obedience to duty in various forms, such as the Will of God and the laws or rules which express a Divine Will or other categorical imperative. These include the Hebrew-Christian and Moslem ethics, the ethical system of Immanuel Kant, the Intuitionists Schools, and John Rawl's Contractual Justice School.

On the other end of the spectrum of ethical systems are what Francoeur refers to the consequence-oriented ethical system. These ethical systems focus on the outcomes of action to determine their ethical nature. Francoeur divides the consequence-oriented ethical theories into two basic groups; the act consequence-oriented theories, and the rule consequence-oriented theories. The theories differ in whether they rely on general rules to decide the morality of behavior or not. Both, however, have as a guiding principle, Utilitarianism, "the most good for the most people".

Beauchamp and Childress (1983) state there are two ethical theories which must be considered when asking the question, "which ethical theory is most satisfactory?": Utilitarian, or Deontological. Beauchamp and Childress (1983) indicate that one should concentrate on these theories in an attempt to answer this question because these are well developed ethical theories which "have received the most attention in recent years." Harron, Burnside,
and Beauchamp, (1983) state that most Western moral conceptualization falls within the two leading moral orientations or types of ethical systems -- Deontological systems and Utilitarian systems. They describe these ethical systems in a prelude to discussing the relationship between health care systems and human values. They state that Deontology and Utilitarianism must be understood because these systems are the analytical tools which are the rallying points for moral philosophers and theologians in their decision making deliberations. In their discussion of biomedical ethics and the law, Humbar and Almeder (1984) choose Utilitarianism and Deontological Intuitionism/ Theologism as the examples of the two most relevant and important ethical traditions; ethical traditions within which most other ethical theories may be classified.

The distinction between consequentialistic and duty-based ethics is as old as philosophy itself. A distinction is assured because the two basic elements of ethical inquiry, the search for what is “good”, and the search for what is “right”, are not necessarily logically inclusive. That is, it is possible to conceive of something as good and not right; and of something as right and not good. For the Consequentialists/Utilitarianists, that which is right is that which is good. The consequences of action determine the goodness and rightness of action. A thing is most good which brings the most happiness to the most people. For duty-based ethics, or Deontological ethics, the right action is not necessarily the good action. It is possible for an action to be morally right and obligatory and yet not lead to the best consequences. The basis of moral obligation for Deontologists is not good
consequences. It comes from duty derived from such sources as rational insight, conscience, God's revelation, and intuition. A philosophical basis for this distinction between Consequentialist/Utilitarian ethical theory and duty-based/Deontological ethical theory is clearly evident as early as the writings of Plato and Aristotle. The seeds of both Utilitarian ethics and Deontological ethics are evident in the writings of both. Both Plato and Aristotle identify happiness as the highest good: attainable through "Knowledge" by Plato, and through the "perfect fulfillment of human nature" for Aristotle (Maritain, 1964). Epicurus (300 B.C.) later suggested that happiness was achievable through obtaining pleasure and avoiding pain. Hume, Bentham, and John Stuart Mill expanded and refined these conceptions to include the "principle of utility" — "the principle which approves or disapproves of every action whatsoever, according to the tendency which it appears to have to augment or diminish ... happiness..." (Bentham, 1948). A basis for Deontological ethics is also readily apparent in the writings of both Plato and Aristotle. The Rationalism and Idealism of Plato, especially as amplified by St. Augustine, suggest idealized deductive reasoning as the means of moral understanding (Marrou, 1958). Man's duties are prescribed by transcendental ideals. Aristotle, at least as modified by Thomas Aquinas provides us with guiding moral absolutes which are found through either of two harmonious sources, scientific discernment of natural law or rational deduction of Divine Law, both of which are absolute and universal (Copleston, 1955). Kant's ethical rationalism is an extension of this
development with a heavy emphasis on motive and man's rationality as the source of unconditional moral obligation, i.e. categorical imperatives of duty (Hunnex, 1971).

The generally accepted definition and description of Utilitarianism are still to be found in the writings of this ethical school's founder, John Stuart Mill (Mill, 1861). A general definition and description of the Deontological approach in ethics must be derived from the writings of many philosophers. However, the ethical treatises of Immanuel Kant provide a good source of a philosophical justification for a rationalistic Deontological ethical paradigm, and for the structure and content of normative ethical principles which can be logically derived from such a paradigm (Ross, 1930). The Deontological and Utilitarian paradigms can be summarized as follows.

UTILITARIANISM

Utilitarianism is a teleological ethic concerned with the consequences of actions. It eschews us to consider consequences of actions in order to determine the morality of conduct. States of being free of pain and infused with pleasure are considered intrinsically good. Pain and distress are considered intrinsically negative states. The rightness of an action is derived from its consequences. "Right" conduct is conduct which produces net benefit over harm. Utilitarianism injects a strong social variable into the formula of teleological ethics. The morality of conduct depends not upon the net consequences of action to any individual, but
rather, the net consequences to all. In moral decision making, one must calculate the consequences of all discernible actions and inactions and choose the one which will produce the maximum net social benefit over harm (Mill, 1861).

DEONTOLOGICAL

The Deontological tradition in normative ethics, entomologically meaning the "study of duty", defines "right" as an intrinsic aspect of conduct, not derived from consequences of action. An action may be morally obligatory regardless of whether its consequences produce human weal or woe (Kant, 1785) The motto, "Let justice be done though the heavens fall" conveys the spirit. Moral rules are believed by most Deontologists to be universally valid, admitting no exceptions (Olson, 1967) Some Deontologists may go so far as to suggest that it can happen that one moral rule may conflict with another in the world of human affairs. With respect to these moral dilemmas, however, it is not conceded that utility is a means of disengaging oneself from the dilemma's impaling horns (Ross, 1930). From whence do the rules derive which Deontologists hold in absolute regard? They may derive from many sources; such as one's own personal communion with god; conscience; revelation and theological canon, for example the Ten Commandments; and rational necessity, such as Immanuel Kant's categorical imperatives.

The Utilitarian and Deontological paradigms have been both directly and indirectly supported in the writings of various authors in recent years.
as these authors have struggled with the bioethical issues surrounding treatment decision making for developmentally disabled neonates. Battle (1987) discusses two important issues in detailing the obligation she suggests that health professionals have regarding treatment of disabled neonates with life threatening medical problems. Battle provides a detailed agenda for society's provision of ongoing services to surviving "miracle babies", but it is the second issue that is important to this thesis. She argues strongly that physicians should take a Utilitarian approach in their decision whether to treat or not to treat seriously ill neonates. She suggests that many physicians are driven to save some children because of the "professional challenge, and their own egoist pleasure of success which reaffirms (their) own omnipotence." She details her activities as Chief Executive Officer and Medical Director of the Hospital for Sick Children in Washington, D.C. as she daily walks among the consequences of the technology and professional egoism that has "allowed us to create a new agony, an existence somewhere between life and death" that has devastating repercussions for the families involved. Battle suggests that the child's potential quality of life and the impact of the child's survival on the child's family and upon society's limited resources should be considered in each decision to treat or to withhold treatment.

Subramanian's (1986) discussion of decisions regarding whether to treat impaired newborns in the countries of India, Nepal and Sri Lanka, indicates that for these countries, a Utilitarian approach is most common. Physicians are totally autonomous and almost always behave
paternalistically toward their patients and the families of patients. It is suggested that decisions are made based upon medical factors, the families' capabilities, and the cost to the family and to society to provide treatment. Limited medical resources are a reality in all three countries; therefore, utility is strongly considered in the delivery of resources, i.e. could the "limited resources be utilized more beneficially on another patient."

Taft (1987), looking at the issue from the perspective of a hospital manager, believes that the reality of limited resources may force a rationing system which should include Utilitarian decision making as the selection process. She states that some of the problems inside hospitals are the result of "defensive" decision making rather than a Utilitarian approach. Taft states that some infants have bills totaling one million dollars, and that limited resources, if better cost control is not achieved, may require explicit ranking of cases based on cost-benefit assessments. Simms (1986) in research meant to consider the effect of developmentally disabled children on caretakers and families, solicited the opinions of mothers of severely mentally disabled young adults. She found that twelve of fifteen mothers thought that "severely handicapped infants" should be allowed to die rather than saved by medical treatment, because among other things, of the potentially destructive effect the child can have upon the family. This is supported by the research of Pahl and Quine (1984), who, in their "attempt to illuminate the overall reality of caring for severely mentally disabled children", parents of severely disabled children were asked what they would do if they knew that an expected child would be
"severely mentally handicapped." Seventy-eight percent of parents answered that they would want the pregnancy terminated. Both Simms (1986), and Pahl and Quine (1984), suggest their research is supportive of the need to take a Utilitarian approach to decision making regarding the provision of treatment to severely disabled infants. Kuhse and Singer (1987) state that the "principle of equal consideration of the interests of all those affected by a decision" is such a fundamental principle in ethics that it cannot be disregarded. They state that there are many factors which should be taken into consideration when deciding whether to provide treatment, including the interests of the parents and any other children in the family. They state that it is "often pointed out that the survival of a handicapped child is also the creation of a handicapped family." Lister (1986), in a straightforward argument for a Utilitarian approach to decision making, states that physicians must always consider the social costs involved in maintaining an infant's life. While he discredits the interests of the child's family as a potential override of the infant's interests, he strongly states that an infant "should only be treated if the costs are within established societal limits". Berkowitz (1986) indicates that in the case of treatment decisions regarding anencephalic infants, the discomfort of those around the patient, rather than the comfort of the patient, may dictate the course to be taken. Schoeman (1985) argues for a special form of limited Utilitarianism, or, perhaps limited Consequentialism. Schoeman suggests that neither the child's best interests or the interests of society should be the focus. The measure, however, remains a measure of utility; the utility the child's survival will have on the family attaining its goals and ends. Schoeman
suggests the relationship of the child to the family is a special and "intimate" one, not supervened in general by the individual's or society's goals and ends. Therefore, parents should be permitted to compromise the child's interests for ends related to family goals and purposes. Treatment decisions should be made by the parents using this limited Utilitarian perspective, according to Schoeman, unless the decision demonstrates "gross ineptitude in moral reasoning."

As previously indicated, arguments for Deontological approaches to decision making may be based on obligatory rules of conduct as the sources of moral guidance. Few authors refer to these guiding ethical paradigms as Deontological. Instead, their references are to "duty", "obligation", "rules of conduct", and "individual rights", all elements of a Deontological ethic. These suggested sources of moral guidance have been varied, and include divine guidance through theological canon and revelation, intuition, natural law as discerned through scientific observation, and moral categorical imperatives for conduct discernible through reason. Although the sources of moral guidance may vary, the defining characteristic of a Deontological approach is the reliance upon immutable rules for guidance in the decision making process. For example, Rosner (1983) states that the Jewish physician especially finds himself in a number of moral quandaries because of the recent advances in biomedical technology and therapeutic procedures. These advances have raised questions for the Jewish physician that, according to Rosner, are more than questions of humanitarian principles, but
which also require divine guidance, answers that must be sought in the Torah. For Rosner, and many other Jewish physicians, the guiding moral principles are Deontological; rules derived from moral principles to be found in the Torah. Rosner states the answers to questions, such as the treatment decision making procedures for developmentally disabled children with life threatening medical complications, are to be found in the Torah. The answer to these questions will be "eternally-valid answers to even newly formulated queries." Rosner indicates that since "every moment of human life is also of infinite value," any life that can be prolonged, should be prolonged.

Davis (1986) states that we must move away from a pragmatic Utilitarian assessment of individual worth in our decisions to treat or to withhold treatment, and must utilize a "rights based" approach. Arguments for rights are basically arguments for 'claims' based upon a Deontological ethical paradigm or moral principle. Davis suggests a Deontological approach should be taken based upon the genetic code of the organism. From fertilization, the human conceptus would have the absolute rights that are the a priori possession of all human life. These rights must apply, according to Davis, to all human life, regardless of situation, handicaps, or deficits. As long as the genotypic expression is human, the phenotypic expression of the organism is inconsequential. Davis appears to believe strongly that human rights are absolute, although the source of the absolute rights are never clearly delineated.
Many critics of a Utilitarian-based treatment decision-making process, or any other selection process which could result in selective non-treatment of infants, argue that we must adhere to a Deontological principle of 'sanctity' of life. Although many argue that 'sanctity of life' standards are vague and meaningless as a guide to decision making (Arras, 1984) the general principles of this Deontological standard are discernible. Sanctity of life means literally that life, in some basic sense, has absolute value over worth (Lyon, 1985). All life must be viewed as an end with transcending value. Because of the transcending and absolute value of human life, we have a duty to value and respect all human life equally, regardless of our own conclusions of the relative worth or utility of a particular life, including our own. The most obligatory, or Deontologically pure form of the sanctity of life position, is often referred to as "vitalism". Paris (1982) an advocate of this position, describes the obligatory ethical rule as, "life is the ultimate value, and something that is to be preserved regardless of prognosis, regardless of cost, and regardless of social considerations". Perhaps a less absolute interpretation of the duties required of a "sanctity of life" position is held by another ethicist, Paul Ramsey. Ramsey (1978) is a formulator of a current "sanctity of life" position, suggesting that each child possesses equal dignity and intrinsic worth (i.e. sanctity) and, therefore, no child should be subject to the withholding of treatment on the basis of the potential of life. Ramsey does suggest, however, that with particularly dire prognoses, i.e. the child is in
the process of dying, or permanently comatose, heroic forms of treatment may be withheld. It is not clear if, in fact, there is substantial difference in Paris' or Ramsey's respective positions.

Published research and thoughtful discourse are impetus for evolution and change in societies which esteem rationalism, and whose institutions are predisposed systemically to respond to new information and new ideas. The additional variable to this equation of social responsiveness to new ideas and information... is politics. The Reagan Administration's strong adherence to a Deontological ethical perspective regarding treatment decisions for developmentally disabled neonates has been a strong force for the adoption of a Deontological decision making paradigm. The Reagan Administration's initial involvement in the issue of which ethical paradigm should be utilized for bioethical decision making was in response to the 1982 "Baby Doe" case previously mentioned, in which an infant was born with Down Syndrome and treatable esophageal atresia. The parents refused permission for surgery, the attending physicians were divided on the decision's validity, a circuit court upheld the decision, and the Indiana Supreme Court would not intervene. The child died nine days later. In response to this, President Reagan, through the Department of Health and Human Services, issued a notice informing all hospitals receiving federal assistance, that to maintain such assistance, they must utilize a strict Deontological approach in bioethical treatment decision making in which all children, regardless of the nature of any developmentally disabling or medical condition, were to receive life sustaining treatment. In addition to
the considerable support which was evident (Turnbill, Guess, & Turnbill, 1983) in response to the Administration's Deontological stance, there was also considerable opposition from such professional organizations as the American Medical Association and the American Hospital Association (U.S. vs. University Hospitals, 1984). These organizations were against the strict Deontological approach to decision making and were for a Consequentialist ethical paradigm for treatment decision making.

All of the Administration's attempts to formalize a Deontological paradigm were struck down by federal courts on procedural and applicability grounds (U.S. vs. University Hospitals, 1984). Congress attempted to settle the issue in 1984-85 by formulating compromise law, rule, and guidelines derived from the work of a task group representing medical, disability, and "right to life" organizations. Basically, this task group consisted of both individuals and organizations dedicated to a Consequentialist/Utilitarian ethical paradigm, and individuals and organizations committed to Deontological ethical principles. They were instructed to derive a workable compromise. Their final product is now the law governing treatment decision making for newborns, The Child Abuse Amendments, P.l 98-457 (1985). The compromise was not wholly successful due to the inherent impracticality of making compatible two inherently dissonant ethical paradigms. The final product was a law both sides could agree with, as long as they disagreed about the definition of key words and phrases within the law, such as "virtually futile," "imminent," "near future," "merely prolonging dying," etc. A final attempt by the Administration to instill definitions of
terms concordant with a Deontological ethical paradigm into the Amendment with the force of law was thwarted by the Consequentialists, and instead, the "clarifying definitions" were attached to the Amendment as non-binding interpretative guidelines. The conclusion was a law which did not settle the question, "What ethical paradigm should be utilized in treatment decision making for developmentally disabled neonates with life threatening medical complications?" However, the Reagan Administration's philosophical adherence to a Deontological ethical perspective, and their commitment to the formal establishment of such a decision making paradigm, was strongly demonstrated, and its adherents may continue to represent a dominant intellectual and political force.

There appears to be little current literature which reports, suggests, or supports other ethic systems or paradigms as appropriate for ethical decision making. There is, however, substantial recent literature which identifies combinations of specific ethical principles which should be used to guide ethical treatment decision making for developmentally disabled neonates with life threatening medical conditions. A considerable portion of the literature suggests that the principles of "quality of life" and "social transcendence" should guide this decision making. The "quality of life" principle can be described as the need to assess and consider the future quality of a person's life as an important variable in a decision of whether to intervene to prolong life (Caplan & Cohen, 1987; Brennan, 1986). Basic assumptions of this principal are that some life situations can be worse than death, and, in such situations, it may be unethical to support or prolong
such life (Caplan & Cohen, 1987). The principle of "social transcendence" can be described as the requirement that decisions not be based upon the potential social utility of a person's life.

The Bioethics Committee of the Canadian Pediatric Society (1986) reports that both "quality of life", referred to as "best interests" of the child, and "social transcendence" are principles which should be used in treatment decision making. The Committee indicates that best interests of the child can be defined as the sum of potential benefit over harm that can be derived from a potential treatment. The Society states that careful consideration must be given to all potential outcomes of both treatment and non-treatment. Their adherence to the principle of "social transcendence" is apparent in their statement that no outside interest, either that of parents and family, or that of other providers of care, can override the interests of the child, or can be considered as a reason for withholding treatment. For example, they suggest that analgesics should be used to control severe pain in severely ill infants, even if they hasten death, and even if contrary to the parents' requests. Victoroff (1986) states that in decisions to treat or to withhold treatment, the key issue is what is in the best interests of the child, totally apart from what might benefit anyone else. Victoroff states that such "social transcendence" is important because interests can be conflicting, and in many cases, almost always will be. For example, most families will make decisions considering the interests of other family members as well as the developmentally disabled infant. The author states that the quality of life is a legitimate concern in the determination of the
The Infant Bioethical Review Committee of the Albert Einstein College of Medicine has established a set of principles upon which decisions for critically ill infants are made (Fleischman, 1986). The overriding principle is that care should be provided which is "reasonably thought to be in the infant's best interests". The principles indicate that parents have the decision making right and responsibility in most cases, but, cannot be allowed to choose an action which would be against the infant's best interests. The guidelines indicate that a determination of the child's best interests be the sum benefit minus harm of any treatment considered. The guidelines indicate that treatment should be withheld, or withdrawn, if such treatment imposes a burden which lacks compensating benefits for the infant. Gustaitis (1988) states that infants, legally, have the same privacy rights to refuse treatment as adults have. This means they have the right to die, if such a choice could reasonably be determined as in the infant's best interests. Gustaitis suggests that it is appropriate that Guardians-ad-litem or hospital ethics committees be appointed to make such decisions as "surrogates" for the child if the parents are unable or unwilling to make reasonable choices. Keyserlingk (1987) states it would be foolish to pretend that quality-of-life considerations should be or could be excluded from medical decision making. He suggests that decisions whether to support a life medically be made based upon whether a particular life is worth living. Decisions to stop supporting life do not necessarily imply philosophically that life has no value, but rather, suggests that for a particular person, life is no longer worth living. Keyserlingk suggests that decisions to withhold treatment should be made out of respect for persons
when living becomes meaningless and excessively burdensome. Mason and Meyers (1986), in a paper which traced the development of parental rights to make medical decisions for developmentally disabled neonates in the United Kingdom and the United States, state that although the British Medical Association adopts the principle, "There is no justification for usurping parents' rights," the British courts clearly uphold the principle of "putting the interests of the child first," and uphold the concept of selective non-treatment in cases of children whose prognoses are "intolerable." The British courts indicate the child's best interests supercede the parents' rights to choose, and the state as "parens patriae" should intervene to support the child's best interests. The authors argue that "quality of life -- not in the sense of social utility...but solely as judged by a physiological existence..." should be the criterion for decisions to treat, or not to treat.

Brennan (1986), in characterizing the physician/patient relationship as "humane paternalism", feels that a contractual relationship exists between the physician and the patient, which requires the physician to seek the best interests of the patient and "ignore issues that would interfere with their care," including the interests of the parents and the interests of medical science. This is clearly a call for "social transcendence". The best interests of the patient, according to Brennan, are actions which promote the "cure" of the patient; but when cure is not possible, are guided by efforts to promote comfort and relief of pain, even at the expense of prolonging life.
Mahon (1988) delineates a nurse's responsibility in decision making regarding newborns with congenital anomalies. Among the responsibilities, she indicates that although physicians write the orders, nurses perform the action, and, are therefore legally and morally responsible for their actions. Mahon believes that nurses should participate in the decision making process. Decisions should be based upon the best interests of the child. She states that it is in the best interests of a child not to support life if the child is terminally ill and in ceaseless pain. She states "the deepest controversy" exists in cases of non-treatment of a newborn with a developmental disability that could lead to the infant's death. Mahon is suggesting the utilization of a "quality of life" criterion for decision making. Mahon also suggests that nurses insure their decisions transcend social utility. She states that due to the emotional trauma of giving birth to a child with severe disabilities, parents often are unable to make decisions in the child's best interests. Mahon believes that the nurse must guard against parents making decisions based not upon the interests of the child, but upon the interests of others.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research began its work in 1980. In 1983, the report "Deciding to Forego Life-Sustaining Treatment" was published. One of the topics this report discussed was treatment decisions for seriously ill newborns, including specific recommendations and conclusions about how decisions should be made, and who should make them. This Commission established the infant's best interests as the criterion for
treatment decision making. While the words "quality of life" do not appear in the recommendations, the Commission's statements regarding treatment are clearly concordant with the general "quality of life" criterion (Ross, Bayley, Michel, & Pugh, 1986). The Commission report appears equivocal regarding the utilization of social utility as a medical decision making criterion. While it strongly affirms the infant's best interests as the appropriate standard for treatment decisions for seriously ill newborns (Ross, Bayley, Michel, & Pugh, 1986), in other sections of this same report it is suggested that social decisions regarding the limits of availability of treatment may supercede patients' autonomous wishes for vigorous treatment. (Presumably we can infer that if social utility could supercede the autonomous wishes of a competent patient for treatment in his/her best interests, it will also supercede the substitute request for treatment in the best interests of the incompetent patient.)

Perhaps the best attempt to articulate a decision making criterion based upon the principles of "quality of life" and "social transcendence" can be found in the report of a project by The Hastings Center, Briarcliff Manor, New York, which began in 1984 and was completed in 1987. The purpose of the project was to discern if a broader consensus regarding the ethics of neonatal care existed than was apparent in existing public debate. After assembling a group of knowledgeable participants to "grapple with the controversy of existing ethical paradigms and also within paradigms that the group itself might create", they concluded that "a child centered best interest standard" was most appropriate. They concluded that "quality of
life" judgments were ethically proper, and, in a practical sense, inevitable. The report indicated that "quality of life" should not refer to the social worth of a person's existence as determined by a Utilitarian criterion "measured by balancing the burdens and benefits to others, especially to family members", but rather to "the present and future characteristics of the infant, judged by standards of the infant's own well-being and not in terms of social utility." The Hastings Center Report further indicated that a consensus existed to equate "quality of life" with the "best interest" standard. The report indicated this standard should be used as objectively as possible to determine if continued life would be in the infant's best interests with the clear understanding that certain states of being marked by severe and intractable pain and suffering can be viewed as worse than death, and that the possibility exists that an infant's best interest can lie in withholding or withdrawing medical treatments resulting in death (Caplan and Cohen, 1987).

Hughes (1989) administered a questionnaire to psychologists, social workers, physicians, and nurses to assess the types of decisions they would make in a bioethical dilemma. The questions presented hypothetical but typical case situations in which a choice had to be made to treat or not to treat a seriously ill newborn with developmental disabilities. The questions were formulated so that answers to the questions indicated a choice of action concordant with a specific ethical paradigm or set of ethical principles. Eleven percent of respondents made choices which would be concordant with a Deontological paradigm; 32% made choices concordant
with a Utilitarian paradigm; and 57% made choices indicative of utilization of the principles of "quality of life" and "social transcendence", principles which together Hughes referred to as the paradigm of "vicarious egoism". Hughes suggested that the philosophy of Epicureanism was an ethical paradigm which, when applied to bioethical decision making, may provide decisions concordant with the integrated principles of "quality of life" and "social transcendence".

The philosophy of Epicureanism comes down to us as scattered fragments of letters from Epicurus to his students, the codification of Epicurus' advice to his followers (Principal Doctrines, circa 300 B.C.), and writings of the Roman poet Lucretius (99-55 B.C.). Epicureanism is a Consequentialist ethic. An action is good or bad depending upon the consequences of that action. A right action is an action which brings about good. A good consequence, and hence a good action, is an action which increases or maintains pleasure, or decreases or prevents pain. An action is good which increases the quality of life, i.e. increases pleasure or reduces pain. An action is bad which decreases quality of life, i.e. decreases pleasure or increases pain. In choosing among possibilities, the action which is judged to have the potential of providing the most net good over bad is the morally correct choice. Future consequences of present actions are an important consideration. Epicureanism is a philosophy of ethical egoism (Hunnex, 1971). The maximization of one's own happiness is the proper end. One should always further one's own interest and not consider the interests of others in choosing one's actions (Hunnex, 1971).
Epicureanism ignores the social utility of actions. To apply an egoistic ethical paradigm such as Epicureanism to a situation in which a person is incompetent, such as in the case of developmentally disabled newborns with life threatening medical problems, the principles would have to be applied vicariously by a competent person charged with the responsibility of acting in the child's best interests (Hughes, 1989).

SUMMARY

A review of the literature suggests there are many who believe that bioethical decision making for seriously ill neonates with developmental disabilities should be guided by the integrated principles of "quality of life" and "social transcendence", and, that there are many practitioners who presently utilize these principles in their daily practice to guide their own bioethical decision making. A review of the literature also suggests that where an ethical paradigm is required for guidance in bioethical decision making, most believe the guiding ethical paradigm should be either a Utilitarian or Deontological paradigm. It has also been suggested, however, that a vicariously applied paradigm of ethical egoism, such as Epicureanism, may provide bioethical decisions more concordant with the combined principles of "quality of life" and "social transcendence".

GOAL OF RESEARCH AND HYPOTHESES

It is the goal of this research to determine if the decisions arrived at utilizing a vicariously applied Epicurean decision making paradigm by a
"bioethics committee" in the process of treat/no treat decision making for developmentally disabled neonates with life threatening medical complications, will be more concordant with decisions arrived at using the combined guiding principles of "quality of life" and "social transcendence", than will decisions arrived at using either a Utilitarian or Deontological paradigm.

To arrive at this determination, the following questions will be answered by testing the following hypotheses. The questions and hypotheses are:

1) Does the utilization of different ethical paradigms by a bioethics committee produce different decision making outcomes? It could be that there are other sufficient variables that could consistently effect certain outcomes regardless of the ethical paradigms used to guide the decision making process. Or, the behavioral outcomes produced by the utilization of various ethical paradigms, even when uncomplicated by intervening variables, may be intrinsically very similar or the same. In either situation, the choice of the guiding ethical paradigm may be superfluous. The hypothesis to be tested will be: "Different decision outcomes will result from bioethics committees using the different ethical paradigms (Utilitarianism, Deontological, and Vicarious Epicureanism) as guiding structures in the bioethical decision making process."

2) Are the decisions arrived at by using various ethical paradigms similar to the decisions arrived at using the combined principles of "quality of life" and "social transcendence." Various ethical paradigms could be
related to these principles. They could be related in different ways (different factors), and to different degrees. The hypothesis to be tested is: "The decision outcomes arrived at using the ethical decision making paradigms, a) Utilitarianism, 2) Deontology, and 3) Vicarious Epicureanism, when separately compared to the decision making correctness criterion, will each demonstrate a relationship factor."

3) Are we more likely to get decision outcomes from the utilization of the Vicarious Epicurean paradigm in bioethics committee deliberations which are similar to decision outcomes utilizing the combined principles of "quality of life" and "social transcendence", than we would get from using either the Utilitarian or Deontological paradigms? The hypothesis to be tested will be: "Bioethical decisions arrived at using the Vicarious Epicurean paradigm will yield results more concordant with the decision making correctness criterion, a criterion based upon the integrated principles of "social transcendence" and "quality of life", than the decisions arrived at utilizing either a Deontological paradigm or a Utilitarian paradigm."
The goal of this research is to determine if a guiding ethical paradigm, "vicarious epicureanism", will produce decisions more concordant with decisions arrived at using the combined integrated principles of "social transcendence" and "quality of life" than would decisions arrived at using either a Utilitarian or Deontological ethical paradigm.

For the purposes of this research, "quality of life" refers to an assessment criterion which considers the potential effects upon the quality of a person's life that treat/no treat decisions may have. Utilizing a "quality of life" criterion, the best decision is the decision which would provide for the individual's "Summum Bonum." A basic presupposition of a "quality of life" criterion as a normative ethical standard is that some life is so painful, lacking in human dignity, and so hopeless, that death is a qualitatively better choice.

For the purposes of this research, "social transcendence" refers to an assessment criterion which rules out any consideration of the potential social utility of the client/patient's life. For example, "social transcendence" would prohibit consideration of the effects the child's life
or death may have on other family members in a treatment decision, or a weighing of the potential positive contribution to society that a person's life may effect, or the use of a selection criterion for the utilization of resources which use social utility as an aspect of such selection criteria.

SUBJECTS

The subjects of this research were individuals who volunteered to act as voting members of bioethics decision making bodies, which will be referred to as "ethics committees." The decision to use these analog bioethics committees was made for two reasons. 1) It was important for the "ethics committees" decisions to be logically consistent with particular guiding ethical paradigms. The literature suggested that existing bioethics committees may produce inconsistent decisions. In this research, we were more concerned with what bioethics committees should conclude when using a particular guiding ethical paradigm in it decision making activities, than what real, existing ethics committees do conclude. Despite many requests, we were unable to obtain the participation of existing ethics committees in the research.

The basic responsibility of the subjects in this experiment was to consider archival medical, developmental, social, and psychological data, and with those data, utilize guiding ethical paradigms to arrive at decisions to treat or to withhold treatment for seriously ill developmentally disabled
neonates. We attempted to acquire subjects with education and experience in utilizing medical, developmental, social, and psychological case data, and with education in bioethics.

The Bowling Green State University (BGSU) Philosophy Department, Bowling Green, Ohio, has an "applied" philosophy curriculum developed specifically to educate medical students, pre-med students, and students in the allied health professions, in the bioethical issues and problems associated with the delivery of medical and health services. The curriculum is developed specifically to provide philosophy majors with the education and training necessary to assume the role of "ethicist" in the medical and health services fields, such as consulting ethicist to hospitals, or as facilitators of hospital ethics committees. Many of the students who enroll in the medical ethics course offered by the BGSU Philosophy Department have majors in other fields of study, including psychology, medicine, nursing, and other allied health professions. Specifically, students were sought from those attending the medical ethics class entitled "Philosophy of Medical Ethics" taught in 1987 by Dr. Kathleen Dixon. The curriculum for this class was developed to address ethical problems in the delivery of medical services, including the moral dilemmas associated with treatment decisions for patients with multiple problems, the terminally ill, and the incompetent. (See Appendix A, Course Curriculum.) Fifteen students from Dr. Dixon's class volunteered for participation in the study. Each student/volunteer was paid $40 for participation in the research. The median age of the participant group was 20 years, the mean age was 21
years. The group included 7 nursing students, 3 graduate students in philosophy, 2 medical students, 2 students in physical therapy, and one student in medical engineering.

APPARATUS AND MATERIALS

CASE FACT SHEETS

Twenty case fact sheets were developed from actual cases of developmentally disabled neonates with life threatening medical complications. Cases were selected from hospital case files, individual interviews with families and physicians, and from the literature. The cases were required to have the following characteristics to be considered as sources for the development of case fact sheets and inclusion in this research:

1) For every case, there had to have existed either "considerable question" whether to vigorously treat or not to treat; or, "conflict" regarding whether to treat or not to treat. For the purposes of this research, "considerable question" was indicated by referral to an ethics committee for consideration; "conflict" was indicated by the existence of such difference of opinion regarding treatment that court intervention was sought. All cases, therefore, were either referred to ethics committees, or to courts of law, or both. "Conflict" cases, by definition, are cases in which there are both
"treat" and "no treat" decisions from different authorities. For "considerable question" cases, an equal number of "treat" and "no treat" decisions were selected for the development of fact sheets.

2) In addition to the above criteria, the cases were selected for "special difficulty." For purposes of this research, "special difficulty" was defined as having a high degree of moral conflict inherent in its content. Moral conflict can be a moral dilemma regarding conflicting rights, e.g., conflict between rights of the parents vs. rights of the neonate vs. rights of the state, or, moral conflict between goods, e.g., situational conflict between life versus freedom from pain. Cases were evaluated and certified by unanimous vote as having "special difficulty" by a three-person committee composed of a developmental psychologist, a physician, and a philosopher.

Once the cases were selected, fact sheets were developed from all existing and available case records and other available sources of information. Each case fact sheet included only the following information:

a) Description of the developmental disability;
b) Description of the medical problems with pre-treatment prognosis;
c) Description of treatment options with post-treatment prognosis;
d) Short social history of family, including psychological status, if available;
e) Recommendations of attending physicians, if available;
f) Opinion or wishes of the parents, if available;
g) Other case history data if relevant to the child's medical,
    psychological, or social condition, if available.
(See Appendix B for five case examples.)

RESEARCH EXPLANATION SHEET FOR SUBJECTS

An explanation sheet was prepared for all participants. The handout included: 1) information describing the decision making process regarding treatment of developmentally disabled neonates with severe, life threatening medical conditions; 2) description of the plans for the utilization of paradigm groups for decision making within this research; 3) description of pertinent procedural activities of the research; and 4) a description of the participants' responsibilities with respect to the research activities. (See Appendix C).

REQUIRED READING FOR SUBJECTS

A packet of required reading materials was distributed to each volunteer when they were selected for participation in the research. The readings were selected by Dr. Kathleen Dixon, BGSU philosophy professor, the instructor of the class from which the students were recruited. Dr. Dixon was asked to select readings to exceed no more than a total of 50 pages which most concisely and clearly set forth the basic philosophical principles of the three ethical paradigms utilized in this research; 1)
Epicureanism, 2) Utilitarianism, and 3) Deontological ethics. Dr. Dixon was instructed to use whatever resources she felt were appropriate. Once Dr. Dixon selected the packet of readings, they were checked for their appropriateness by two philosophy department chairmen.

The subjects were instructed to read their packets thoroughly before the day of the case review. In addition, they were instructed to further review or study any additional materials they felt could be helpful to them in their pending task of case review and decision making.

PROCEDURES

The first procedure was to assess the twenty study cases and arrive at treat/no treat decisions based upon the combined moral principles of "quality of life" and "social transcendence." Four experts in medicine, psychology, philosophy, and social work were selected to determine the case by case decisions which would follow from utilization of the two combined moral principles. After the first group arrived at decisions of "treat" or "no treat" using the combined integrated principles of "quality of life" and "social transcendence," the second group, consisting of similar membership, performed the same activity. There was agreement between the groups in 18 out of 20 cases. The two groups further discussed the two cases in which they disagreed, until a consensus "treat/no treat" decision was obtained.
These 20 consensus treatment decisions were established as the “correctness criteria" against which the decisions of the different paradigm groups would be compared for concordance.

In asking for volunteers for participation in the study, Dr. Dixon read from the prepared statement which briefly explained the goal of the study, some general information regarding the responsibilities of the subjects, the schedule of activities, and the remuneration available after completion of these activities. After fifteen subjects volunteered, they were given the handout instruction form, which again explained the goal of the study, some general information regarding their responsibilities, and the schedule of activities. (See Appendix C) They were also given a packet of reading materials with instructions. These materials included 50 pages of relevant readings in the philosophy of ethics, setting forth relevant principles of the three ethical paradigms utilized as conditions of the independent variable in this study. The subjects were instructed to read and study the handout materials in preparation for their meeting on the day of the experiment. The three readings were: 1) "The Categorical Imperative," from Foundations of the Metaphysics of Morals written by Immanuel Kant, 2) Selected segments of two letters of Epicurus and the Principal Doctrines. Epicurus' advice to his followers on correct living, written about 300 B.C.; and 3) excerpts selected from J.S. Mill's Utilitarianism, written in 1863. (See Appendix D).

On the day of the experiment, all subjects were initially congregated. At this time they were given an information sheet (see Appendix E) which
detailed the day's schedule and their activities and responsibilities. This information was also read aloud by the Experiment Coordinator, as all subjects read along on their instruction sheet. Each subject was then randomly assigned to one of three paradigm groups; 1) Utilitarianism; 2) Deontological; and 3) Vicarious Epicureanism. After their assignment they were congregated into the three “ethics committees”, each committee containing all of the members of one of the paradigm groups. Although separated into the three subgroups, all subgroups initially remained together in the same room. At this time, the Coordinator passed out the first of twenty case fact sheets to each subject. As the subjects read along silently, the Experiment Coordinator read the case sheets aloud to the entire group. All relevant and available information was included in the case fact sheets. No additional case information was given. However, the Experiment Coordinator did further describe details of medical, psychological, or social conditions if the request for further clarification or description was made by any subject, and if the information was available. The subjects then congregated into their respective, assigned, “ethics committees” located in separate settings. Each “ethics committee” considered the case fact sheet information and as a group, utilizing the principles of their assigned ethical paradigms, arrived at a consensus decision to treat, or not to treat, the developmentally disabled neonate with life threatening medical complications under consideration. Each “ethics committee” had an experiment facilitator available to keep group members on task, and to reiterate the group’s responsibilities and activities, if necessary. The consensus decision was noted when achieved. After twenty minutes, if a
consensus had not been reached, a vote was taken regarding the decision. The vote was recorded with each "committee" member's vote identified. When all three groups had either arrived at consensus or voted, they again congregated into a "committee" of the whole. Case fact sheet #2 was then presented in an identical fashion to case fact sheet #1. All procedures regarding case #2 were the same as for case #1. Treatment decisions for cases #3 through #20 were arrived at using the same procedures.

METHOD

The research design was a laboratory study in which one condition was manipulated: the ethical paradigm used for decision making. Participants were randomly assigned to one of three, five-member decision groups. Each group was assigned one of three ethical paradigms to utilize in their treatment decision making activities. All three groups were presented case material derived from hospital records of developmentally disabled neonates with life threatening medical complications. All three groups were presented the same case materials at the same time. The decisions arrived at by the three "ethics committees" were then evaluated for their concordance with a "decision criterion" derived from decisions made utilizing the normative ethical principles of "social transcendence" and "quality of life."
DATA ANALYSIS

A test for equality of correlated proportion developed by McNemar (Hays, 1981) was used to test the first hypothesis: Different decision outcomes will result from using the different ethical paradigms as guiding structures in the bioethical decision making process.

Binomial probabilities were calculated to test the second hypothesis: The ethical decision making paradigms, a) Utilitarianism, b) Deontology, and c) Vicarious Epicureanism, when separately compared to the decision making correctness criteria, will all demonstrate a relationship factor with respect to their respective bioethical decision outcomes. Binomial probabilities were calculated to test whether decisions arrived at utilizing each of the bioethical decision making paradigm groups were in accordance with the decision making correctness criteria at better than chance level.

Fisher exact probabilities test of association (Hays, 1981) was used to test the third hypothesis: Bioethical decisions arrived at using the Vicarious Epicurean paradigm will yield results more concordant with the decision making correctness criteria than the decisions arrived at utilizing either the Deontological paradigm or the Utilitarian paradigm.
CHAPTER IV

RESULTS

The first hypothesis was developed to test whether there would actually be any difference in the decision outcomes when the various ethical paradigms were used to guide the decision making process of ethics committees. Our expectation is that the ethical paradigms are sufficiently different, and their power for shaping behavior significant enough, to produce different decision outcomes when different paradigms are used to guide the decision making process. It could be, however, that guiding ethical paradigms are so similar in structure and content that they will produce similar decision outcomes. Or, it could be that there are other sufficiently powerful variables intervening in the decision making process to assure a specific and particular outcome regardless of the guiding ethical paradigm utilized. The hypothesis to be tested is: "Different decision outcomes will result from using each of the three different ethical paradigms; 1) Utilitarianism (-P.U.), 2) Deontological (P.D.), and 3) Vicarious Epicureanism (P.E.), within the ethics committees as guiding structures in the bioethical decision making process."

Table 1 shows a breakdown of the case decision outcomes of each paradigm group in comparison to the criterion reference.
### TABLE 1

CASE DECISION OUTCOMES FOR EACH PARADIGM GROUP
WITH CRITERION REFERENCE

<table>
<thead>
<tr>
<th>PARADIGM</th>
<th>Case No.</th>
<th>Vicarious Epicureanism</th>
<th>Utilitarianism</th>
<th>Deontological</th>
<th>Criterion Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>NO (3-2)</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>YES</td>
<td>YES (3-2)</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>YES</td>
<td>YES (3-2)</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>YES (4-1)</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>8</td>
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<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>9</td>
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<td>NO</td>
</tr>
<tr>
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<td>10</td>
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<td>YES (3-2)</td>
<td>YES</td>
<td>YES</td>
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<tr>
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<td>YES</td>
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<tr>
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<td>15</td>
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<td>YES (3-2)</td>
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<td>NO</td>
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<td>YES (4-1)</td>
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<td>YES</td>
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<td></td>
<td>20</td>
<td>NO (4-1)</td>
<td>NO</td>
<td>NO</td>
<td>NO</td>
</tr>
</tbody>
</table>

**TOTALS**

**CORRECT** 19 14 14

Yes = "Treat"
No = "No Treat"
The total "correct" decisions for each paradigm group, when compared to the criterion reference, are listed at the bottom of the table. To determine the differences in decision outcomes among the three guiding paradigms, the distribution of the treatment decisions into either treat or no treat categories for each paradigm group were compared to the distribution of treatment decisions for each of the remaining paradigm groups. A test for equality of correlated proportion developed by McNemar is used to test the first hypothesis (Hays, 1981). The McNemar test is a non-parametric statistic expressed in terms of probability. Using the McNemar test, we tested whether the true distribution of outcomes for paradigms differed. With the three paradigms, it was necessary to compare P.E. to P.U., P.E. to P.D., and P.U. to P.D. to exhaust all the comparison combination possibilities. We asked, for each possible pairing of paradigm groups, do the two paradigm groups, considering all treatment decisions, show the same true proportion of case decisions to treat, and the same true proportion of cases chosen not to treat. In other words, considering the twenty "treat"/"no treat" decisions, does \( P_1(T) = P_2(T) \), where \( P_1(T) \) is the proportion of cases chosen by one paradigm group for treatment, and \( P_2(T) \) is the proportion of cases chosen by the other paradigm group for treatment. A significant result will allow us to conclude that the true distribution of decisions for the paradigm groups compared, are different. A significant difference in the distribution of decision outcomes would allow us to conclude that different decision outcomes will result from using different ethical paradigms as guiding structures in the bioethical decision making of ethics committees. Table 2 shows the "treat/no treat" decision distributions when comparing decision distributions between all possible combinations of paradigm groups.
TABLE 2

DECISION OUTCOME DISTRIBUTIONS USED IN MC NEMAR TEST FOR EQUALITY OF CORRELATED PROPORTION

<table>
<thead>
<tr>
<th></th>
<th>P.E.</th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>A)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P.D.</td>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P.D.</td>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>C)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P.E.</td>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>1</td>
</tr>
</tbody>
</table>

P.D. = Deontological Paradigm Group  Yes = "Treat"
P.E. = Vicarious Epicurean Paradigm Group  No = "No Treat"
P.U. = Utilitarian Paradigm Group
The results of the McNemar test for correlated proportions of decision outcomes selected by each paradigm group into one of two mutually exclusive and exhaustive categories, either "yes", treat, or "no", do not treat, were as follows:

1) Using the McNemar test for correlated proportions, we find that the P< .0000, that the true distribution of decision outcomes between Paradigm Vicarious Epicureanism and Paradigm Deontological, do not differ.

2) Using the McNemar test for correlated proportion, we find that the P< .0002, that the true distribution of decision outcomes between Paradigm Utilitarian and Paradigm Deontological do not differ.

3) A non-significant result, P< .1249, was found between decision outcomes of Paradigm Vicarious Epicureanism and Paradigm Utilitarianism. We cannot, therefore, conclude that the distribution of decision outcomes for the two paradigms differ.

The second hypothesis was developed to assess whether the relationship between the correctness criteria and the decision outcomes of each of the guiding ethical paradigms was more than a chance relationship. Our expectation is that decisions arrived at using the Vicarious Epicurean Paradigm would be significantly related to the Correctness Criteria. Our hypothesis should test this. It is also important to determine if decisions arrived at using either the Utilitarian or Deontological Paradigm are significantly related to the Correctness Criteria. The hypothesis to be tested is: "The decision outcomes arrived at utilizing the three guiding
ethical paradigms, Utilitarianism, Deontological, and Vicarious Epicureanism, when separately compared to the decision making correctness criteria, will all demonstrate a relationship factor." To test this hypothesis, binomial probabilities were calculated to determine the chance probabilities of the distribution of correct/incorrect responses of each of the guiding paradigm groups. See Table 1 for a comparison of the case decision outcomes between each of the paradigm groups and the correctness criteria. The Vicarious Epicurean Paradigm group had 19 out of 20 correct responses. Both the Utilitarian and Deontological Paradigm Groups had 14 out of 20 correct responses.

The calculated binomial probabilities indicate the $P < .0001$ that the Vicarious Epicurean Paradigm group could have scored 19 out of 20 responses correct by chance alone. This strongly suggests that a relationship factor exists between the correctness criteria and the Vicarious Epicurean Paradigm.

The calculated binomial probabilities indicate the $P < .0594$ that either the Deontological or Utilitarian paradigm groups could have scored 14 out of 20 responses correct by chance alone. This approaches a significant level and may suggest that we should consider and further explore the possibility of relationship factors existing between both the Deontological and the Utilitarian Paradigms and the correctness criteria.

The third hypothesis was developed to test whether, by using the Vicarious Epicurean Paradigm, an ethics committee was more likely to
arrive at decision outcomes concordant with the correctness criteria than by using either the Deontological Paradigm or the Utilitarian Paradigm. The hypothesis is: "Bioethical decisions arrived at by an ethics committee using the Vicarious Epicurean Paradigm will yield results more concordant with the decision making correctness criteria than the decisions arrived at utilizing either the Deontological Paradigm or the Utilitarian Paradigm." We used the Fisher exact test of association to test the hypothesis (Hays, 1981). The Fisher exact test is a test of association similar to the Pearson $\chi^2$ test of association. It is useful when the sample size is small enough to rule out the use of the $\chi^2$, such as in the present case. The sample size is small enough to allow the computation of exact probabilities using the Fisher exact test. The Fisher exact test allows us to compute the probability of obtaining the found distribution of decision outcomes between two paradigm groups, then by taking this probability as the significance level, test the hypothesis that the obtained result is purely a product of chance. The Fisher exact test is a non-parametric statistic expressed in terms of probability. The null hypothesis was tested with the hopes of rejecting it and accepting the alternate hypothesis.

$H_0$: Correctness is independent of group membership (difference in the amount of correct responses is not significant.)

$H_a$: Correctness is associated with group membership.

See Table 3 for a comparison of the distributions of correct/incorrect decisions between the Vicarious Epicurean Paradigm Group (P.E.) and the Utilitarian Paradigm Group (P.U); and, between the Vicarious Epicurean Paradigm Group (P.E.) and the Deontological Paradigm Group (P.D.).
TABLE 3

COMPARISON OF DISTRIBUTION OF DECISION OUTCOMES BETWEEN PARADIGM GROUPS

A) P.E. P.U.

* Correct Decisions 19 14

* Incorrect Decisions 1 6

B) P.E. P.D.

* Correct Decisions 19 14

* Incorrect Decisions 1 6

P.E. = Vicarious Epicurean Paradigm Group
P.U. = Utilitarian Paradigm Group
P.D. = Deontological Paradigm Group
Our computations using the Fisher exact test of association indicate the $P < 0.0457$ that the distribution of decision outcomes between the Vicarious Epicurean Paradigm and the Utilitarian Paradigm is the result of chance. This warrants our rejecting the null hypothesis and accepting the alternate hypothesis: "correctness is associated with group membership" in comparing the correct decision outcomes between the Vicarious Epicurean Paradigm and the Utilitarian Paradigm.

Our computations using the Fisher exact test of association indicate the $P < 0.0457$ that the distribution of decision outcomes between the Vicarious Epicurean Paradigm and the Deontological Paradigm is the result of chance. This warrants our rejecting the null hypothesis and accepting the alternate hypothesis, "correctness is associated with group membership" in comparing the correct decision outcomes between the Vicarious Epicurean Paradigm and the Deontological Paradigm.
CHAPTER V
DISCUSSION

The Vicarious Epicurean and the Deontological paradigms were found to produce significantly different outcomes. (See Table 2a, p.59) Thirteen of the 20 decisions between the two groups were concordant. All seven of the discordant decisions were Vicarious Epicurean decisions to “not treat” versus Deontological decisions to “treat”. There were no decisions which fell into the category of Vicarious Epicureanism to “treat” and Deontological paradigm decisions “no treat”. We can conclude that in cases where there is “considerable question” whether to “treat” or “conflict” regarding whether to “treat”, and the case has “special difficulty”, many more children will not receive treatment, or will have treatment terminated, if the guiding ethical paradigm is Vicarious Epicureanism, rather than Deontological. In these cases, the Deontologists would probably support their paradigm outcomes with arguments that it is morally wrong to allow any individual to die if you have the means of preventing the death, and morally wrong to facilitate an individual’s death with any action. The Vicarious Epicureans would probably support their discordant “no treat” decisions with arguments that they were reducing the net suffering of the individual; that given the circumstances, it was in the neonate’s interest not to live; and that prolonging a life of pain and indignity with extraordinary means was inhumane.

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The Utilitarian and the Deontological paradigms were also found to produce significantly different outcomes. (See Table 2b, p.64) In comparing the Utilitarian and the Deontological paradigms we see treatment decision outcomes which are concordant eight times out of twenty. Of the twelve decisions between the two paradigm groups which were discordant, eleven were in the category of Utilitarian Paradigm "no-treat" versus Deontological Paradigm "treat". Only one case out of twenty was in the category Deontological Paradigm "treat" versus Utilitarian Paradigm "no treat". We can conclude that in cases where there is "considerable question" and "conflict" regarding whether to "treat", and in cases with "special difficulty," many more developmentally disabled neonates with life threatening medical complications will not receive treatment, or will have treatment terminated, if the guiding ethical paradigm is Utilitarian, than if it were Deontological. As indicated earlier, the Deontologists would probably argue that it is morally wrong for any individual to die if there is a means to prevent it. The Utilitarians would probably argue that in the eleven discordant treatment decisions in which they chose "not to treat", the calculated social utility for each case supports their no treatment decisions. They may argue that after weighing the interests of all involved, including the infant, the parents and family, and society; and, after considering the just distribution of limited medical resources, it was in everybody's best interests and in the interest of distributive justice, that the "no treatment" decision be selected.
A non-significant result was found between decision outcomes of the Vicarious Epicurean and the Utilitarian paradigms. (See Table 2c, p.64) In comparing the Utilitarian and Vicarious Epicurean paradigms we see fifteen decisions which were concordant and five which were not. In comparing the decision outcomes between the Deontological paradigm and both the Vicarious Epicurean and the Utilitarian paradigms, there appeared to be more likelihood that there would be "no-treat" decisions with either the Vicarious Epicurean or Utilitarian paradigms than with the Deontological paradigm. In comparing the five Vicarious Epicurean and the Utilitarian discordant decisions, we see one in the category of Vicarious Epicurean "no-treat" versus Utilitarian "treat", and four in the category of Vicarious Epicurean "treat" versus Utilitarian "no-treat". This may indicate a tendency toward more "no-treat" decisions when the Utilitarian paradigm is used in comparison to the Vicarious Epicurean paradigm. Further research and analysis would have to be conducted to substantiate this possibility.

Most of the difference between Vicarious Epicureanism group decisions and Utilitarian group decisions will probably have to do with the difference in how the two paradigms consider social utility in moral decision making. Social utility is the basic tenet of Utilitarianism. Epicureanism is characterized by ethical egoism. Both are Consequentialistic ethical paradigms. Both weigh heavily the potential consequences of any action considered with respect to the interests of the neonate. For Epicureanism, that is all that is considered: the best interests of the neonate. For Utilitarianism, there are other interests that are
considered, interests which could, in this paradigm structure, outweigh the interests of the neonate, such as the interests of the parents, the family, the community, or society. Given the different interests that can come into play in a Utilitarian decision, we can ask the following question: Are these additional interests more likely to result in more "treat" or more "no-treat" decisions when compared to a paradigm which only considers the neonate's interests? Hypothetically we can envision instances in which decisions based purely upon the neonate's interests would normally warrant a "treat" decision and, in the same instance, would cause substantial harm to the family and use up considerable amounts of limited medical resources. Literature clearly supports the contention that there are many such instances (Battle, 1987; Taft, 1987; Lister, 1986). We could expect that these numerous cases could end up in a category of Vicarious Epicurean "treat" versus Utilitarian "no-treat". Hypothetically, there would appear to be few instances in which the interests of others would outweigh a "no-treat" decision which was in the best interests of the patient. The case in this study in which there was a decision outcome in the category of Vicarious Epicureanism "no-treat" versus Utilitarian "treat" was an example of the only scenario this author can hypothesize which could potentially produce such a decision outcome. In this case, there was an anencephalic newborn, in which it was felt by the Vicarious Epicurean group that it was in the child's best interests "not to treat". The Utilitarian group also felt it was in the child's best interests "not to treat", but they believed it was in society's best interests, interests which outweigh the best interests of the child, to continue treatment until it was determined if organ
transplantation was possible, or, if research knowledge could be gained as a consequence of further treatment. While this case represents a very circumscribed class of variables, it is one which will arise on occasion.

While the data did not show a significant difference between the decisions arrived at when using the Vicarious Epicurean paradigm compared to decisions arrived at utilizing the Utilitarian paradigm when tested for equality of correlated proportion, when tested for association with a correctness criteria, it was determined that correctness was significantly related to paradigm membership. The significant findings, when tested for association, indicate that there are different factors associated with membership in different paradigm groups producing different decision outcomes. These conflicting findings suggest that further research may be needed to determine if we can expect significantly different decision outcomes when ethics committees utilize the two ethical paradigms, Vicarious Epicurean and Utilitarian. Perhaps using a larger variety of cases and a method of analysis more sensitive to small but consistent difference between variables would show paradigm differences. Given the findings available from the two analyses and the very real philosophical differences between the two paradigms, we can conclude that, while further testing is necessary to arrive at firmer analysis, the two paradigms may very possibly produce different results.

The relationship between the Vicarious Epicurean paradigm and the correctness criteria was significant. The relationships between both the
Utilitarian and the Deontological paradigms and the correctness criteria approached but escaped significance, with both groups exhibiting a decision outcome distribution of 14 out of 20, which by chance alone would appear less than 6% of the time. We can conclude that there is considerable likelihood that all three paradigms have factors which are related to the correctness criteria and which will result in "correct" decision outcomes in a majority of cases. Given that all the paradigms are very possibly related to the correctness criteria, and all may produce correct answers most of the time, it was important to determine if we could conclude from the data that one paradigm was more related, and therefore, more likely to produce "correct" decision outcomes. Our computation used the Fisher exact test of association; comparing the probability of distribution between two paradigm groups' correct and incorrect responses allows us to conclude that "correctness" is associated with paradigm group membership when comparing the Vicarious Epicurean Paradigm group with the Utilitarian Paradigm group, and, when comparing the Vicarious Epicurean Paradigm group with the Deontological Paradigm group. In both instances, correctness was significantly more related to the Vicarious Epicurean Paradigm group than to either the Utilitarian or the Deontological group.

The research data suggests that, very possibly, all three ethical paradigms will produce different decisions when used to guide bioethical decision making. Our data suggests that the Vicarious Epicurean Paradigm will produce "correct" decisions almost all the time, decisions that will be concordant with the normative ethical principles of "social transcendence"
and "quality of life". The Vicarious Epicurean Paradigm will produce "correct" decisions more often than either the Utilitarian or the Deontological Paradigms. However, both the Utilitarian and the Deontological Paradigms may well produce correct decisions a majority of the time.

There were two decisions that were not unanimous for the Deontological Paradigm. The Utilitarian Paradigm had five such decisions, and the Vicarious Epicurean Paradigm had eight. No statistical analysis was performed to determine if these apparent differences were, in fact, significant. It appears, however, that intra-committee member decisions may be more or less consistent, depending upon which ethical paradigm is utilized in the decision making process. This might be a matter for further research.

Literature tells us that our society's historical ethical goals regarding decisionmaking for treatment of developmentally disabled neonates with life threatening medical problems are not clear. There is no consensus. The various individuals, groups, and systems involved in the infant bioethical decision making processes have often produced inconsistent conclusions about what is a right and good decision, and, have often produced inconsistent decisions. Our research findings support the contention that decisions of various loci of decision making authority produce inconsistent decisions. Experimental "ethics committees" utilizing different ethical paradigms, which are used within societies to guide
bioethical decision making, produced decisions which were significantly different. As has been indicated earlier, decision making goals have included such varied and sometimes conflicting principles as:

1) maintaining the sanctity of life; 2) furthering the best interests of a child and/or family; 3) achieving the highest level of social utility; 4) facilitating the optimal quality in an individual’s life; and 5) fulfillment of an ethical duty intrinsically applicable to the situation. Many of these goals may be irreconcilable. For example, the best interest of a child may be different from the best interests of a family. Or, a decision based upon the "sanctity of life" may not facilitate the achievement of the highest quality for a child’s life. Or, the fulfillment of a perceived ethical duty may not be the action which would achieve the highest level of social utility. Because these guiding principles are ethical principles, they have often been difficult to compromise and difficult to abandon. Unable to compromise and unable to convert the disparate, the various factions of our pluralistic society have vied to proselytize and formalize their own specific goals and guiding principles regarding this decision making process. Part of this effort has included the championing of various loci of decision making authority by the various factions of our society, based upon their respective beliefs that specific loci of decision making authority are best suited for the utilization of specific ethical paradigms. Decisions presently emanate from various loci of decision making authority, including the parents of the child, attending physicians, parents and physicians in conference, parents with theological counselors, the courts, and infant ethics committees.
At the same time that there is so much discord and so much disagreement regarding proper bioethical guiding principles, and despite the reality of the existence of many championed, accepted, or condoned loci of decision making authority, there has been a developing support by many disparate elements of society for the utilization of infant bioethics committees as the proper locus of decision making authority for treatment decisions regarding critically ill neonates with developmental disabilities. The literature review tells us that the number of infant bioethics committees has been increasing significantly over the last ten years. While some authors caution regarding the efficacy and morality of using bioethics committees, it appears that a majority of authors, practitioners, and those required to make bioethical decisions, support the development and utilization of bioethics committees. Our literature review indicated that most medical and health care associations in the United States and Canada support the development and utilization of infant bioethics committees, and recent Federal legislation strongly recommends the utilization of bioethics committees for infant ethical treatment decisions.

Why is there such a present focus on ethics committees? What is it that its proponents, so varied and factious, expect ethics committees to do regarding treatment decisions for seriously ill neonates? It is the expectation of many that, by utilizing a bioethics committee to make ethics-related treatment decisions, hospitals, communities and society in general will have a sufficient condition for "right" and "good" decision outcomes. Therein lies one of the problems which was the basis for this
research. The utilization of an ethics committee as the locus of decision making authority may not be a sufficient condition for a morally correct bioethics decision. Our research findings indicate that ethics committees utilizing different ethical paradigms will produce significantly different outcomes when compared to a correctness criteria based upon the principles of "social transcendence" and "quality of life", and may, in general, have differing factors which will tend to produce different decision outcomes. The use of a consistent guiding ethical paradigm may be a necessary condition for moral decision making within and between ethics committees. A consensus-guiding ethical paradigm may be necessary to achieve consistent ethical decisions across society and to fulfill the requisites of distributive justice. If justice necessitates consistency, and consistency necessitates a consensus ethical paradigm, then justice necessitates a consensus-guiding ethical paradigm for ethics committee deliberation.

It is probably legitimate to presume that the various concerned individuals, groups and systems involved in the evolution of our society's approach to bioethical decision making for children, regardless of which locus of decision making authority or which guiding ethical paradigm they favor, are attempting to produce "right" and "good" treatment decisions for seriously ill, developmentally disabled children. The means to a "right" and "good" decision is the issue. Since at least the time of Aristotle, an important element of "right" and "good" has been the concept of justice. Justice, according to Aristotle, consisted of treating equals equally, and unequals unequally, proportionate to their differences (Benn, 1972). The
just application of standards and rules implies their consistent application; "The right... to be treated alike..." (Benn, 1972, p. 298). Questions of justice according to Hume, Mill and many other philosophers presuppose conflicts of interest (Benn, 1972). A claim of medical benefit or a claim of treatment rights is a claim based upon rights justified by some standard or rules of distributive justice. The consistent application of standards or rules and equal treatment are basic elements of justice. The literature review indicated that most agreed that justice necessitated consistency in bioethical decision making and in the delivery of medical services, and, that an important aspect of the concept of justice was the right to equal treatment. The right to equal treatment would appear to imply that individuals in similar circumstances deserve the same moral consideration. Therefore, it would appear to follow, consistency in bioethical decision making should be expected and demanded. Similar cases should receive similar consideration and similar medical treatment for justice to be served. Our research suggests that the establishment of infant bioethics committees as this society's primary locus of decision making authority may not be sufficient to assure consistent moral decisions.

The literature suggests that portions of our society, perhaps even a majority of health service workers who work with critically ill neonates with developmental disabilities, approach bioethical decision making regarding these infants from the perspective of the integrated principles of "social transcendence" and "quality of life". At the same time, literature suggests that the two ethical paradigms, Utilitarianism and Deontological,
are the two ethical paradigms of choice for ethical decision making. The research findings indicate that both Deontological and Utilitarian paradigms will produce bioethical decisions concordant with the integrated principles of "social transcendence" and "quality of life" a majority of the time. At the same time, our research indicates that decisions arrived at by "ethics committees" utilizing the Utilitarian and the Deontological paradigms will produce significantly different decisions. A possible explanation for the apparently diverging tendencies for the two paradigms to, at once, produce decisions that are significantly different, and at the same time produce decisions that are, respectively, significantly similar to the same correctness criteria, is: each paradigm shares different but strongly related factors with the integrated principles of "social transcendence" and "quality of life", but differ significantly in other factors, and these factors all strongly influence the process of decision making in "ethics committees". An analysis of the basic principles of the two paradigms would appear to support the research findings. The Utilitarian paradigm should share many of the philosophical elements which make up the principles of "quality of life". A Deontological ethical paradigm should support the philosophical concept of transcending value, which is the practical result of utilizing a normative ethical principle such as "social transcendence". At the same time, the two paradigms have major philosophical differences with respect to moral choice and evaluation of action, and, appear to have major philosophical principles which are not concordant with the integrated principles of "social transcendence" and "quality of life". For example, a Utilitarian paradigm is based upon the
concept of social utility; a concept that "social transcendence" repudiates. A Deontological paradigm would not consider "quality of life" a legitimate value base. These differences would suggest that there may be a better paradigm available for infant bioethical decision making. In spite of the logical implications of these deductions, the fact that either existing paradigm is likely to produce a majority of decisions concordant with decision outcomes based upon normative principles embraced by society's members may lessen pressure for any significant change in the process of bioethical decision making. It may be that in spite of the logical implications that there may be a better philosophical guiding paradigm for infant bioethical decision making, the fact that either of the two most often championed ethical paradigms will produce decisions in agreement with the majority of people, the majority of the time, has produced an intellectual, moral and political complacency that has prevented the emergence of an even more concordant guiding ethical paradigm.

Upon considering the emergence in the recent literature of indications of a growing commitment of many to the integrated guiding ethical principles of "social transcendence" and "quality of life", it appeared possible that a different ethical paradigm may have more efficacy in achieving bioethical decisions concordant with those principles than either a Deontological or a Utilitarian paradigm. It appeared that an ethical paradigm of philosophical egoism, if strictly applied by a person or group for the neonate, as if they could be the neonate, but competent to make an informed decision, would possibly provide decision outcomes more
concordant with the integrated principles of "social transcendence" and "quality of life" than either a Deontological or a Utilitarian paradigm. Epicureanism was chosen as the alternate ethical paradigm because it was philosophically egoistic; because of the balance Epicureanism suggests between the value of happiness and the value of a state of being pain free; and, because of the value the philosophy recognizes in suffering in the present to achieve later and greater happiness, or the avoidance of present limited pleasure in order to avoid associated later greater pain. Our research showed that a vicariously applied paradigm of philosophical egoism, such as Epicureanism, when utilized as a guiding ethical paradigm by an "ethics committee", will produce decision outcomes significantly more concordant with the integrated ethical principles of "social transcendence" and "quality of life" than either a Utilitarian or a Deontological paradigm.

In considering the generalizability of the findings, the similarities and differences between the analog committees and real hospital bioethics committees must be considered. To complicate matters, what we really want to know is how similar our analog committees are to real ethics committees whose members have the capability to make logical and philosophically consistent decisions, and whose members have been trained in, and instructed to use, a specific philosophical paradigm. This is important because there is considerable literature suggesting that real ethics committees may be composed of members whose ethical decision making abilities are questionable, and whose decision making consistency is
doubtful. The development of analog committees was, in fact, an attempt to develop an analog of a real bioethics committee whose members were capable of sophisticated ethical reasoning, and who were trained and committed to making bioethical decisions using a specific ethical paradigm. Such is the goal of any ethics committee. Hopefully, this will evolve into the typical reality over the next several years. The validity of this research was dependent upon the analog ethics committees having this capacity. Toward this goal, we selected analog committee members with a combination of health care knowledge and ethical decision-making training and ability. Whether, in fact, our analog committees' decision outcomes would be analogous to any existing bioethics committee would be dependent upon the real committee's training and capability. To the degree to which any particular real committee would be capable of sophisticated ethical reasoning, be generally knowledgeable of health care facts, and, have members committed to making decisions guided by one of the ethical decision making paradigms used in this research, we should expect decision outcomes analogous to those of our analog committees.

We can conclude that if consistency is to be achieved in moral decision making in and among infant bioethics committees, then a consensus-guiding ethical paradigm will have to be arrived at by our society. If our society continues to evolve toward a commitment to ethical decision making guided by the integrated principles of "social transcendence" and "quality of life", a vicariously applied ethical paradigm of philosophical egoism, such as Epicureanism, will produce ethical
decisions more concordant with those principles than either a Deontological or a Utilitarian ethical paradigm. We also can conclude that if our society does not adopt a consensus-guiding ethical paradigm, then the establishment of numerous infant bioethics committees will not produce just and morally consistent decisions. Distributive justice will not be served by a society condoning a pluralism of discordant ethical paradigms utilized by infant bioethics committees for bioethical decision making. In such a society of formalized pluralistic ethics, a strong argument can be made for maintaining the locus of decision making authority with the parents of critically ill neonates with developmental disabilities, and their attending health care specialists, as a more empathetic, and probably equally consistent and just, means of achieving ethically valid treatment decisions. If our society does adopt a universal guiding ethical paradigm and a process for its just application, then a strong argument can be made for placing the final locus of decision making authority in a bioethics committee staffed by capable and informed members.
APPENDIX A

COURSE CURRICULUM FOR MEDICAL ETHICS COURSE
Course Calendar:

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
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<tr>
<td>R 8/27</td>
<td>Course Introduction</td>
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<td>T 9/01</td>
<td>Ethical Theory</td>
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<td>R 9/03</td>
<td>Ethical Theory</td>
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<td>T 9/08</td>
<td>Ethical Theory</td>
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<tr>
<td>R 9/10</td>
<td>Ethical Theory</td>
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<tr>
<td>T 9/15</td>
<td>Models of Medicine and Nursing</td>
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<tr>
<td>T 9/22</td>
<td>Codes of Ethics</td>
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<td>R 9/24</td>
<td>Codes of Ethics/Power and Beneficence in Medicine</td>
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<td>T 9/29</td>
<td>Power and Beneficence in Medicine</td>
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<tr>
<td>R 10/01</td>
<td>Truth-Telling—IN-CLASS QUIZ PART OF TAKE HOME AND 1st TAKE HOME DISTRIBUTED</td>
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<td>T 10/06</td>
<td>Truth-Telling</td>
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<tr>
<td>R 10/08</td>
<td>Informed Consent</td>
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<tr>
<td>T 10/13</td>
<td>Informed Consent—1st TAKE HOME DUE</td>
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<td>R 10/15</td>
<td>Informed Consent</td>
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<tr>
<td>T 10/20</td>
<td>Provider Interaction: Responsibility, Conflict &amp; Authority</td>
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<td>R 10/22</td>
<td>Provider Interaction: Power &amp; Gender</td>
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<tr>
<td>T 10/27</td>
<td>Privacy &amp; Confidentiality</td>
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<tr>
<td>R 10/29</td>
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<tr>
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<td>Suicide</td>
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<td>R 11/12</td>
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<td>R 11/19</td>
<td>Definitions of Death &amp; Their Effects</td>
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<td>T 11/24</td>
<td>Euthanasia</td>
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<td>T 12/01</td>
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<td>Selective Non-Treatment of Defective Newborns</td>
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<tr>
<td>R 12/10</td>
<td>Selective Non-Treatment of Defective Newborns</td>
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</tbody>
</table>

Course Policy: Grades for this course will be based on A) three take home exams, the first of which will have an in class quiz component, and B) class attendance.

Take-Home Exams: Take home exams will contribute equally to your final grade. They will all be grounded in/based on the assigned reading material. I may give you an actual medical case or an issue to discuss and analyze in terms of authors’
theories. I will expect you not only to thoroughly understand what you have read or we have discussed, but I will also expect you to develop your own critical assessment and position on reading material and issues. (The goal of this course is not only to familiarize yourself with a variety of important issues and literature but to develop critical thought processes, genuine, reflective personal analysis.) N.B. You will be permitted to rewrite ONE of your first two take home exams, should you wish to do so in order to raise your grade on that exam. While rewrites may be turned in at any time prior to 12/11/87, I advise you to turn them in as soon as possible to avoid overburdening yourselves at the end of the semester.

DEADLINES: I have indicated on the course calendar when take homes will be due. I will notify you one week in advance of any alteration in schedule. The final take home exam is due in our scheduled exam period. NOTA BENE: I EXPECT YOU TO TURN IN YOUR TESTS ON TIME, BARRING EXCEPTIONAL CIRCUMSTANCES.

CLASS ATTENDANCE is of vital importance as lectures will not only highlight or summarize reading material (including "translating" difficult sections into "plain English"), but will include a critical discussion of readings which you will be held accountable for on tests. Further, I will be providing in lectures quite a bit of data and analysis that is not contained in any of your reading assignments. Consequently, good class attendance and good class notes will be of critical importance to your receipt of a desirable grade. FOREWARNED IS FOREARMED: I will keep a record of daily attendance. With more than FOUR unexcused class absences, your final grade will automatically be lowered ONE LETTER GRADE. If you come in late to class BE SURE to check with me so that your presence is noted and an "absent" marking removed. Last but not least: you will be required to finish all reading assignments prior to class. Medical Ethics has a number of fascinating issues and concepts that cannot be fully discussed without your informed participation. Come to class prepared to discuss the articles and their applications. Your efforts to participate will positively affect your final grade. Good attendance AND good participation will help move you to a higher grade should you hang between grading levels.

EXTRA CREDIT: Extra Credit projects are available that are capable of adding up to 0.5 to your earned test average. Your final grade will be determined by taking the average of your three take home tests and adding up to 0.5 for a successfully completed extra credit project and debiting for any problems in class attendance.
PLEASE NOTE:

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APPENDIX B

SAMPLE CASE STUDIES USED IN RESEARCH
CASE 1 - TWIN B

Two and a half months ago, two identical twins were born. They were born prematurely, in the thirty-first week of gestation. Twin A weighed 49 ounces (1400 grams.) Twin B weighed 50.4 ounces (1440 grams.) Both premature babies were diagnosed with Down Syndrome. Twin A was found to have an incomplete esophagus, which was treated successfully with surgery two days after birth. Twin A went home from the hospital three weeks after birth. Twin B was less fortunate. Part of his bowel became gangrenous. This portion was surgically removed. Surgery was also needed to repair a perforated colon. Because of the bowel problems, a tube had to be inserted into the heart to administer nutrients. The child became very weak and ventilator dependent. The child required 100% oxygen, developed fluid in the lungs, and then pneumonia. Over the last month, Twin B's kidneys failed, and his liver has not functioned properly. His blood pressure had to be supported by drugs. On three occasions during the last month, death has appeared imminent as a result of organ failures, but each time Twin B's condition was stabilized with intense effort.

PROGNOSIS: Without continued intensive medical effort, Twin B will almost certainly die. With continued intensive medical effort, there is a 50% chance Twin B will survive these early medical complications. Twin B is at risk of exhibiting several developmental sequeliae related to the numerous organ system failures of his first 2 1/2 months of life, including additional neurological problems beyond the cognitive deficits associated with Down Syndrome. However, the degree of risk is uncertain. The neonatologists and pediatric consultants are unable to predict with any reasonable degree of certainty what level of special care, beyond that usually required for patients with Down Syndrome, would be necessary as a result of the long term consequences of Twin B's multiple medical problems.

Twin B's parents, John and Susan, are in the sixth year of marriage. They appear devoted to each other. They have a healthy 4 1/2 year old son at home who appears normal and well adjusted in all respects. In addition, Twin A has been home from the hospital for nearly two months. His development has been as expected, and his medical condition is good. Both Susan and John work, and their children are watched by John's mother while they are away. Susan is a waitress. John is a salesman, and he is often
away from home for weeks at a time. The family's income allows them to live modestly. The hospital and medical bills have been, and would continue to be, paid through John's employment health insurance.

The parents are very worried about the effect that Twin B could have on their marriage, and on their ability to provide for their other children, the 4 1/2 year old son and Twin A. They wish that heroic efforts of treatment be stopped. The neonatologist and pediatricians are split. Some agree with the decision, some do not.
CASE 2 - MARY

Mary was born prematurely at twenty-seven weeks. She had a very low birth weight of 21.9 ounces, or 625 grams. Soon after admission to intensive care, she was found to have severe bleeding in the brain, a Grade 4 bilateral intraventricular hemorrhage, complicated by a post hemorrhagic hydrocephalus. A CT scan revealed a "bizarre brain anatomy," a picture which was "mostly hole." The diagnosis indicated that very little cerebral tissue remained undamaged. Neither a spinal tap nor cerebral shunt was considered a possible net benefit because of the probable complications of either procedure. Therefore, needles have to be inserted through Mary’s skull every two days to relieve pressure. Mary also has chronic lung disease, probably a result of ventilation. She cannot breathe on her own. For the last five months she has had a tube down her throat. Her trachea has become so scarred and narrow that if the tube were removed, she would be unable to breathe. A tracheostomy could bypass this problem, but this would insure that Mary would have to remain hospitalized for another seven months. Her general prognosis would not be affected by this procedure -- her chronic lung disease would not be cured, and her brain damage would not be lessened.

PROGNOSIS: If heroic treatment is terminated, Mary will almost certainly die of complications from her lung disease within days. With treatment, Mary will probably survive the medical problems after many more months of intensive medical intervention. The degree of chronicity of her lung disease is uncertain, but it is probable that this will remain a significant problem, even a disabling one, for the rest of her life. The extent of Mary’s brain damage suggests that she will have severe cerebral palsy and significant intellectual and other neurological problems, if she survives. Mary can reasonably be expected to be profoundly retarded if she survives.

Mary was born to a 23-year old woman. This was her 4th pregnancy. The first ended in miscarriage, the 2nd was a still birth, and the 3rd child died within 6 hours of birth. Mary’s father is 24. Both parents desperately want to start a family. Both parents work. The father is an engineer. The mother is in business management. The parents were extremely ambivalent about
whether to continue treatment for Mary. Their final choice has been to continue treatment.

The neonatal team responsible for Mary's medical treatment describe continued treatment as "therapeutically ridiculous." They state that the intensity of treatment required to maintain her life was "grossly disproportionate to the expected outcomes." They felt their time in working with Mary was "robbing" other patients in the full neonatal intensive care unit.
CASE 3 - BABY A

After an uncomplicated delivery, Baby A was born in distress. The initial APGAR rating was 2. Baby A was limp, very blue from lack of oxygen, and the heartbeat was very irregular. However, after several minutes the baby’s heart beat was stabilized, his color was good, and he was breathing easily on his own. The second APGAR was 7. At this time the attending physician diagnosed Baby A as having Down Syndrome. It was soon discovered that Baby A also had esophageal atresia and a tracheoesophageal fistula. This meant that the esophagus did not connect properly to the stomach, and the baby would be unable to eat. Also, the stomach was connected directly to the trachea, allowing digestive enzymes to enter the trachea, potentially destroying the lungs. The child’s heart appeared to be slightly enlarged, the significance of this was questionable. There were no other medical complications.

PROGNOSIS: Without surgery, Baby A will die within a week. With surgery there is every expectation that the atresia and fistula can be successfully repaired. It is a “rigorous” surgery, but with a high degree of success. “Follow-up” surgery several years later is frequently required. With medical intervention it could reasonably be expected that Baby A could develop free of medical or other complications beyond those normally expected with Down Syndrome.

The parents have been married for seven years. Both are school teachers. They have had two previous children, a girl age 6 and a boy age 3. The mother is 31, the father is 34. They have very adequate insurance coverage and a comfortable income. The parents have chosen not to treat.

The pediatricians involved in the case are in disagreement. One supports the parents’ decision. The other two are vehemently opposed and have threatened court action if surgery is not agreed to.
CASE 4 - BABY C

Baby C is a girl born with no apparent complications of delivery, full term. She was born with a combination of birth defects. Baby C had a myelomeningocele at level L 3-4. The baby had microcephaly with a head circumference of 30 centimeters (less than 3/1000 that small) and hydrocephalus. Ultrasound examination revealed that cerebrospinal fluid had caused a "moderate" dilation of 3 of the 4 ventricles of the brain. Also, the baby had a facial deformity which prevented her from closing her eyes or sucking; a thumb abnormality; and a prolapsed rectum. The lower extremities were athetoid and the upper extremities were spastic.

PROGNOSIS: Without treatment, Baby C has a 50% chance of living for two months, a 10% chance of living one year, and a near zero chance of living two years. With treatment, Baby C's estimated life span was as much as 20 years. Surgery could reasonably be expected to be successful. The herniation of the myelomeningocele could be repaired and a shunt could be inserted to relieve the pressure of the hydrocephalus. It could reasonably be expected that the child would be permanently incontinent of bowel and bladder, with substantial paralysis of the lower extremities. Baby C may also suffer from spastic cerebral palsy in the upper extremities. Epileptic seizures would be a good possibility. Constant pharmacological intervention would be needed to prevent fatal kidney infection. This still would probably be the final cause of death. Baby C would almost certainly be mentally retarded, probably in the profound or severe range. The prolapsed rectum was not easily remedied and would probably cause considerable pain throughout the baby's life.

Baby C's father is a 30-year old building contractor. Her other is a 23-year old housewife. They are Catholic. Their socio-economic status is upper middle class. They have chosen not to treat. All attending neonatal staff concur. However, due to an anonymous telephone call to a local attorney, there was a court action requiring treatment. This decision was overturned on appeal. Baby C is now 7 days old and the case has been referred to an Ethics Committee. She is presently receiving nutrients and antibiotics intravenously.
CASE 5 - BOBBY

Bobby is 19 months old. He was born prematurely. Ventilation was required. As a result of ventilation, Bobby's lungs were badly scarred, and he developed bronchopulmonary displasia. He now needs the ventilator for an indefinite amount of time, perhaps permanently. The cost of treatment is $3000 per day.

The only other present medical problem are Bobby's extremely large, protruding eyes, caused by unknown pathology. While "hauntingly attractive," he has trouble closing them and must be administered eye drops daily.

Bobby is restricted to his bed and his physical development is delayed, almost certainly due to his limited activity. He is essentially bedridden because of his dependence upon the ventilator. He appears intelligent with good social and emotional development, smiling and responding to conversation and social contact. He hasn't learned to talk, as the throat tube of the ventilator has prevented development of verbal expression.

PROGNOSIS: Without treatment, Bobby would die within hours. With treatment, Bobby's life can be prolonged indefinitely, although lung disease could be reasonably expected to be the cause of death in the first two decades. Bobby will probably remain bedridden and on the respirator throughout his life. While his social and cognitive development are delayed due to environmental deprivation, a normal potential probably exists. No locatable family exists.
Philip was born after a normal delivery. At birth his outward appearance was normal. Philip weighed 9 pounds at birth. Within a day it was determined that Philip had a slight heart murmur, slight case of jaundice, and hypoglycemia. There was still not strong cause for concern. When Philip was five days old, he turned blue and stopped breathing. Nurses revived him. He was found to have three cardiac abnormalities; a hole between the heart chambers, a blocked valve, and an extremely small set of pulmonary arteries. The net effect was that the body was getting almost no oxygenated blood. Philip was also found to have an abnormality of the pancreas, which resulted in extreme overproduction of insulin, i.e. hyperglycemia. Over the next two months Philip had three heart surgeries and two surgeries of the pancreas. His gall bladder was also removed. After the surgeries he developed a "mysterious" viral infection, followed by necrotizing enterocolitis. A heart catheter for hyperalimentation was implanted. He was now on constant ventilation with tracheotomy. He developed bronchopulmonary dysplasia (lung disease.) At three months he had still another surgery. The diuretic lasix given to prevent fluid build-up around the heart caused kidney stones to develop! They were removed. They found at this time that he had only one functioning kidney. After the operation, Philip began to slowly and steadily get better. He was scheduled for release from the hospital at eight months, with permanent heart problems and chronic diabetes from removal of the pancreas. At this time Philip experienced three cardiac arrests in one day and was put back on a ventilator. Philip underwent two more surgeries, one on his trachea to relieve a blockage which was causing vomiting, and another heart operation in an unsuccessful attempt to repair a valve. Since then, Philip has suffered grand mal seizures and a series of strokes. He is paralyzed on one side and has regressed dramatically in intellectual functioning, exhibiting moderate mental retardation. Philip remains on hyperalimentation through a heart catheter and ventilation. He receives morphine constantly for pain. He is 10 months old and expresses his discomfort vehemently.

The parents are both lawyers with a family income in excess of $100,000 per year. She is 39, he is 46. They have three other children; daughter 20, son 15, son 8. He had a vasectomy undone to conceive Philip. They have good insurance, but due to the extreme nature of Philip's problems, medical bills are a burden and could become moreso. Both the parents and the physicians
are looking to the committee for guidance in a decision to treat or not to treat.

PROGNOSIS: If treatment is discontinued, there is no certainty of imminent death. There is a good possibility that if the ventilator is disconnected, Philip would get enough oxygen to keep alive, but not enough to adequately oxygenate the brain. He very likely could suffer severe brain damage. If treatment is continued, the expectations are that Philip will most probably continue his present slow but progressive deterioration.
CASE 7 - MICHAEL

Michael was born 4 weeks prematurely after normal labor and delivery. Birth weight was 2300 grams and APGAR was 2. Resuscitation was required. Michael was feeble and presented with multiple evidence of genetic abnormality. The consulting geneticist diagnosed Trisomy 18, a chromosomal abnormality in which three number 18 chromosomes are present instead of the normal pair. In the first 24 hours, Michael required further resuscitation for two apneic episodes. His sucking reflex was very poor, and a nasogastric tube was inserted for feeding.

PROGNOSIS: Babies with Trisomy 18 have limited capacity for survival. Even with optimal management, they fail to thrive. Without intervention, Michael would likely die from an apneic episode or from starvation within a few hours or days. With medical intervention, he could potentially live up to a year. Statistically, 30% of infants with Trisomy 18 die within the first month and 50% die within two months. Only 10% survive the first year. They are severely mentally retarded and have multiple physical anomalies.

Michael's parents are middle class professionals. His father was 36 and his mother 41 at the time of his birth. Michael's mother delivered her first child, a normal girl, at age 36 and began trying to conceive a second child one year later. For four years she underwent extensive fertility testing and treatment with fertility drugs. A pregnancy at age 40 ended in miscarriage in the third month. Mrs. J. was despondent for several months following the miscarriage and required professional psychological intervention. She then conceived Michael. She refused to undergo amniocentesis because of her fear of precipitating another miscarriage.

Mr. J. has chosen not to treat, and the family pediatrician and geneticist concur with his decision. Mrs. J. has requested that the doctors do everything possible to keep her baby alive and to help him live as normal a life as possible. Mr. J. is very concerned that his wife is denying the seriousness of the baby's condition, and that if she cares for the child for even a short time, his eventual death will precipitate a severe depression. He is worried about the possible effect of his wife's preoccupation with the infant and subsequent depression on their six year old. He thinks that the baby should be allowed to die as quickly as possible, has requested removal
of the feeding tube, and has asked that the baby not be resuscitated. Because of the family's inability to arrive at consensus, the case was referred to an ethics committee for recommendation.
CASE 8 - TAMMIE

Tammie was born six weeks prematurely weighing 1700 grams. She progressed well until her fourth week, whereupon she developed severe necrotizing enterocolitis. This caused a large segment of her lower bowel to degenerate. A portion of her bowel was removed surgically. On the average, her normal bowel would contain 250 centimeters of intestine. Hers now contained 35 centimeters. All of her ileum was also removed.

PROGNOSIS: The essential medical question is, does Tammie have enough bowel left that she might be capable of natural digestion at a later time? The answer is equivocal. Statistically, Tammie falls right on the cusp. Children with more bowel usually are capable of natural digestion at a later time. Children with less bowel usually are not. Treatment would primarily consist of hyperalimentation. Without treatment, Tammie would starve to death over a period of a couple of weeks. With treatment, Tammie’s life would be extended with the following qualifications and potential consequences. First, as long as Tammie is required to be treated with hyperalimentation, she would be tethered to her IV tube and food pump. This would significantly restrict her environmental interactions. Second, there is a slightly less than 50% chance that Tammie’s bowel will eventually prove capable of supporting her nutritional needs, and Tammie could be freed from the hyperalimentation tether. Thirdly, we probably could not expect that Tammie could survive indefinitely if permanently restricted to nutritional support by hyperalimentation. 15-20% of patients die of cirrhosis of the liver by the third year of dependency. Also, eventually the limited number of sites available for attachment of an IV catheter could be expected to wear out after a decade or two of abuse. A significantly restricted life and an eventual long suffering death could almost be assured for Tammie if she would end up confined to permanent hyperalimentation therapy. Her life could be extended several decades, however.

Tammie’s father is 39 and self-employed. Tammy’s mother is 34 and self-employed. They have no other children. The marriage appears solid. Tammie’s family is very well off financially, and expense is not a problem.
The parents are unable to make a decision regarding treatment. They indicate they "want to make the best decision for Tammie." They are looking to the ethics committee for guidance. The attending physicians are also seeking guidance from the ethics committee.
CASE 9 - BABY J

Baby J was born with multiple anomalies. The baby had an exposed urinary bladder, mild fluid build-up in the head, ambiguous genitalia, a spine disconnected from the pelvis, no anus, agenesis of the colon, and a meningocele at the base of the spine. Urine and feces were excreted into the exposed urinary bladder. This made feeding difficult since waste excreted into the exposed bladder increased the risk of infection. Baby J had a normal small bowel, kidneys, heart, and lungs. The baby's cognitive status was impossible to assess completely. Based upon the diagnosis of hydrocephalus and data obtained from neurological assessment, mild to severe mental retardation could be projected.

PROGNOSIS: Without treatment, Baby J would likely die within a few weeks from infection. Because of the multiple anomalies, Baby J's prognosis with treatment is ambiguous. Multiple specialists were consulted about possible treatments. The baby was found to be chromosomally male (XY), but because of the non-functional genitalia, it was recommended that the infant be considered female, and if she survived, raised accordingly. Abdominal surgical options included a diverting colostomy to prevent the bowel from emptying into the exposed bladder, followed by surgical efforts to enclose the bladder within the body. The meningocele was unsightly; however, any surgery on the sac would be cosmetic, not therapeutic. There is no immediate need to provide a shunt or drain for the mild fluid build-up in the head since it is believed to be draining through the spinal column into the meningocele. Surgery on the sac would not restore functioning to the infant's legs, which had atrophied in the womb. Efforts to redirect the draining of the hydrocephalus would require surgery initially every three months or so. None of these procedures would affect the prognosis for the development of the infant's cognitive capacities. Mild to severe mental retardation would still be projected. The child would be nonambulatory and would need a wheelchair. Eventually the child would very likely develop scoliosis and ultimately be confined to bed. Urinary tract infection would be a constant threat. The child could of course experience morbid and life threatening complications from any of the above interventions. In fact, with the number of possible
problems expected, the child is given a 50% chance of surviving five years.

Baby J's father is a college professor, age 37. Baby J's mother is a business administrator, age 29. They describe themselves as "faithful Roman Catholics." They have one other child, a two-year old boy. The parents have chosen not to treat. The attending physician concurs.
CASE 10 - KATHY

Baby Kathy was born after normal term following an uncomplicated delivery. At birth Kathy would not breathe. The delivery team spent over 30 minutes struggling to initiate and stabilize her respiration. As a result, the case records show asphyxiation at birth. Kathy was also found to have non-functional kidneys. All other organ systems appeared normal.

PROGNOSIS: Without treatment, Kathy would die within days or weeks due to the non-functioning kidneys. With treatment, Kathy could be expected to survive in the near and intermediate term with regular kidney dialysis. The goal would be to obtain a kidney transplant. The long-term survival prospects for the baby being sustained on kidney dialysis are 50% for 5 year survival. The long-term survival prospects with the kidney transplant are 80% for a 5-year survival, with, of course, much more freedom. Kathy would also be projected to be mildly to moderately mentally retarded. There was also a slight chance of mild cerebral palsy and/or epilepsy as future sequelae of the asphyxiation at birth.

The baby's father works on an automobile plant assembly line. The mother is a full time parent and housekeeper. He is 29, she is 25. They have another child, a two-year old girl. They have expressed concern about the impact this child would have on the rest of the family. The family is modest, their insurance coverage minimal. They have determined they would have substantial trouble meeting the financial requirements of providing medical treatment for Kathy. The parents have chosen not to treat. The attending physician states she will defer to the parents' wishes and does not express her opinion.
CASE 11 - BABY M

Baby M was born 5 weeks prematurely, weighing 1900 grams (66 ounces.) The prognosis at birth was good for recovery. However, after admission to intensive care, the baby's condition deteriorated unpredictably and rapidly. Her kidneys failed. On day four of her life, the baby had a cardiac arrest, was resuscitated and placed on a ventilator with 100% oxygen at high pressures. Cardiotonic drugs were given to increase blood pressure, urine, and cardiac output, and pulmonary blood flow. On day six, a pneumothorax (air in the chest) led to a second cardiac arrest. Baby M was again resuscitated. Chest tubes were inserted to relieve the condition. Within twenty four hours, other pneumothoraces led to a third arrest. Resuscitation followed with more chest tubes. On the seventh day, Baby M was found to have a bilateral grade 4 intraventricular hemorrhage. Ventilation continued. By day 12, Baby M developed hydrocephalus, which could not be immediately shunted. Repeat spinal taps were used to release pressure. These had to be stopped by day 15 due to other complications. Baby M was considered too unstable for repeated spinal taps to relieve the fluid buildup in the head. It is now day twenty. The fluid buildup has stabilized. All life support systems are in place. The infant is blue and unconscious, but for the present, stable.

PROGNOSIS: Without treatment, Baby M would almost certainly die within hours or days from the results of any of several life threatening medical complications. With treatment, Baby's prognosis is still extremely critical. While presently somewhat stabilized, the baby could die at any time. If Baby M does survive these acute medical problems (best estimate is 20% - 30% chance, but the reliability of the estimate must be questioned) she almost certainly will have severe cerebral palsy and severe to profound mental retardation.

The father is 29, the mother is 30. The mother does not work. The father is a machinist. The family income is modest. Their insurance coverage is good. This is the fourth pregnancy for the couple. The earlier pregnancies ended in miscarriages. The parents are members of a conservative Christian denomination. Religious symbols adorn the infant's bed. The couple's pastor visits the room daily and prays with the family by the child's bed. The family has stated they believe the several cardiac arrests followed by successful resuscitation is a clear sign to them that "God wants our child to live." The
family is adamant in wanting the treatment to continue. It is also clear that many of the attending medical staff feel it may be in the best interests of the child if treatment is discontinued.
CASE 12 - BABY ANN

Baby Ann was born prematurely at 24 weeks gestation, weighing 648 grams. Baby Ann was born outside the hospital and brought to the emergency room in grave condition. Her mother has a history of drug addiction and received no prenatal care. Immediately after admission, her APGAR rating was 2. The second APGAR was 5. Baby Y's diagnosis was hyaline membrane disease, prematurity, and drug addiction. Further diagnostic workup revealed abnormal cortical development, including absence of the corpus colosum and holencephaly (porousness, indicates a generalized sparsity of cortical tissue affecting many areas of the brain.) Ann was put on a respirator, but her lungs were so underdeveloped that they could not be kept expanded. Treatment for this requires a special pulse-respirator. However, use of the pulse-respirator increases the possibility significantly that the neonate could experience grade 4 ventricular hemorrhage, a life threatening complication. Currently Baby Ann receives phenobarbital for seizure activity. There are frequent apneic episodes. She is in need of the pulse respirator. Her condition remains very unstable.

PROGNOSIS: Without treatment, specifically the pulse respirator, Ann will die at any moment. With treatment, her prognosis is still precarious and difficult to assess. The best estimate is that with the pulse respirator and other appropriate medical interventions, Ann has a 30% chance of survival. Recent research suggests that if she survives, she will have a 70% chance of having a developmental disability and a 40% chance of having a very debilitating developmental disability. The chances of mental retardation are 50%.

Baby Ann's father is unknown. The baby's mother is 24, unmarried, an indigent, and an active heroin addict. She also has a history of other substance abuse, including cocaine and alcohol. Baby Ann's mother has given two previous children to the grandmother to raise shortly after their births. The grandmother is the legal guardian for both children. Both children were normal births. The grandmother would also have responsibility for the care of Ann. The grandmother is on Aid to Dependent Children and lives on marginal income. She has no medical insurance other than medicaid. The grandmother tells the attending physician to do whatever is necessary to treat Baby Ann, but expresses concern and reluctance to care for another child, especially one needing special care. The physicians seek guidance.
CASE 13 – JOHN

John was born full term after an uncomplicated delivery. Ultrasound at 18 weeks indicated no complications. At delivery, John was diagnosed as having Cloverleaf Syndrome. This is a very rare syndrome with only 5 previous live births occurring in the United States. This condition usually involves severe craniofacial malformations, underlying abnormal brain development, inadequate development of oral passageways, ocular protrusions because of shallow orbits, and frontal and side bossing of the skull. The initial APGAR was 8. Further medical evaluation revealed immature lung development, deafness, and a slightly enlarged heart.

PROGNOSIS: Without surgery Baby John will die within 7-14 days. With surgery, the prognosis is unclear. Previous medical treatment for similar cases has included numerous surgical procedures on the cranium to allow for more normal brain development and to relieve intracranial pressure. These procedures have been only minimally successful with average life expectancy being 8-13 months, depending on the number of associated medical anomalies. Baby John appears to be much more healthy than other reported cases. There are also better techniques for cranial reconstruction than were available even a couple of years earlier. So little is known about this condition that a prognosis will, by necessity, be somewhat unreliable. There is a very significant risk for severe cognitive deficits associated with the abnormal brain development. Additionally, John will require numerous surgical procedures to correct the craniofacial malformations. It is difficult to predict the risk factors associated with the procedures considering his cardiac and respiratory problems.

The parents have been married for 7 years. This is their first child. They are a professional couple who have just decided to begin a family. Parents are 37 and 34. They have an upper middle class income, adequate insurance coverage, and the financial resources to provide for a child with special needs. The parents have chosen not to treat. Their physician agrees and issues a "no code" on the infant. Hospital nursing staff are extremely upset and disagree with the treatment plan.
Baby Jill was the second born of fraternal twins. She was born after 30 weeks gestation and weighed 1000 grams. She was born not moving. She required ventilation and drugs to increase cardiac output. At one month she had successful heart surgery to repair a valve. Baby Jill had a class III cranial hemorrhage and hydrocephalus. A shunt was inserted to drain excess cerebrospinal fluid. At three months, Baby Jill had progressed and was well enough to leave the hospital with her brother, who was doing very well. At this point, Baby Jill contracted meningitis. As a result of the meningitis and high fever, Baby Jill suffered extensive neurological damage and the hydrocephalus exacerbated. After three shunt operations, Baby Jill was found to be in need of a fourth. Intracranial fluid pressure was still increasing to abnormal levels. Baby Jill was totally immobile and showed no signs of alertness.

PROGNOSIS: Without treatment, Baby Jill would probably die in a matter of weeks. There is a slight chance that Baby Jill would not die. In this case, her neurologic status would almost certainly be compromised further by the withholding of treatment. With treatment, Baby Jill has a good chance of surviving. Baby Jill would almost certainly be severely mentally retarded with cerebral palsy.

Baby Jill's mother is 35 years old and works as a secretary. Her father, age 34, is a salesman for a large pharmaceutical company. During Baby Jill's earlier problems, the parents were strongly disposed to treat. At this point, the parents have chosen not to treat. The attending physician disagrees.
CASE 15 - RANDY

Randy was born after normal pregnancy and delivery with no medical complications. Shortly after birth he became blue, and heart rate and respiration were abnormal. Diagnosis was patent ductus arteriosus, which is a cardiac defect causing failure to oxygenate blood appropriately. Randy was treated using ventilation, but physicians were not able to achieve and maintain appropriate blood gas levels. Randy was transferred to a specialized neonatal intensive care unit in another city for ECMO, surgery to repair the cardiac anomalies. During the ambulance ride to the hospital he experienced four cardiac arrests and was resuscitated each time with extreme difficulty. Surgery was performed successfully, and Randy was returned to the hospital in his home city. Subsequently, as a result of the cardiac arrests, his EEG indicated no activity and he required multiple life support systems for life maintenance. One week later, some minimal brain activity was detected, but major organ system damage had occurred in addition to the pervasive neurological damage.

PROGNOSIS: Without treatment using life support systems, Randy would die within hours. With intensive specialized care, he could be sustained for an extended period of time. Prognosis is still very poor. On the slim chance that he would recover and be independent of life support systems, he would be expected to have profound mental retardation, cerebral palsy, and/or epilepsy.

Randy's parents are both in their early 20's. This is their first child. Their income is moderate; both work at unskilled jobs. The family has some medical insurance through the father's job. The parents have chosen to maintain life support systems and treat at all costs. The attending physicians have recommended discontinuance of life support systems because of the extreme cost and poor prognosis.
CASE 16 – DAVID

David was born two months prematurely to a 14-year old runaway. She had had no prenatal care and was brought to the hospital emergency room in labor by the local police. David was diagnosed as having Down Syndrome shortly after birth. His birth weight was 1642 grams, APGAR scores were 5 at one minute, and 7 at three minutes. The attending physicians diagnosed severe microcephaly and esophageal atresia, in which the esophagus is not connected to the stomach.

PROGNOSIS: With surgical intervention, the prognosis is excellent medically. Without corrective surgery, the child will die within a week. The likelihood of moderate to severe mental retardation as a result of the microcephaly is high.

David's mother told the social worker at the hospital shortly after David's birth that she had been repeatedly sexually abused by her father, and that David is his child. She indicated that she had been living outside the home since she learned she was pregnant, and her parents knew neither her whereabouts nor about her pregnancy. She asked that the baby be allowed to die and her parents not be notified. Her request could not be honored because the laws in her state required that her parents be notified, as she was a minor.

David's grandparents were notified and both unequivocally denied the sexual abuse allegations, refused to see the infant or to be involved in any way. The social worker referred the case to child protective services, who requested the assistance of the ethics committee in determining whether to treat. The agency is concerned that with the history of incest and the likelihood of severe mental retardation, it will be very difficult to find an adoptive family for David, and he might never have a permanent home.
CASE 17 – Baby Bill

Baby Bill was born 4 weeks post-mature. He was diagnosed as anencephalic. Baby Bill would respond to stimulation in a gross manner. His medical condition was stable. He had many reflexes including a partial sucking reflex. No other organ deficiencies were noted. He was an otherwise healthy baby.

PROGNOSIS: Without treatment, Baby Bill will die within a week, due to an inability to digest food. With treatment, Baby Bill could be maintained indefinitely on life support, including hyperalimentation. He would remain profoundly retarded.

Baby Bill was born to an indigent 32-year old psychotic woman. She is unable to make an informed decision.
CASE 18 – BABY REBECCA

Baby Rebecca was born with a painful and little understood autoimmune condition that causes a very painful and progressively deteriorating condition of the skin and connective tissues. Over 60% of the child's skin was presently involved. The condition resembled 2nd and 3rd degree burns. No treatment is available. Palliative procedures include drugs for pain and wrapping. The drugs are only partially effective in relieving pain.

PROGNOSIS: Without treatment, Baby Rebecca will die of infection within several days. With treatment, Baby Rebecca will probably die within several months. Her life would be characterized by a good deal of pain and suffering. There is probably less than a 1% chance of a miracle cure being discovered before Rebecca would die in spite of heroic treatment.

Rebecca's parents are both professional social workers. He is 29, she is 31. They are looking to the ethics committee for guidance.
CASE 19 - JENNIFER

Jennifer was born with an L1-L2 myelomeningocele after a long and difficult labor. The pregnancy was full term and without incident. During the delivery, the cele was ruptured, exposing the open deformity to aseptic conditions and greatly increasing the risk of infection. Jennifer's head was somewhat enlarged, and tests indicating a mild to moderate degree of hydrocephalus, which likely existed for a period of time in utero. The baby's lower extremities were seriously hypotonic and appeared to be at least partially paralyzed. She displayed rocker-bottom feet and hip dysplasia, which are characteristic conditions suggesting unevenly impaired neural stimulation of the lower body. Shortly after birth, she had a series of epileptic seizures. She was treated with phenobarbital.

PROGNOSIS: With immediate interventions, Rebecca's life could be saved. The myelomeningocele would need to be surgically repaired to prevent further rupture and infection, although such surgery would not correct any of the neurological sequelae of the myelomeningocele. A shunt would need to be inserted to drain cerebrospinal fluid and to relieve the pressure on the child's brain, which could prevent further brain damage, but would not correct any significant brain damage resulting from the hydrocephalus in utero. Antibiotics would need to be started immediately to prevent infection/meningitis. Even if Jennifer were stabilized at this point, the degree of hydrocephalus would suggest at least moderate mental retardation. The neurological damage will most likely cause lifelong problems of the urinary tract, predisposing her to the risk of chronic urinary tract, bladder, and kidney infections which have the potential to be lethal without ongoing physical and pharmacological management. The degree of deformity in the lower extremities will require multiple corrective surgeries at a later date. The attending physician has indicated that the placement and degree of damage in the myelomeningocele would make the reconstructive surgery more difficult than usual, and with a lesser chance of success. There is a good likelihood that Jennifer will never walk, that she will have little or no motor control and no feeling below the level of the defect.
Jennifer was the 2nd child born to a 19-year old unmarried mother with mild mental retardation who lives independently only with the consistent help of a volunteer from the county's ARC. She has rejected the infant as being "deformed" and wants nothing to do with her. The baby's grandmother believes it a sin to withhold medical treatment, but at age 58, refuses to consider raising this child. There is no other family. If treated, a lifelong placement would need to be found where Jennifer would receive the wide array of medical, educational, and social services she will need.
CASE 20 – FRANK

Frank was born at a rural county hospital. Since his mother had received no prenatal care, his term was not known. His birth weight was 2320 grams. He presented with severe malformations and was immediately transferred by ambulance to a larger city neonatal intensive care unit 30 minutes away. He required resuscitation during the ride for 3 episodes of apnea. A geneticist was consulted. Frank’s pattern of symptoms suggested a pervasive chromosomal defect and a tentative diagnosis of Trisomy 13 was made pending confirmation by follow-up chromosomal study. Frank’s immediate life endangering problems were serious cardiac deformities, including a ventricular septal defect and patent ductus arteriosus. In addition, the infant’s brain was seriously affected; holoprosencephaly defect with incomplete development of the forebrain was noted. He had a moderate degree of microcephaly.

PROGNOSIS: Without resuscitation for apnea and immediate cardiac surgery, Frank will die within a matter of hours. The natural history for Trisomy 13 children reflects a high morbidity; 44% die within the first month, and 69% by 3 months. Only 18% survive the first year. Survivors have severe mental retardation, seizures, and fail to thrive. It is not known at this time whether Frank is a full Trisomy 13 or a Mosaic, in which some cells have normal chromosome configurations. The clinical picture for Mosaic children may be less severe: they may display the full pattern of malformation or have a near-normal phenotype. Survival is usually longer and the degree of mental deficiency is variable. The geneticist cannot make a firm diagnosis of full Trisomy or Mosaic without awaiting the results of the chromosome study.

Frank’s mother and father live on a working farm. He is 48, she 46. Frank was an unplanned pregnancy, her “change of life” baby. The family’s four other children are grown and emancipated. Mr. J. has a chronic heart condition that requires special ongoing care and treatment. Mrs. J. has arthritis and is limited in her ability to lift, carry, and bend. They want to do what is best for the baby, and would consider not treating if the doctors recommend it. They express concern about their advanced age and do not want their children to have the responsibility for caring for Frank at such time as they are not able.
APPENDIX C

EXPLANATION OF RESEARCH FOR SUBJECTS
EXPLANATION OF RESEARCH FOR SUBJECTS

Some children are born with developmental disabilities complicated by life threatening medical problems. For many such neonates, decisions are made, at or near birth, to either vigorously treat, or to withhold medical treatment. The majority of the children not treated in such circumstances will die. The locus of decision making responsibility for such decisions may be the parents, attending physician and nursing staff, agencies of the State such as children service agencies or courts of jurisdiction, or ethics committees. This research will explore aspects of the decision making process of ethics committees.

Literature suggests that the decision making process of ethics committees is, and should be, guided by the principles of certain ethical paradigms. We are interested in exploring the effects of utilizing various ethical paradigms as the normative standard for these compelling decisions. This research will analyze the processes and outcomes of decision making groups who are charged with the responsibility of choosing to treat, or not to treat, developmentally disabled neonates with life threatening medical complications.

We are looking for volunteers who will participate as members of experimental decision making groups, i.e. "ethics committees." These volunteers will each be appointed to one of several "ethics committees." Each "ethics committee" will be assigned a specific ethical paradigm as its
guiding normative standard. Each "ethics committee" will be given fact sheets detailing important case information from actual medical case records of developmentally disabled neonates born with life threatening medical complications. For every case, each "ethics committee" will be asked to make a decision either to vigorously treat, or to withhold treatment, based upon the case information, utilizing the precepts of the ethical paradigm assigned to that committee. Fifteen to twenty cases will be presented to each committee.

Volunteers should expect to commit approximately five to seven hours of their time to this experiment, spread over two meetings. The first meeting will take approximately one hour. At this meeting, volunteers will be assigned approximately fifty pages of reading. The second meeting will take approximately three to five hours. During the second meeting, each volunteer will be assigned to decision making groups and will be given between fifteen and twenty cases for review and decision. Volunteers will receive $4/hour for their time of participation.

It is our hope and belief that the products of this research will stimulate and influence the development of curriculum guidelines and content for preservice and inservice education and training of the various disciplines and professions involved in the decision making processes regarding treatment of developmentally disabled neonates with life threatening medical complications.
APPENDIX D

READINGS FOR SUBJECTS IN THE STUDY
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READINGS FOR SUBJECTS IN THE STUDY

The subjects were given a total of 50 pages of required reading as part of the responsibilities in this research. Those readings can be found in the following resources.


APPENDIX E

SUBJECT INSTRUCTIONS
SUBJECT INSTRUCTIONS

Each of you will now begin the fact sheets for the first case. This will be the first of twenty cases we will consider today, to decide to "treat", or "withhold treatment" for each case. The fact sheets you will be given will contain all the relevant case information available. You must make a decision to vigorously treat, or to withhold treatment, for each developmentally disabled, severely ill child, based upon this case information, utilizing the precepts of the ethical paradigm assigned to your "ethics committee." I will verbally go through each fact sheet with you at the beginning of each case presentation. Each of the three of us will then act as a case facilitator for one of your "committees." If you have questions, we will provide clarification of case facts, if we have the information. After the case presentation, you will take five minutes to consider the facts. Then you will discuss the case with your group members and work toward a consensus decision to "treat" or "not to treat." When you have arrived at a consensus, the case facilitator will record it, and you will move to the next case. In the event your group cannot arrive at a consensus, a vote will be taken, and you will move on to the next case. However, you are strongly encouraged to work hard to arrive at a consensus. Each subsequent case will be presented in the same fashion. Your responsibilities are the same for each case. Now let's begin with the first case.
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