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Caring Choices: Decision-making about Treatment for Catastrophically Ill Newborns

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CARING CHOICES:

DECISION MAKING ABOUT TREATMENT
FOR CATASTROPHICALLY ILL NEWBORNS

Betty Wolder Levin

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy
under the Executive Committee of the
Graduate School of Arts and Sciences

COLUMBIA UNIVERSITY
1986
ABSTRACT

CARING CHOICES:
DECISION MAKING FOR
CATASTROPICALLY ILL NEWBORNS

BETTY WOLDER LEVIN

Decision making for catastrophically ill newborns has recently emerged as a social issue. Advances in biomedical technology and practice, and changes in other economic, social and political factors have led to controversy about norms to guide treatment choice. While much has been written on how such decisions should be made, there has been little social science research on how such decisions are actually made.

The purpose of this dissertation is to elucidate the way that clinicians think about treatment decisions for catastrophically ill newborns. The focus is on decision making with respect to the limitation of treatment in those situations in which clinicians feel that an infant is terminally ill and/or severely impaired. The aim is to place the issue in its broad social context, explicate how clinicians categorize information, examine how clinicians utilize these categories in making decisions, investigate the process of decision making in the context of social change, and elucidate some of the ethical and policy questions.
A major finding of this research is that treatment of catastrophically ill newborns is heavily influenced by the way that clinicians conceptualize the issues involved in treatment choice. Rather than a clear cut choice "to treat" or "not to treat," decision making is a complex process in which clinicians, and sometimes parents, make decisions about which treatments are appropriate to give at a particular point in time. Clinicians conceptualize this as a choice about "the aggressiveness" of treatment. A model is derived to explain clinician decision making. Clinicians are seen to categorize characteristics of patient condition along the dimensions of quality of life, uncertainty, critical condition and social value; treatments are categorized according to aggressiveness, ordinary/extraordinary means, withholding and withdrawing treatment and passive/active euthanasia. Each of these dimensions is culturally determined. There is variation in clinician conceptualization of characteristics of patient condition and treatment, the goals of treatment, and the norms for decision making.

The primary mode of research for this study was participant observation in a neonatal intensive care unit (NICU). Treatment choices in routine and problematic cases were observed and clinicians were interviewed to elicit information on factors relevant to the decision making process. In addition, clinicians from other NICUs were interviewed and meetings and conferences were attended. Documents in the clinical, legal, bioethical, social science, and popular literature were analyzed and a survey on treatment choice for catastrophically ill newborns was conducted.
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Treatment choice for catastrophically ill newborns is an intellectually complex, ever changing, and emotionally difficult topic. From the time that I began research on neonatal decision making nearly nine years ago, through the final production of this dissertation, a multitude of people provided assistance without which this work would not have been possible. I greatly appreciate the help of members of the groups listed below, as well as those individually named, who each made significant contributions to the final product.

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xi
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CHAPTER ONE

CARING CHOICES: INTRODUCTION

Recent advances in biomedical technology and practice have dramatically increased the ability to prolong the lives of critically ill patients. Although, in most cases, the use of life saving technology is seen as clearly beneficial, in some cases its use has been seen as inappropriate for it leads to suffering on the part of patients and their families. Clinicians, bioethicists and others have felt that traditional medical ethics have been inadequate to deal with the new technologies. Yet, daily, clinicians, patients, and families have had to made choices about the care of the critically ill.

While clinicians, philosophers, theologians and legal scholars have written much on issues concerning medical ethics and the care of the critically ill, social scientists have done little research on this topic (Fox 1984). As a result, much has been written on how decisions should be made, but relatively little research has been done on how decisions are actually made. Such research is important in at least two respects. It can contribute toward the development of social theory by providing a context in which to study the effects of rapid technological change on cognitive systems and behavior. Second, by providing an analysis which critically examines assumptions usually made in discussions concerning the care of the critically ill, it can contribute towards a resolution of ethical issues and the development of social policy.
Background to the Problem

This dissertation will focus on decisions in neonatology, the specialty which provides care to critically ill newborns. Much of the bioethics literature concerns treatment decisions in neonatology, for these decisions exemplify the ethical issues which arise from rapid changes in medical technology and practice. Recent developments have enabled neonatologists to save the lives of many previously non-viable newborns. While most of these newborns will have no lasting impairments, others will have severe disabilities. For still others, treatment can do no more than prolong the dying process. Decisions to limit treatment lead to the death of some babies, and the limitation of treatment affects the timing of death for others.

While the limitation of treatment has been an issue of concern to clinicians and bioethicists for over fifteen years, it has only recently emerged as a salient political and social issue, following the announcement of the Baby Doe Directives. These directives, issued first in the Spring of 1982, and subsequent revisions, represent the first attempt by the Federal Government to regulate treatment of the critically ill. Now, such questions as: "Which Babies Shall Live?" and "Who Should Decide?" are being widely discussed.
While much has been written concerning how decisions should be made in neonatology, there has been little examination of the basis on which decisions are actually being made. Most of the literature on the choice of treatment for the catastrophically ill infants has concerned ideal norms that the authors have felt should guide behavior, rather than the behavior norms which are important in guiding actual practice. (For a review of such work, see the President's Commission Report 1983; Weir 1984.)

For example, even those articles written by clinicians, based on series of cases (e.g. Duff and Campbell 1973), do not analyze the factors which have affected decision making, but rather are primarily concerned with recommendations for policy to affect future cases. Articles by philosophers have done much to explicate and evaluate the values and principles which underlie various positions (c.f. Arras 1985). Those by legal scholars present a range of positions concerning the applicability of laws pertaining to homicide, manslaughter, child neglect and discrimination against the handicapped (c.f. Robertson 1975; Ellis 1982). However, no previous study has examined the way that perspectives from the bioethical or legal domains have been incorporated into the process of clinical decision making to affect decisions in actual cases.

There is an extensive and growing social science literature on death and dying (Riley 1983; Palgi and Abramovitch 1984), on technology
in medicine (Fox 1976; Reiser 1978) and on clinical decision making (Elstein et al. 1982) but relatively few studies have focused on decisions to limit treatment. The most comprehensive study, by Diana Crane (1977), indicates that physicians' norms are changing; they are moving away from a purely physiological definition of life to one based on a social definition. "The treatable patient is one who, if treated, is capable of resuming his social roles even minimally and temporarily" (p. 11). In some cases, in which patients can't resume their social roles, treatment is withheld. Although not discussed in much detail in her book, Crane's data shows that even when some treatments were withheld, other treatments are provided (Crane 1975). Christina M. Mumma and Jeanne Quint Benoliel (1984) found that even when patients had conditions labeled by their physicians as either grim or terminal, and had been designated "no code" (they would not be resuscitated if their hearts stopped), they still received cure oriented treatments.

From research based primarily on participant observation in two neonatal intensive care units, Renee Anspach (forthcoming) found that "physicians and nurses, because of their [differential] experience in the intensive care nursery, differed systematically in their views of the infant's prognosis." These differences in views of prognosis affect their evaluations of future quality of life for the babies, and, in turn, their attitudes toward life and death decisions. No other study has focused on the conceptualization of such treatment decisions. Recently Guillemin and Holmstrom (1986) have published a study on neonatal decision making. It examines the social relations of parents.
and staff in the unit and places the development of neonatal intensive care within the context of the American medical system.

Medical anthropologists have studied the relationship of conceptualizations about illness and treatment behavior of healers in many Non-Western societies and the relationship of those conceptualizations and behavior to economic, political and social factors. Recent work by medical anthropologists and other social scientists interested in the social construction of medical work have begun to examine biomedicine as a sociocultural system. For example, Gaines and Hahn write:

Concepts, explanations, and prescribed reactions to conditions of health and illness are constructed in social interactions, both collaborative and conflictual; that is suffering, welfare, and responses to them are socially defined. These same conditions (and reactions to them) are also socially affected in another way: they are produced or caused by human social interactions which distribute the members of society and (other) resources in time and space and by activity. Pathogenic sources and resources for their amelioration are distributed in the same sociocultural process.

(Gaines and Hahn 1985:9)

Studies looking at biomedicine both in the clinical and wider societal context have looked at how clinicians and other members of society use cultural symbol systems "both as models of and for reality and action as well as examining how the material and social conditions of society shape the models (Gaines and Hahn 1985). As material and social conditions change, so too does the ideology and practice of medicine" (Colombotos and Kirchner 1986; Baer 1982).
A recent concern of some anthropologists has been to develop an understanding of the cognitive processes used in making decisions in various contexts. They have emphasized the limitations of using formal models of decision making to account for decisions made in natural settings. Instead, they have stressed the need to examine the structuring of decision choices, the organization of knowledge into meaningful cultural categories, the goals involved, and the contexts in which the decisions are made. They find that variation along these dimensions can be used to account for variations in behavior (Young 1983; Mathews and Nardi 1983).

Background to the Study

The research for this dissertation began in 1977 when I was invited to work for the "Task Force on Ethical and Value Issues in Neonatology." This interdisciplinary task force was composed of clinicians from the Neonatal Intensive Care Unit (NICU) of Columbia-Presbyterian Medical Center and academics from other parts of Columbia University. My work involved observing in the NICU and participating on the task force. I had very little previous knowledge about bioethics or experience in clinical settings, none in critical care. I had come with a background in anthropology and interests in reproduction, ethnicity and other subcultural differences, and technological and social change.

From a brief introduction to the bioethical literature and the popular media, where there had recently been many articles on Karen Ann
Quinlan, I thought that the ethical problems would involve decisions about "pulling the plug." I pictured this as a choice between giving "treatment" -- using all possible means to promote survival -- and "no treatment" -- the cessation of all treatment. I was perplexed to find that all treatments were never withheld; rather, for some babies who were catastrophically ill, some treatments were given which would increase the babies' chances for survival, while others were withheld. While I couldn't understand why only some treatments were being given, the physicians and nurses working in the unit seemed to feel that such partial treatment decisions were perfectly natural. When they explained what they were doing, they sometimes talked about patients, treatments, and choices in a way that I couldn't comprehend.

I hypothesized that not only, as Crane had found, were norms changing concerning which patients would be treated, but other norms and concepts were changing as well. In fact, I felt that I was dealing with a different subculture. Clinicians seemed to have an elaborate cognitive system to deal with the complex issues they dealt with daily, using concepts and norms which were somewhat different from those shared by most members of the larger society.

Here was a situation in which technology was changing very rapidly. Traditional norms were felt to be inadequate guides to

1 The ideological system used by philosophers, bioethicists, and others professionals who discussed the ethics of decision making in neonatology seemed to comprise yet another subculture in which questions were framed, and concepts were used in a way which seemed to be different from both those of the clinicians and those shared more widely by members of the culture.
behavior. Yet, clinicians had to make decisions about how to act. Their behavior was relevant to and, I assumed must be shaped by ideas about, some of the most critical concerns of our society including life, death and disability, suffering and mercy, parental and professional responsibility, the uses of science and technology, and the role of God and of human action.

Research in the neonatal intensive care unit seemed to provide an ideal setting in which to study sociocultural change in the wake of changing technology. My entree into the NICU also seemed to provide an excellent opportunity to study the ways that the people who had the most experience in dealing with deciding about care for catastrophically ill newborns thought about the factors involved.

Statement of the Problem

The research questions addressed in this dissertation are: How do clinicians conceptualize choices about limiting care in an NICU? What factors affect these conceptualizations? More specifically: How do clinicians choose which treatments to give and which to withhold from the range of possible treatments, in caring for catastrophically ill newborns? How do material and social factors affect the way that clinicians think about treatment choices?

In this dissertation, the manner in which clinicians structure decision choices, how they organize information into culturally relevant
categories and what norms and goals they use to guide treatment behavior will be explicated. This cognitive system, used to make treatment choices for catastrophically ill newborns, will be looked at as it takes place within the larger sociocultural system.

The dissertation reports on research which has investigated material and social conditions which may impact on neonatal care, in general, and those factors that pertain to the development and use of medical technology in particular.

More generally, this dissertation illuminates issues relevant to anthropological research on decision making, intracultural variability, and social change. It is also intended to provide substantive information on decision making about the critically ill which may be of use to clinicians, bioethicists, and others interested in critically evaluating clinical practice and developing social policy.

Discussion of Terms

Catastrophically Ill Newborns

The dissertation concerns the treatments of catastrophically ill infants, babies who are ill and whose illness or condition is socially defined as a catastrophe, (a disaster, calamity or serious unfortunate occurrence) by his or her family and/or professional caretakers.)
That term is used, as opposed to other terms sometimes used to refer to such infants, such as anomalous, damaged, deformed, defective or disabled, because those terms seem to imply that it is the physical state of the child which defines the problems. Catastrophically ill defines a social rather than a physical state, as the term "illness" may be used to refer to a social entity in contrast to a "disease" which may be defined as a biological entity (Fabrega 1979).

A child may be defined as "catastrophically ill" because of the presence of a serious illness, prematurity, and/or present or future expected impairment. Not all children with the same physical conditions will be defined as catastrophically ill. Catastrophically ill infants include, but is not limited to, infants who are critically ill. It also includes, but is not limited to, those infants for whom caretakers consider the limitation of treatment.

Treatments

In this dissertation, the term treatment is used broadly to refer to anything that a clinician does to promote the health of a patient. It includes such things as therapeutic and diagnostic medical and surgical procedures, drugs, provision of fluids and nutrition, use of isolettes or dressings to maintain a sterile environment, and social interaction intended for the benefit of the patient.
Clinicians

The term "clinicians," when used without qualification in this dissertation, refers to the physicians and nurses who work in neonatal intensive care. It is used to refer to individuals who share a knowledge base as a result of socialization in these medical and nursing specialties - neonatologists and neonatal nurses. It is also used to refer to other physicians (e.g. residents, pediatric surgeons) who work with catastrophically ill newborns.

The clinical model

The focus of this dissertation is the development of a model for use in elucidating clinicians' conceptualizations of treatment choice. Clinicians do not appear to use a single conceptual model. The model developed here can be used to understand the range of factors felt to be important by clinicians, their norms and their goals.

It is an analyst's model used to understand the actors' cognitive system. It was derived from observation of clinicians' behavior, including treatment choices and explanations of why those choices were made. It includes concepts meaningful in other domains, such as law, religion, and bioethics, as they are significant to clinicians. The model is comprehensible to clinicians and acknowledged to be a representation of relevant factors.
Methodology and description of the site

This dissertation is based on data collected by a variety of methods. The principle source of data has been participant observation, mostly in one neonatal intensive care unit. In addition, a survey of attitudes about neonatal decision making was conducted, and documents were examined from the clinical, bioethics, legal and popular literature. A more detailed account of aspects of methodology appears in the appendix.

Description of the Site

Most of the research for this dissertation was conducted in the Neonatal Intensive Care Unit (NICU) at Columbia-Presbyterian Medical Center. It is one of the most modern looking areas of the hospital complex. Formerly a small, dark unit on the second floor of the aging pediatric hospital, the unit was moved into newly renovated quarters on the top floor in 1974. In 1983, the other half of the floor was renovated and the labor and delivery area was moved from another floor in an adult wing of the hospital to be adjacent to the NICU.

From the large windows surrounding the neonatal unit, one can look out over much of Northern Manhattan, Harlem and the South Bronx, home to many of the families of babies who are admitted to the unit. Other
babies' families come from other areas of New York City and Northern New Jersey, Westchester, and Southern Connecticut. About 55 babies a month are admitted to the unit, about 60% born in the hospital, 40% from other hospitals in the City and suburbs. About half of the infants are private patients, the other half are "service," usually Medicaid, patients. As is typical of the New York City patient population, most of the private patients are White, many of the service patients are Black or Hispanic; some of the service patients are the children of very young mothers.

The unit is built in two main sections, a nine bed acute care unit for infants needing maximal care, and a twenty-four bed semi-acute unit for infants discharged from the acute section and other babies needing less acute care. The unit usually runs "over census;" all of the beds are usually filled, with additional babies sometimes sent down to other floors where the normal newborn nurseries are located. On "the floor" (the term used to refer to the entire unit) there are additional rooms

2 All specific figures and descriptive information refers to the period of most intense field work, the "ethnographic present" for this study, 1982. Over the course of the research period, there were some changes in organization and structure. For example, work patterns of house staff and nurses changed as did the administrative structure of the hospital. The number of admissions rose from about 500 per year in 1977 to about 700 per year in 1985). None of these institutional changes had major significance for the problems addressed by this research.

During the period of research, there were some significant changes in the treatments available and their use. After the completion of the primary data collection period, in the Spring of 1983 the Baby Doe Regulations were widely publicized; in December of 1983, a Neonatal Ethics Review Committee was established. Each of these may have had a significant impact on the way that decisions are conceptualized and/or made. When the time of data collection is significant, it will be noted in the text.
for physicians and nurses offices, a social worker's office, a staff lounge, research labs, offices for a follow-up study, a parent lounge, a breast feeding room, and utility rooms. One room in the labor and delivery suite, a "transitional nursery" for care of infants immediately after birth, is also part of the neonatal service.

The acute care unit is a single large room separated by walls and doors from the rest of the floor. The room is built around a central nurses station. The sickest babies are admitted to this section first. Almost all babies are in isolettes, plastic walled "incubators" with port holes on the side through which clinicians can provide care and their parents can touch them. Some of the babies can be taken out and held by nurses or parents for feedings or rocking, but most babies in this unit are very sick and remain in their isolettes, lying still most of the time, dressed in only a diaper or nothing at all.

The majority of the babies admitted to the unit are premature (below 37 weeks), many are very premature, very low birth weight (under about three pounds), some with less than 25 of the normal 40 weeks gestation. There are also a number of babies with cardiac conditions, with other congenital conditions, and infants who have suffered birth accidents or for other reasons are seriously or critically ill.

All of the babies are attached to monitors which continually beep and frequently sound alarms when there are irregularities in a baby's heart beat or quirks in the machinery. Most of the babies need
respiratory support and are attached by tubes to machines, respirators\(^3\) (sending bursts of air to the baby's lung) or CPAP (delivering a continuous flow of positive pressure air to assist breathing). Most of the babies have IVs, some more than one. Many of the infants have stuffed animals, other toys, pictures of family, or religious objects that their parents have placed in their isolettes.

Numerous times each day, nurses draw blood by pricking the babies' heels or doctors draw blood by IV which is checked in a small lab adjacent to the unit or sent downstairs for more elaborate tests. Technicians wheel portable X-ray equipment into the unit so that the conditions of baby's lungs and the placement of tubes can be examined. Portable ultra-sound equipment is also used frequently to see if the babies have had bleeding in the brain. Almost all of a baby's treatment, including minor surgical procedures, takes place in the unit. As results of tests come in, they are noted and discussed and adjustments are made in the care of the babies.

The semi-acute section is more crowded. While some of the babies are also very sick and are in isolettes, attached to monitors, respiratory support and IVs; others are not as sick and are in open basinettes, dressed in tee shirts and wrapped in blankets. Most of these babies can be held for feedings. Although the babies in the acute section rarely smile or cry, these healthier infants are more animate. Some of the babies started in the acute section, others are larger

\(^3\) The correct term for such machines is "ventilator", but they are commonly called "respirators". They will be referred to as respirators throughout this dissertation.
premature infants, children of addicted mothers, babies who are stable awaiting or recovering from surgery, or who have other conditions that generally are not as critical as those of babies in the more acute section. Occasionally, a terminally ill baby might be on the semi-acute side if it is not felt that more intensive care would be of benefit.

The average baby stays about 19 days. Premature babies generally stay until close to their due date (i.e. three months for a baby born at 27 weeks). Much of the time is spent "growing" on the semi-acute side. If a baby has serious complications, however, the stay can be much longer. In rare cases, babies have lived for years in the NICU and then have died there. The mortality rate for the entire floor is about 8%, or about one death per week. The vast majority of babies go home with no significant problems. The costs of care are approximately $1000.00 a day.

While the first impression that strikes a visitor is probably the high technology character of the floor, the atmosphere is not cold or stark, but bright and busy. There are many people involved in providing care to each baby. Though the unit is busier during the day, many clinicians are there each night, weekends, and holidays. The nurses and the house staff (residents and neonatal fellows) deliver most of the direct care.

The clinicians working in the NICU care very deeply about the well being of the babies. They realize that many of the decisions they make each day could be crucial in determining a baby's future health and/or
survival. The majority of decisions are seen as "medical" or "nursing" decisions, but the clinicians are keenly aware that many are "ethical decisions" as well. Many clinicians are involved at various levels in making decisions about the care of each baby. Most routine decisions are made by the house staff and nurses, attending physicians establish the standards and either make or sanction the majority of the most important decisions. Most doctors and nurses who work in the NICU are very dedicated to their work; many spend innumerable hours beyond that officially required, watching over and caring for critically ill babies.

There are about 100 nurses on staff. A nurse can take care of only one or two babies at a time in the acute care unit; they can usually care for three or four on the semi-acute side. The nurses monitor the babies' condition, do some tests, give medications, feed and clean the babies, and provide support to the parents. The nursing leadership on the floor is comprised of a nursing care coordinator, two head nurses, assistant head nurses and an educational coordinator.

Nurses make independent nursing care decisions and carry out doctors' orders concerning medical management. Many of the neonatal nurses are highly trained and have worked for many years in neonatal intensive care. They often know more about neonatal conditions and treatment modalities than some doctors, especially the residents, and frequently know more about the families. Although they are not licensed to make medical decisions, their knowledge is usually respected and they are sometimes very influential in decision making.
Two second year residents are "on rotation" each month to care for the babies in the acute unit. One third year resident and three first year residents care for the babies on the semi-acute side. At least one resident is present to take care of the babies on each side round-the-clock. They devise the everyday care plans for the babies, in consultation with more senior physicians. They write the orders and carry out most medical procedures. They also care for sick babies immediately after birth in the delivery room. In addition, at all times at least one of the eight neonatal fellows (doing 2 years post residency training in neonatology) is working on the floor or helping to transport sick babies to the unit. They perform some routine and many of the more complicated procedures both in the nursery and at delivery. They help to teach and supervise the care given by the residents. Both residents and fellows talk to parents about the care of their infants.

One or two of the ten attending neonatologists are "on service" each month. They may leave the hospital, but an attending is always "on call"; they frequently return in the middle of the night. They are the people primarily responsible for overseeing the clinical care on the floor. While the more junior physicians make most of the routine decisions, except in an emergency situation, attendings play a major role in making major decisions.

Although parents may choose another doctor, the attending physician on service becomes the private doctor for most patients admitted during the month. Service patients, as well as private patients, have an attending physician. While the care provided by the
nurses, residents and fellows is the same for private and service patients, attendings frequently are more closely involved in following the care of their private patients and frequently spend more time talking to their parents.

In addition to the neonatologists, physicians from other services are involved in the care of the infants. Columbia is relatively unique among neonatal units in having a full time anesthesiologist who oversees the respiratory care of the infants. As in other centers, physicians from Cardiology, Cardiac Surgery, Pediatric Surgery, Infectious Disease, Neurology, Neurosurgery and other services, are frequently involved in the care of infants. Sometimes babies are the patients of doctors from other services, then these doctors may make major decisions, more often they serve as consultants to the neonatologists who are the primary decision makers. Neonatologists often serve as consultants to obstetricians who make decisions before a fetus is born. Once the baby is born, typically the obstetricians are not involved in the baby's care.

A full time social worker is assigned to the unit. She provides psychological support to parents and helps them obtain services. In some units social workers are very involved in decision making. At Columbia, at the time I did field work, the social worker didn't become involved at all in treatment decisions. Numerous technicians also are involved in the infants' care, taking X-rays, doing EKGs, etc. They too, do not play a role in decision making.
Officially, parents have the legal right and responsibility to make health care decisions for their children. The ideology of the unit strongly supports the importance of parental decision making. In actual practice, however, since the parents typically have little previous knowledge about their baby's conditions and the options for treatment, they are very dependent on information from the clinicians; the ways that clinicians frame treatment decisions are very important in determining what treatment choices are made. In general, parents did not spend more than a few hours a day in the unit, many were there much less.

Research Strategy

In conducting field work, my primary research strategy was to observe and record ongoing behavior. I watched and recorded information as nurses and physicians delivered direct care to the babies and conducted diagnostic tests. I read and recorded information from the hospital charts, the nurses' Kardex, and other unit records. I followed the physicians as they conducted work rounds and sign off rounds, as they twice daily discussed the care of each baby. I attended the nurses "report" where they discussed the care of each baby at the change of each shift. I observed daily teaching rounds where the care of a particular baby or for a particular problem were discussed, weekly perinatal and social service rounds, and monthly mortality and morbidity rounds. I attended special meetings of physicians and nurses called to discuss the care of infants who presented particular problems. I
watched approximately 15 births and observed care in the transitional nursery immediately after birth for at least twice that number of babies. I attended a memorial service. I observed minor and major procedures including surgery and cardiac catheterization. I observed in the follow up clinic and attended "alumni" days when babies who "graduated" from the unit returned for a yearly picnic. I spent a lot of time in the staff lounge, and in other settings, where informal conversations about the babies took place.

Early in my research, I decided that I would focus on the behavior and conceptual system of clinicians. I decided not to conduct regular interviews with parents or plan to observe private conversations between parents and clinicians. At the suggestion of clinicians, I did conduct long interviews with three mothers and had shorter conversations with a few others. In the course of my observations, I did overhear and observe numerous conversations with parents and other family members in the unit. I conducted extended interviews with some parents I encountered through personal connections who had infants cared for in other intensive care units.

When I first started my research, I felt that I know too little to impose on families who were going through such a traumatic time; later I realized that many parents would like an opportunity to talk with someone about their experience. By then, however, I had decided to concentrate on understanding the perspective of the clinicians. Working with parents would have changed the nature of the research.
Over the course of fieldwork, from 1977 to 1985, I spent approximately 1300 hours in the unit at Columbia. Most of time I wore a white lab coat, the type worn by fellows, attendings and the nursing leadership as well as research scientists. Sometimes I would "hang out" at the nurses station in the acute unit, reading charts, going over to listen as a group of clinicians would discuss a case. Other times I would follow a single clinician as he or she worked. When I talked to a new clinician, I would introduce myself as an anthropologist interested in studying how decisions were made in neonatology. I wore a name tag that had my name on it and "Division of Sociomedical Sciences." At times, I became a familiar fixture in the NICU, fading into the background of familiar faces in white coats. Often, when I followed a clinician to another location or a new person came into the unit, they probably assumed I was a doctor, nurse, visitor, student, or one of the many other types of observers common in the teaching hospital.

Despite my efforts to keep a low profile, and to make it clear than I was interested in understanding behavior, not judge it, my role was often misunderstood. I was sometimes referred to by terms such as "the ethics lady." For years, one attending, not really joking, referred to me as a "spy." Sometimes as I would walk into the unit, someone would say "Here's a real case for you" or something else that would make clear that I represented the gaze of "ethics;" generally, however, I think that the clinicians ignored my presence and did basically what they would have done if I wasn't there. They were very busy and had important work to do.
Sometimes I would sit down and have long conversations with a clinician about a particular case or issue. Over the years, the director of the nurseries, two attending physicians, an assistant head nurse (who now works in another NICU), a clinical nurse specialist, the educational coordinator, the nursing care coordinator, and a former NICU nurse/Assistant Professor at the Nursing School became my key informants. Their help has been invaluable in exploring the issues in neonatal decision making in depth.

I was fortunate in that my observations in the unit had started at the invitation of the task force; in the words of Charles Bosk, I was an "invited guest" (Bosk 1985). I was never denied access to any situation I asked to observe. I promised that I would not reveal the individual identities of clinicians or babies I observed. For years, the staff tolerated my presence before I revealed my own opinions about the issues about which I had interrogated them. I gave the first real feedback on my observations in 1983, after I had finished the most intensive part of my field work. I had assumed I would use a pseudonym for the hospital. When I showed a paper I had written, to the Director of the unit, in which I had used vague terms to refer to the hospital, he requested I identify it in my papers; academic medicine is exactly that - academic as well as medicine.
Significance

While the cognitive processes involved in decision making have been studied extensively in the laboratory by psychologists and others, there has been relatively little research on the cognitive processes used by people to inform behavior in natural settings (Mathews and Nardi 1983). There has been even less research on variation in cognitive systems in natural settings. Although there have been many studies of social change, both in the situation of culture contact (e.g. Spicer 1961), and evolutionary change in sociocultural systems (e.g. Steward 1955), there has been little research on relatively small scale indigenous social and technological changes and variation and change in cognitive systems. This research is intended to provide data and analysis of variation in a natural setting in the use of norms, categories and goals. It is also intended to investigate the impact of material and social changes in the larger context on changes in conceptual systems.

During the past few decades, issues of biomedical ethics have emerged from relative obscurity to become a "primary medium through which fundamental aspects of our social, cultural, and cosmic way of thinking, feeling, and believing about ourselves, our society, this planet, and the universe are gradually being altered" (Fox 1980:45). The current debate about treatment for catastrophically ill newborns reflects unresolved issues in our culture concerning ethics and values in regard to the definition of life and personhood, the value of children, obligations to dependent persons, and the appropriate use of
technology. This study provides information on aspects of treatment choices for the critically ill which have received little attention but which have crucial individual and societal implications.

It is intended to be of use in trying to resolve the ethical and value issues concerning the care of the catastrophically ill. The current level of biomedical technology creates a situation in which decisions must be made concerning the prolongation of life and the timing of death for many critically ill patients. As the power of the technology increases, the potential economic and social costs can only increase. The implications of the situation have not been fully faced by many clinicians, nor by society at large. Information on how such decisions are made may help to clarify the conscious and unconscious basis for decision making in clinical practice and can be useful in the profession and public debate on these issues.

Outline of the Dissertation

The second chapter of this dissertation examines the issue of treatment choice for adults. It provides cross cultural and historical information on the withholding of medical treatment and a review of the legal, ethical and sociological literature on the issue.

The third chapter examines the development of care for newborns. It provides a brief cross cultural and historic survey, and examines factors leading to the development of neonatal intensive care. Factors
leading to concern about the issue of withholding treatment from newborns are presented and the legal, ethical and sociological literature is discussed.

The fourth chapter examines categorization, goals, norms and decision making. Theoretical concepts are discussed and examples drawn from medical and other settings are provided. The use of these concepts to examine neonatal decision making is introduced.

In the fifth, sixth, and seventh chapters, the conceptual system of clinicians is examined in detail. Clinicians' conceptualization of characteristics of patient condition, characteristics of treatments, and goals and norms for care are presented. General areas of consensus and controversy are explicated. Examples drawn from participant observation and from the survey are discussed.

In the eighth chapter, recent changes in the conceptualization of decision making and treatment behavior are explored in more depth. Then the first published debate on decision making for newborns, variation in the treatment infants, changes over time in the treatment of infants with spina bifida and those who are premature are discussed. Perspectives on the Baby Doe regulations and clinicians interpretations of the regulations are presented and general trends in changes in decision making are discussed.
In the final chapter, the dissertation is summarized and conclusions are presented. Theoretical and substantive implications of the study are presented as part of a discussion of problems for future research, and of decision making and social policy.
CHAPTER TWO

UNPLUGGING THE MYTH:
BACKGROUND TO WITHHOLDING TREATMENT

The ethical issues involved in withholding medical treatments from critically ill patients are often presented as a new problems attributed to amazing progress in the ability to support life which has occurred during the past thirty years, or, to declining social values. The issue has certainly gained salience, and there are new dilemmas due to new technological developments. Questions concerning the aggressiveness of treatment for critically ill patients, however, have probably been raised as long as there have been efforts made by humans to prolong life. Questions have been debated in the Western medical and philosophical traditions prior to the recent medical advances.

This chapter will begin with an historical sketch of some of the issues pertaining to choices about the aggressiveness of treatment for adults. Information on laws and current practices will also be presented. Participant observation and chart review studies of the care of the terminally ill and surveys of decision making about the withholding of treatment will also be reviewed.
Euthanasia - Cross Cultural and Historical Perspectives

In every culture, healers and or family members make decisions about how to care for critically ill patients. Each culture has a range of available techniques and must decide which are appropriate in a given situation. Although systematic cross cultural data on this issue is scarce (Kunstadter 1980), it seems reasonable to suppose that healers and family members may consider such factors as the potential risks, suffering, and resource use (as culturally defined) in making decisions about how to treat patients (Christine Paddock, personal communication 1983; Young 1983).

Decision making about withholding treatment can be thought of in the context of possible acts toward a critically ill patient. One can consider four types: 1) acts to prolong life, for the benefit of the patient, 2) acts to end life, for the benefit of the patient, 3) acts to prolong life, to harm the patient, and 4) acts to end life, to harm the patient. Those that fall in the second category, those intended to bring about death for the benefit of the patient, either by acts of omission or commission, can be thought of as euthanasia, that is, a "good death."

In many primitive cultures, shamen were seen as functioning both to heal and also to harm, in some instances, causing death. In some situations, healers may have used preparations to hasten and or ease deaths which could not be prevented. The fact that the Hippocratic Oath dictates that physicians shall not do anything to actively bring about
death, probably means that such requests were made, and that healers in other contemporary traditions were perhaps engaging in such practices.

According to David Amundson (1974), the Hippocratic Corpus defines medicine as having three goals: 1) Doing away with suffering of the ill, 2) Lessening the violence of their ailments, and 3) Refusing to treat those who are overmastered by their diseases. Decisions were often made not to treat based on the belief that the medical arts could not be of help, and might even lead to patient suffering or hasten death. The option to treat or not to treat was up to the physician. Decisions were based primarily on prognosis. Prolonging the life of an individual who could not ultimately recover was seen as unethical.

The conceptions of death have been very different in different cultures and through time in the Western Cultural tradition. For example, while in the contemporary Western imagination death is often seen as a deep violation against the proper order of things, rather than as part of that natural order, other cultures have a very different view. (Carse 1978; Palgi and Abramovitch 1984). The meaning of efforts to extend life will vary with beliefs about death as well as with changes in political, economic and social changes in society.

A distinction between ordinary and extraordinary treatments have a long history. In the 16th and 17th centuries, Catholic theologians, such as St. Alphonsus and Paul Laymann held that "no one is held to extraordinary and very difficult means to preserve his life, such as the
amputation of a leg, unless his life be necessary for the common good (O'Donnell 1956:57).

A traditional role of the physician was often to provide comfort and assistance to the dying. In part, this involved recognizing the point in time at which the patient could be said to be dying so that the patient could deal with unresolved social or spiritual issues. From that point when the patient was defined as dying, the physician was not to do anything which might be seen as causing suffering. Most often, deaths were the result of infectious diseases or accidents, and occurred rapidly (Aries 1974; Reiser, Dyck and Curran 1977; Gruman 1978).

19th century issues relating to euthanasia

Fry, in his article on the history of euthanasia, traces the change in the use of the term "euthanasia." At first it was used for "spiritual euthanasia" referring to the state of mind at the time of death. Between 1870 and 1890 the current connotation emerged; since then it has been used for the giving or omitting medical treatments to bring about "a good death" to relieve suffering. Yet even earlier, "euthanasia" was sometimes used to refer to decisions to forego treatment. There had been debate about the use of "heroic" medicine in the early 19th century. Fry paraphrases a paper published in 1829 by C.F.H. Marx entitled "De euthanasia medica prolusio," in which the physician author urged his peers to:
... accept responsibility for his patient's 'spiritual euthanasia.' This is to be accomplished by providing physical and moral comfort and by avoiding the use of heroic medications which are likely to be worthless.

Yet Marx clearly differentiated this from acts meant to hasten death, which he felt would not be consonant with the physician's mission to save life.

(1978:494-5).

In addition to stopping the useless treatment of terminally ill patients, within the medical profession, earlier technological developments have also led to situations in which practitioners have had to deal with questions concerning conflicts between the traditional medical goals of relieving suffering and preserving life.

Before anesthesia was developed, surgeons had to consider the ethical issues involved in deciding if the benefits of surgery would justify the pain. When anesthesia was first introduced, and its use was very risky, there were debates about the ethics of risking death for the relief of pain. It was resolved by what Pernick refers to as a "moderate utilitarian measurement to pros and cons, a calculus of suffering" (1983). The end of the 19th century through the 1930's saw a debate on the issue of active euthanasia which was advocated by some physicians (Reiser, Dyck and Curran 1977). A majority of physicians rejected the notion that their role should be to actively end life. The debate concerning the ethics of giving pain medication for the purpose of relieving suffering which, as an unintended but not unforeseen consequence might shorten the life of the patient, extended past the middle of the 20th century (Fry 1978; Reiser, Dyck and Curran 1977; Williams 1957).
Rise of the Technological Imperative: the Battle Against Death

The debate concerning active measures taken which would cause death did not involve a significantly different situation in earlier periods than it does today. As a result of recent technological developments, however, questions concerning the cessation of treatments intended to prolong life do take place in a significantly different context. In the past, the power of clinicians to actually prolong the lives of critically ill patients was very limited. In this century, especially since World War II, the power of medicine to significantly prolong life has increased greatly. Whereas, in the past the withholding of life saving treatment made little difference, it can now have a significant effect on survival.

Although much of the reduction in mortality actually occurred because of improvements in diet, sanitation and other preventive health measures, the great reduction in mortality rates from infectious diseases led to great faith in the power of scientific medicine. There was optimism that medicine could conquer disease, and hope that a new cure to many diseases lay just around the corner. The aggressive application of life saving and life prolonging techniques became the rule, often with the hope that if a patient could be kept alive long enough, a new cure would be found.
Indeed, during the post World War II period, the widespread use of recent medical advances have greatly increased the ability to prolong the lives of patients, with the use of such low technology interventions as antibiotics and blood transfusions, as well as, resuscitation and life support techniques. A "technological imperative" developed. Physicians generally accepted the ethic that what ever could be done, should be done (Silverman 1980; Aries 1974; Carse 1978). Medicine was seen as a battle against disease. Militaristic metaphors were used frequently (conquer death, win the war against cancer, magic bullets, etc.) Death became increasingly defined not as a natural event, but as was a technological failure. For example, in 1972, Moser wrote:

To the physician, death is the enemy -- the implacable ultimate foe -- the symbol of failure, ever lurking in the wings, ever hovering near the critically ill patient. The missed diagnosis, the resistant microorganism, the hidden malignancy, the irreversible degenerative lesion -- all represent familiar catacombs. As physicians we accept commitment to the life long conflict. Every instinct, drive and desire -- every intellectual and emotional sinew, has been trained to defeat death.

(Moser 1972:43)

Death was seen as a "medical defeat' either for the physician personally or for the 'state of the art'" (Parsons, Fox and Lidz 1972:396; Levine and Scotch 1970:211).

Anecdotal reports suggest that even during this most aggressive period, in fact, at times, less than the most aggressive means were used (see Chapter III). The questions of which therapies were appropriate have always been culturally determined. Generally, however, the axiom
that the physicians' role was to "preserve life" went unchallenged. At the structural core of contemporary medical ethics was an absolutizing of the value of preserving life (Parsons, Lidz and Fox 1972:395). What was later perceived as a contradiction between the goals of preservation of life and relief of suffering was not recognized as an issue.

While the debate continued about active euthanasia, "passive euthanasia" was not yet seen as a particularly troubling problem. For example, based on a series of lectures he delivered at Columbia University Law School, Glanville Williams wrote about four types of euthanasia:

1) fatal injection, enabling the patient to commit suicide,
2) administering a fatal dose of a drug intended to relieve pain,
3) aiding suicide, and
4) omitting treatment.

Out of 39 pages of text, only one paragraph addresses the fourth type:

(4) We come finally to the problem of killing by inaction. "Mercy killing" by omission to use medical means to prolong life is probably lawful. Although a physician is normally under a duty to use reasonable care to conserve his patient's life, he is probably exempted from that duty if life has become a burden to the patient. The morality of an omission in these circumstances is conceded even by Catholics [reference to Joseph V. Sullivan: Catholic Teaching on the Morality of Euthanasia (Washington, D.C., 1949 p. 64)].

(Williams 1957: 326) Very soon after Williams' lecture series, questions about "omitting treatment" were to emerge as a major social issue.
The Crumbling of the Technological Imperative:

Cultural Contradictions and Technological Choice

A number of factors contributed to the emergence of concern about withholding treatment as a social issue. It developed, in part, because of a perceived contradiction between the goal of medical treatment to save life, and the goals to relieve suffering and to do no harm, seemed to come into contradiction when patients were saved, only to have a poor quality of life. The problem came to be seen as one of inappropriate use of technology. The ethics of limitation of treatment began to be debated in the clinical, legal, and philosophical arenas. The roots of this issue lie both in the technological changes and ideological currents of this period.

Changing Definitions of Death

One often sees the emergence of ethical issues about withholding treatment attributed to technological developments in the ability to provide life support. While not the only factor, it was certainly one of the most important. Previous developments of other new treatments which saved patients with conditions which had been terminal (such as giving insulin to save a patient in a diabetic coma) has also been perceived as bringing a patient "back from death" (Parsons, Fox and Lidz
The development of techniques of resuscitation, however, has an unrivaled effect for they led to the transcendence of the traditional, universally accepted, definition of death.

Since the invention of the stethoscope in the middle of the nineteenth century, controversies about the determination of death had been laid to rest. (Pres. Comm 1981:14-15) Death was defined as "the apparent extinction of life, manifested by absence of heart beat and respiration" (Dorland's Medical Dictionary 1965:387). The development of artificial means to support cardiopulmonary function, such as the respirator, pacemaker and the development of drugs and other forms of stimulation for cardiac resuscitation, was felt to make such traditional definitions obsolete.

Efforts were made to develop new definitions. For example, "clinical death ... when the heart or the lungs or both cease to function" was differentiated from "biological death" which was thought to occur when irreversible changes in the organism lead to the disintegration of vital cells and tissues" (Wasmuth and Wasmuth 1969:352). The feeling developed that, in certain circumstances, efforts to postpone such biological death should cease and be replaced with "more fitting and respectful behavior when a patient has become a dead body" (Pres. Comm. 1981:24). According to Wasmuth and Wasmuth, the question became not "When is the patient dead?" but rather, "When shall 'treatment' and 'more critical support' be withdrawn?" (p. 352).
Although not the main impetus, another important factor compelling the need for a new definition of death, was the development of the capacity for organ transplantation using cadaver organs (kidneys in the 1950s and hearts in the 1960s). (Pres. Comm. 1981:23)

In 1959, several French neurosurgeons coined a phrase, "coma depasse, translated as "beyond coma" to refer to the condition of some respirator dependent patients in which there was a permanent loss of brain function and physiological changes in brain tissue. Since then, numerous criteria and guidelines have been developed for defining and certifying "brain death." One of the most influential was the "Harvard Criteria," published in 1968. (Ad Hoc committee of the Harvard Medical School to Examine the Definition of Brain Death 1968).

Dialysis and Questions About Chronic Life Support

In addition to seeing resuscitation or life support as detrimental in those circumstances where life is prolonged after "brain death" had occurred, the benefit of heroic treatment was questioned in other situations as well. For example:

As one physician from the Seattle dialysis program reflected 'Doctors now find themselves able from time to time to enter a grey, limbo-like area where they are able to prolong life without however, being able to cure the disease or heal the injury ... the first great anxiety, then, that one faces in approaching the question of hemodialysis is whether from the patients point of view the whole procedure will turn out to be a blessing or merely a labored and painful hanging onto life.' [C. E. Norton, 1967]

(Fox and Swazey 1974:203)
Now the ability to provide chronic treatment for what had been terminal conditions created a new class of chronically ill patients who were maintained by what has come to be called "artificial life support."

In part, the perception of a class of treatments as "artificial" and of questionable benefit may be due to the rapid rate of medical developments and their invasiveness. While the first artificial kidney had been developed in the 1940's, hemodialysis could only be used on a short term, intermittent basis. Later, cannulas (tubes) were implanted allowing chronic dialysis in 1960. When the first center opened in 1962, it only functioned on an experimental basis. This new technology could only be made available to a few of the potential patients. A combination of medical and social criteria were used by centers to judge the suitability of candidates such as willingness to cooperate in treatment regimen, medical suitability, and absence of other disabling disease (Fox and Swazey 1974:230). Although the procedure of using a committee with non-clinician members to select patients and the publicity about decision making was a radical departure from past practices, the idea of selecting patients who were felt to have the best chance of benefiting from a new "radical" procedure was usual for utilizing an experimental procedure. As more facilities were developed, and especially after federal support for kidney dialysis was obtained, selection thresholds were lowered and people who would not have initially been seen as candidates, were treated.
Even during the early selection period, however, some patients who were recommended as appropriate candidates, declined treatment and others choose to discontinue after a period of dialysis (Fox and Swazey 1974 [1978]:260-65). Such refusal of treatment forced physicians and others to confront the fact that some people including some who would not be terminally ill with treatment, would choose to forego treatment and die, rather than live with the assistance of chronic treatment.

Public Concern With the Management of Dying

The late 1960s and early 1970s brought a growing public awareness of the changes which had taken place in the nature of medical treatment and the social context of dying. Social commentators noted that "death" had become a "taboo subject." Many felt there was a need to reexamine "death and dying." It became a subject for social inquiry, leading to such classic works as those by Feifel (1959), Sudnow (1967), Glaser and Strauss (1965 and 1968), Brim et al. (1970), Kubler-Ross (1969), Ariès (1974), as well as hundreds of articles, lectures, and conferences. This led some to comment that like "sex," this "taboo subject" had become focus of widespread attention.

One of the major changes in the social situation surrounding death was that increasingly, people were dying in hospitals and other institutions, rather than at home. While in 1949, slightly less than half of all deaths occurred in institutions, by 1967, almost three quarters (73.1%) of all deaths occurred in institutions (Lerner 1970:22-
23). By the mid 1980's, 80% of deaths occurred in institutions (Malcolm 1986).

There was also growing awareness that the reduction in the rate of death from infectious disease which led to a longer life span, led to an increase in survival with chronic conditions. Lerner wrote that people "survive today to a much later age, only to succumb in due time to their degenerative conditions (Lerner 1970:16). Such conditions were recognized as the new leading causes of death and were seen to compromise the quality of life.

With chronic diseases and life supports, terminally ill patients could be kept alive for long periods of time, although not forever. This led to concern about the "management of dying" (Levine and Scotch 1970). The then common practice of concealing prognosis from the dying patient was challenged and changed (Noyes, et al. 1977). Dealing with the dying patient as more than the bearer of a disease, and instead, as a whole person, was encouraged. This was done not only for the benefit of the dying patient who could then be helped to deal with the anxieties, hopes and fears of the last stage of life, it was also encouraged for the benefit of the living, who it was felt could learn about the functioning of the human mind and about the essence of human existence (Kubler-Ross 1969). The notion of "death with dignity" became a positive image of death to contrast with the negative image of death as always representing a failure.
The increased role of technology in the care of the dying was seen as an issue. At first, it was seen primarily as a medical problem: How far should the physician go in keeping the patient alive? Such decisions, however, could not be made on physiological grounds alone. Either implicitly or explicitly, social definitions of life and social characteristics of patients were playing an increasingly important role in decision making about treatment for the critically ill (Crane 1975).

As the psychological, social, and economic implications of the use of technology were realized, it increasingly was seen as a social problem. Issues of the psychological state of the patient who loses control, implications for the relationship of the patient to his physicians and family, the increasing costs of care, and questions of the allocation of resources between categories of patients were all seen as problematic (Levine and Scotch 1970).

Wider Social Concerns Impacting on the Use of Life Prolonging Technology

By the late 1960s and early 1970s, there were other issues of wide social concern which were to have an impact on the care of the dying. Three of the most important will be discussed below. The first was a concern about the power of professionals versus individuals to make decisions which affect those individuals' lives. The second was a concern about the use of technology. The third was a concern about rising costs of health care.
Concerns about Professional Decision Making

During the 20th century, the "professional expert" had come to play a central role in many areas of life. Whereas previously, the family and religious leaders had played most of the key roles in such areas as socialization of the young and care of the sick, in the 20th century, professionals in education and medicine had come to make major decisions affecting the lives of many more individuals. Professionals in industry and the military were making decisions affecting millions. Up until the 1950s, the benefits of professional expertise generally went unquestioned. However, in the late 1960s and early 1970s, perhaps as an outgrowth of the civil rights movement, there was a wide spread challenging of traditional authorities in such diverse areas as the anti-war movement, movements for community control of schools, ecology, increased power for students, laity in the churches, consumers, and welfare mothers. The slogan "Power to the People" characterized movements for social change to give many who had previously been subjected to professional authority, more autonomy in decision making.

One area where the questioning of traditional authority was to be focused was "patient's rights." In the health arena, there was the beginning of the women's health movement, abortion rights, and the natural childbirth movement. Medical research, which had previously been largely dependent on the discretion of the researcher, became subject to review both by other researchers and by "outsiders."
Paternalistic practices which sanctioned the withholding of information from patients was challenged. The medicalization of deviance control and the treatment of the mentally ill was questioned. The basic assumption guiding much of the behavior of physicians and patients, that patients should put their trust in physicians who would paternalistically make decisions for the good of the patient was challenged from a number of perspectives (e.g. Szasz 1961; Duff and Hollingshed 1968; Illich 1976; Barber 1978; Ehrenreich 1978).

There was a call for "demedicalization" for a number of populations such as the behaviorally or physically deviant, and those passing through critical life transitions such as birth and death. In part, this was tied with a demand for "deinstitutionalization" reflected such practices as the release of thousands of mental patients, the mainstreaming of the physically and developmentally disabled, and the call for home birth and hospice care. In addition to a change in locale, it reflected a demand for change in the power relations between professionals and their clients (as they increasingly came to be called). Individual were demanding a role, in some cases the sole right, to be making decisions affecting their own lives and those of their family members.

In some circumstances, some professionals welcomed the opportunity to share decision making about matters about which they felt they had no unique expertise (Graham 1981:269). In general, however, professionals resisted any but token intrusion into what they saw as basically a technical area. In some situations, there was an accommodation of
changes in professional practice (as in the management of childbirth) or inclusion of clients in the decision making process. Questions of professional versus individual or family authority for medical decision making became a major issue in the management of the care of the critically ill and general, and the care of critically ill newborns in particular.

Concerns About the Use of Technology

A second area of societal concern which affected public attitudes toward the use of medical technology was a growing apprehension about risks and dangers of many aspects of science and technology. Whereas in the preceding decades, science was generally endorsed as the key to progress, by the late 1960s, and early 1970s, the benefits of technology were being questioned in a number of areas including the dangers of nuclear war, pollution to the environment, exhaustion of natural resources, threats to civil liberties through computer networks, electronic surveillance, etc.

By that period, there was public concern about a number of aspects of the use of biomedical technology including the effect on social values of the development of an effective contraceptive (the pill), side effects of diagnostic or treatment techniques (such as X-rays), dangers of pain relief medication or mind altering drugs, and changes in the nature of the patient practitioner relationship related to the use of technology (Sidel 1971).
At first, the issue of use of technology for treating the critically ill had relatively little salience. In a 1971 article on "New Technologies and the Practice of Medicine," in which the issues outlined above were discussed, Victor Sidel barely mentions the use of "life support" except to raise the issues involving allocation, cost, use of scarce resources, and problems involving following unusual religious dictates (e.g. Christian Scientists). During the 1970s, burdens associated with the use of technology for some critically ill patients was of increasing societal concern until "artificial life support" became a paradigmatic issue for illustrating negative effects of the use of technology.

In Between Science and Human Values, Loren Graham presents a framework for explicating concern about the use of science and technology. It can be used to examine concerns people have had about the treatment of critically ill patients. These can be seen to fall in virtually all of the categories.

I. Concerns about Technology

A. Concerns about the physical results of technology  
   Destructive Technology

B. Concerns about the ethical results of technology  
   1. biomedical ethics  
   Slippery Slope Technology

C. Concerns about the economic results of technology  
   Economically Exploitative Technology
II. Concerns about Science

A. Concerns about research on human subjects

B. Concerns about distortions in allocation of resources for science

C. Concerns about certain kinds of fundamental knowledge
   1. knowledge itself
   2. knowledge "inevitably" leading to technology

D. Concerns about accidents in the research itself

E. Concerns about the use of science to excite racial, sexual, or class prejudice

F. Concerns about certain modes of knowing

(1981:219)

According to Graham, the first concern that people have is fear of "destructive technology" - negative physical results of its use. An example of this would be the use of chemotherapy in the treatment of cancer, or of neurosurgery to treat a brain lesion, where the effects of treatment may be worse than those of the disease. A second category is "slippery slope technology" where it is feared that the use of the technology may destroy the ethical system. There is fear that decisions to cease using sophisticated biomedical technology to prolong life, would lead down a "slippery slope" to eugenics and active euthanasia. Critics evoke the specter of Nazi medical experimentation and death camps as the ultimate depth of the slippery slope. Changes in biomedicine, particularly the use of life prolonging technology, leads
to increased concern of both clinicians and non-clinician with the ethics of medical practice.

Graham's third area of concern is "economically exploitative technology." Enormous costs are involved in the development and use of some life prolonging technology which will benefit few people. Some question whether so much money should be spent on technology for those in critical condition. They feel that more money should be spent on research and technology that will benefit more people.

The fourth area is "human subject research." Here the goal of therapy is secondary to the acquisition of information. In some situations, patients are not primarily treated for their own benefit (because the chance of success is too small). In such cases, the patient may be treated in hopes that the knowledge gained during treatment may be used to help others with similar conditions in the future. Some people feel it is inappropriate to use dying patients for such research.

Another area of concern is "expensive research." They fear that there will be distortion in the allocation of societal resources which will prevent allocation of resources for research in other area of medicine and to meet other human needs.

Graham also discusses "subversive technology," fundamentally new knowledge that is seen as conflicting with the theories of ruling authorities. For example, Galileo's theories, which were seen as
demoting the place of man from the center of the universe, were felt to challenge church teaching. Today, knowledge that human decisions can lead to prolonging dying or to not sustaining life are sometimes seen as challenging the world view of some individuals. They fear rational decision making about life and death matters that should be determined by "God" or "Nature."

The seventh issue is fear of "inevitable technology." The fear is that "anything that can be done, will be done." There has been fear on the part of some that once technologies are developed, people will not feel that they have the option not to use them.

Eighth is a concern with "accidents in science." The use of life prolonging technology does not raise the specter of mass threat to public safety, such as that feared with the use of atomic energy or recombinant DNA. But, there is fear of unintended moral and economic consequences of "prolonging dying" both for the public at large and for the individual patients and their families.

"Prejudicial science," which exacerbates racial, ethnic, sexual or class prejudices are another area. Some fear that unequal access to expensive life prolonging technologies will exacerbate the racial and social class differentials in survival which already exist. Problems many also arise between members of different religious groups who have different definitions of what constitutes the definition of "death" or what treatment should be given to critically ill patients. For example, there is potential for strains between members of some religious groups
who don't accept "brain death" definitions of death and others who don't want to pay for heroic care for brain dead patients.

Finally, Graham discusses fears about scientific developments changing "ways of knowing." It is argued that the epistemological basis of science is so limited that it is unprepared to handle significant modes of reality and, at worst, is fundamentally alienating to the human spirit. Some would claim that clinicians who use life support to prolong the circulation and respiration of an individual beyond the time when that individual could be capable of human interaction, has limited the focus to a physiological, rather than a social or a spiritual reality, since the first is the only one which science is able to deal with.

Concern with Rising Costs of Medical Care

Finally, a third theme that had an impact on the conceptualization of life prolonging technology was concern about the rising costs of social programs in general, and medical care in particular. Both had rising prominence as national issues in the 1970s. The prosperity of the 1950s and 60s led to confidence that "the richest nation" in the world could and should spend resources to provide a decent quality of life for all citizens, particularly in the area of health; it was seen as a means to demonstrate the benefits of the "American Way." (The Nation's Health 1965)
By the 1970s, however, as the country entered a period of economic recession, there was concern about the rapidly rising expenditures for social welfare, particularly health care. Significant increases in the percentage of the GNP devoted to health care were acknowledged [4.5% in 1950; (Rosenberg, lecture notes 1985) 5.3 in 1960, 7.6 in 1970, 9.4 in 1980 and 10.6 in 1984 (U.S Bureau of the Census 1985:96)]. The costs of Medicare and Medicaid were escalating rapidly. The focus of concern switched from questions of access to questions of cost. The Nixon administration, using the rhetoric of "crisis," predicted a breakdown in the medical system within a few years unless changes were made (Starr 1982).

In particular, the proliferation of critical care facilities and advances in biomedical technology and practice, such as renal dialysis units and intensive care units, and expensive intervention such as open heart surgery and transplants, were identified as adding much to the cost of health care. In place of concern about problems in trying to provide "enough" health care to those with medical need, the public concern switched to a focus on containing the high cost of health care as a medical problem.

Concern about the rising costs of health care and issues concerning the use of life support technology have always had an ambiguous relationship. On the one hand, many have argued that, at least at the level of individual patient, choices should never be made between dollars and lives. It is said that physicians should be able to
provide whatever treatments are of benefit to a patient, especially acute, life saving treatment, without regard to costs.

On the other hand, critics have pointed to the very high cost of a number of life support technologies. They feel that there are limited benefits to "half way technologies," which may support life but are unable to cure the underlying condition, and may in some cases merely prolong dying. They therefore feel that societal resources might be better spent for other social needs. In order to accomplish this, some have advocated public policy decisions to limit resources for expensive medical technologies. The relevance of financial factors in decisions affecting the care of individuals has been even more controversial. While some advocate the cessation of certain types of care so as not to deplete family resources, others felt that such reasons are never justified.

Along with concerns about the rights of individuals to make decisions, and about the use of technology, thus concern about the rising costs of health care and other social programs contributed to concerns about the treatment of the critically ill.

Rising Concern with Bioethics

Since the early 1970s, in part because of the reasons discussed above, there has been a proliferation of works dealing with bioethical concerns. This has included a multitude of books and articles, the
founding of Institutes for the study of biomedical issues, numerous conferences, and the establishment of centers, courses, and ethics rounds at many medical centers. The explosion of interest is perhaps best illustrated by the increase in specialty journals. Whereas, previous to 1970, the only journal devoted to articles on medical ethics was the *Linacre Quarterly*, published since 1932 by the National Foundation of Catholic Physicians, since 1970 the following journals have started publication: *The Hastings Center Report* (1971), *Ethics in Science and Medicine* (1973), *Journal of Medical Ethics* (1975), *Kennedy Institute Quarterly Report* (1975), *Man and Medicine* (1975), *Journal of Medicine and Philosophy* (1976), *IRB: Review of Human Subject Research* (1979), and *Journal for Philosophy and Methodology of Medicine* (1980). (Goldstein 1985)

There has also been a flourish of new journals dealing with Medicine and the Law. Although there have long been journals on forensic medicine, only recently have there been journals devoted to medical jurisprudence. A precursor in the field was *Lex and Scientia*, started in 1964, which dealt extensively with medical issues. In the 1970s and 80s, *Medicolegal News* (1972) (which combined with *Nursing Law and Ethics* to become *Law, Medicine, and Health Care*), *The Journal of Legal Medicine* (1973), *The American Journal of Legal Medicine* (1975), and *The Journal of Health Politics, Policy and the Law* (1976), started publication (Frey 1982).
Since the early 1970s, there has been a plethora of books and articles dealing with various aspects of decisions to withhold treatment from the critically ill. Many have concerned a number of legal cases, including Quinlan, Saikowitz, Fox, Storars, Conroy and Brophy, which have been covered extensively in the popular and professional literature.

The principle that competent adults have the right to refuse treatment had been established long before the 1970s. For example, Judge Cardozo stated in 1914:

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages" [Schloendorff v. Society of New York Hospital, 211, N.Y. 125, 129-30, 105 N.E. 92 (1914)].

(In the Matter of Clair Conroy 1985:19)
A number of cases affirmed the right of a competent adult to make an informed choice to refuse treatment. For example, in the 1962 case of *Erickson v. Dilgard*, the right of a Jehovah's Witness to refuse a blood transfusion was upheld even though refusing treatment was likely to lead to death (Beauchamp and Childress 1979:83). In some cases, however, the courts have ruled that the right to refuse treatment is outweighed by other interests, such as the interests of the State in seeing that care is provided to minor children. For example, in "the Georgetown College Case," blood transfusions were required for the Jehovah's Witness mother of a 7 month old child (Beauchamp and Childress 1979:84). In general, however, the right of a competent adult to refuse treatment has been "broadly construed" (Ackerman and Pope 1982:212).

The issues have been more complex in cases concerning incompetent patients. As discussed above, since the 1960s, there has been an effort to allow the withholding of treatments from patients who are "brain dead." Although there is still controversy in some quarters about aspects of ascertaining brain death, and many states, including New York, do not yet have clear statutes providing a definition of death based on brain function, the acceptance of withholding treatment from individuals with no brain function has been widely accepted in clinical and legal circles.
Since the early 1960s, a number of cases and proposed statutes have dealt with withholding treatment from incompetent patients who were not "brain dead."

Issues in the Case of Karen Ann Quinlan

The best known case, and in many respects the most significant, is the case of Karen Ann Quinlan, a young woman who suffered brain damage which left her in a chronic and persistent vegetative state. She did not meet the criteria for "brain death, yet she had no hope for recovery of cognitive function. Her parents requested that her respirator be removed; her physician refused, and her parents brought her case to the Courts in the State of New Jersey.

In the seminal decision in the case of Karen Ann Quinlan, the Court declared that "a right of personal privacy exists ...[that is] broad enough to encompass a patient's decision to decline medical treatment under certain circumstances" In re Quinlan, quoted in the Pres. Comm. 1983:31).¹

The Courts concluded that Karen's right should not be denied simply because she was not herself competent to exert them. They stated that her "guardian and family" should be permitted to "render their best

¹ Some people question the framing of these issues in terms of constitutional rights (Pres Comm 1983:31).
judgment ... as to whether she would exercise it in these circumstances" (Annas 1976:30).

In their decision, the judges wrote: "We think that the State's interest contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State's interest [in preservation and sanctity of life] (quoted in Ackerman and Pope:215).

In part, the Courts decision was based on the fact that there was considered to be no "reasonable possibility" of Karen's emerging from the coma to a cognitive sapient life. The court therefore wanted confirmation of that prognosis by her attending physician. The Court also stated that it wanted concurrence in the prognosis by an "ethics committee."

In discussing the "ethics committee," the Court quoted at length from a 1975 article by pediatrician Karen Teel in the Baylor Law Review. In it, she suggested the formation of "ethics committees" to share responsibility with the physician for life and death decisions, in part to relieve the physician of legal liability. She suggested membership from such professions as medicine, social work, law and theology. In seeking confirmation of prognosis, the Court might have more appropriately suggested review by a "prognosis committee" composed of medical experts. However, the Court mandate of the review by an "ethics committee" in the Quinlan decision, led to widespread discussion of, and
in some hospitals establishment of a mechanism for multidisciplinary review of some cases involving ethical issues. More recently, the concept of ethics committees was endorsed by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) and the U. S. Congress (Congressional Record 1984).

One of the most significant aspects of the Quinlan decision was that it mandated decision making by family and physicians for incompetent patients with review only by a hospital based committee. The decision explicitly stated that it would be inappropriate for the Court to review each decision involving the withholding of a life saving treatment (Ackerman and Pope 1982:216).

The Quinlan decision had a profound affect on public and professional discourse and debate about the issue of withholding treatment from the critically ill. It served to educate the public about the issue both by raising the question of whether all possible technological interventions should be utilized to prolong life and, if not, who should make such decisions. It set precedents concerning criteria which could be used for making decisions to withhold treatment and it suggested a mechanism for reviewing such decisions. For some physicians, and other health care professionals, it provided the first significant social sanction for discontinuing extraordinary care in some circumstances when the patient was not brain dead, a practice which was to be much discussed over the following decade.
Beyond the initial Court decision, the Quinlan case has served to educate the public further about issues surrounding decisions to withdraw treatment. Although some experts in neurology had suggested that Karen might live after she was taken off the respirator, most people expected that if "the plug was pulled," Karen would die. Her survival for nine years after removal of the respirator vividly illustrated the uncertainty of medical prognosis and raised further questions about the issues in decision making for the critically ill.

The popular image of "withdrawing life support" involves a literal "pulling the plug" of the respirator or pulling out tubes to stop all treatment. In fact, in a clinical setting, many aspects of care are continued even though certain other more aggressive treatments may be discontinued or modified (see Chapter VII). In Karen's case, she was gradually weaned from the respirator, while other forms of respiratory support was provided. She was fed through a nasogastric tube and received excellent nursing care such as frequent repositioning to prevent bed sores. While at first surprising, her continued existence served to educate the public to the fact that withdrawal of extraordinary life support and death are non synonymous. Within the last few years, her treatment has been one of the cases frequently examined in discussions about the provision of more routine care for hopelessly ill patients (for example, see Capron 1984).
Other Legal Cases Pertaining to Withholding Treatment

It is important to remember that there is no clear federal basis for law involving the provision of care to the critically ill. While some decisions, such as the Quinlan decision, rests on constitutional questions, no "right to die" case has been adjudicated by the Supreme Court. Therefore, decisions in one case provide no binding legal precedents for rulings in others jurisdictions. There have been a number of other cases dealing with the care of the critically ill adult. While some decisions have complemented the judicial reasoning of the Quinlan case, others have not. Some of the most significant cases involving adults will be reviewed here; legal cases specifically involved with the care of newborns will be reviewed below (Chapter III).

Contrary to the decision in the Quinlan case, a number of courts have rejected delegating decision making authority to family and physicians without approval by the Courts. For example, in the case of Saikewicz in 1977, the Massachusetts Court ruled that Court approval was necessary before removal of life support from incompetent patients. Subsequently, in the Case of Earl Spring, in 1980, the Court outlined a number of factors to be considered before deciding if a case had to be referred to the courts. The decision, however, did not provide clear guidance about which combination of factors would necessitate prior court approval. (Ackerman and Pope 1982:). Despite the Court decisions which suggest mandatory Court Review, many individuals and organizations, such as the House of Delegates of the American Bar Association, share the opinion that "existing law allows extraordinary
life support systems to be disconnected from terminally ill comatose patients without judicial interventions" (Wallace-Barnhill 1982:60).

It is worth noting that reported cases may be biased in favor of those decisions for which the Courts felt that judicial review was necessary. In other situations, where cases were referred to the legal system and determinations were made that rulings by the Court were not necessary, decisions may have only been made at a lower Court level, and these may be not discussed much in the literature.

Whereas, court decisions have indicated procedures which differ significantly from the non-involvement of the Courts recommended in the Quinlan decision, the legality of a decision to remove "extraordinary treatment" (e.g. the use of a respirator) from a terminally ill, comatose patient has been affirmed by subsequent Court decisions (e.g. Eichner, 1980). There has been variation, however, in decisions about other, more ordinary, treatments. In the 1981 Storars case, for example, the N.Y. Court of Appeals refused to permit discontinuation of transfusions for a profoundly retarded man of 52 who was being treated for bladder cancer (Annas 1981). In the 1985 Conroy decision, the New Jersey Supreme Court ruled distinctions between treatments themselves were not important, and that in some cases it is permissible to withhold any treatment, including feedings (In the Matter of Claire Conroy 1985). In the 1985 decision of a probate court in the case of Brophy, the judge did differentiate between treatments in ruling that most treatment, including antibiotics could be withheld from this patient in a
persistent vegetative state, but that tube feedings would have to be continued (Levin and Powderly 1985).

In addition to differentiations on the basis of treatments, the courts have also differentiated on the basis of knowledge of the incompetent patient's wishes, before the patient was incompetent. For example, in the case of Father Fox, the Court felt that his prior expressed view that he would not want his life to be continued with extraordinary means, was an important factor in deciding that his respirator support could be discontinued (Annas 1981). In the Conroy case, the Court suggested that different standards would be relevant in decision making about withholding treatment depending on the amount of knowledge of the wishes of the patient (In re Conroy 1985). While most of the legal cases involving the withholding of life saving treatment have been civil cases, there have been a few cases involving criminal charges of murder. It appears that in ALL CASES charges were dropped or the defendant was acquitted (Pres Comm. 1983). In the most recent case, concerning the death of Clarence Herbert in 1982, two physicians were charged with murder after discontinuing a respirator and intravenous fluids. The Courts sanctioned joint decision making by the family and physicians and consideration of quality of life, as well as the duration of life, in their decision to acquit (Lo 1984).

In examining the legal basis for decision making regarding the withholding of life saving treatment, some people believe that the current laws are appropriate. For example, the members of the President's Commission concluded that there is adequate discretion in
the criminal law to allow for good decision making while the threat of prosecution provides an appropriate protection against abuse (1983:34-35). On the other hand, others have expressed fears that the current ambiguity in the law leads physicians to practice defensive medicine and sustain treatment even when they feel it would be better to stop according to their medical and ethical judgments (Lo 1984:284). Some people have proposed that State legislatures enact legislation:

granting immunity from civil and criminal liability to all persons who help to effectuate cessation of an extraordinary life support system sustaining a comatose, terminally ill patient, provided such decision is made in good faith with the consent of family members of the patient.

(Wallace-Burnhill, et al. 1982:60)

In recent years, a number of state legislatures have adopted laws dealing with aspects of withholding treatment. The first and best know, the 1976 California "natural death act", expressly states that withholding treatment is not to be construed as homicide or suicide (Pres. Comm. 1983:40). Many states, however, including New York, have yet to adopt such legislation. At the present time (1986), the New York State Governor's Commission On Life and the Law is considering proposals concerning recommendations for legislation on definition of death, "Do not resuscitate" (DNR) orders, and decision making about withholding other treatments.

In sum, although during the past ten years, legal precedents have supported a number of termination of life support decisions, the legal status of many treatment choices remain uncertain.
Some Bioethical Issues Pertaining to the Withholding of Treatments

In the past two decades an enormous literature has developed in the bioethics and clinical literatures on the subject of withholding treatment, particularly from terminally ill patients. It is beyond the scope of this chapter to present a comprehensive review. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research did a masterful job at presenting an overview of the issues in their volume Deciding to Forego Life-Sustaining Treatment (1983). I will briefly discuss some of the literature concerning differentiations between treatment choices, for this will be a topic of concern in Chapters VI, VII and VIII. The literature on treatment choice for children and newborns will be discussed in Chapter III.

One of the main ways that distinctions have been made between treatments is in terms of "ordinary" versus "extraordinary" means. For example, in 1973, the American Medical Association issued this statement:

The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family.

(cited in Kuhse 1981:117)

In differentiating between ordinary and extraordinary means, those who use the terms, generally are attempting to distinguish those treatments
that would be obligatory and those that would be optional. In general, the distinguishing criteria between obligatory and optional treatments has been seen to be whether or not the treatments would be of benefit to the patient. In addition, the terms ordinary and extraordinary means are also used to refer to a distinction between treatments that are simple and those that are complex, and between treatments that are usual and those which are unusual (Pres. Comm. 1983:82-87).

Critics have objected to use of the distinction for two main reasons. First, there has often been confusion between the various definitions (Pres. Comm. 1983:88). Not all simple or usual treatments are seen to be of benefit for some patients. Second, the distinction between treatments that would be of benefit and those that would not, begs the question of what is of benefit. In general, a treatment is seen as beneficial when it sustains a life that is worth prolonging. Therefore the distinction depends on the quality of life of the patient, rather than on the means used to sustain life (Kuhse 1981).

Another distinction that is also made differentiates acts of omission from acts of commission -- whether the behavior under question was an action or a failure to act. One way that this contrast is used is to differentiate between withholding (not starting) and withdrawing (stopping) treatment. Many critics have argued that there is no moral significance to this distinction, but rather it is the intention of the action and/or the outcome, rather than whether it involves a action or conscious decision not to act that is morally significant (Pres. Comm. 1983:60-77).
A distinction is also made between active and passive euthanasia. This is also sometimes discussed in terms of acts of omission and commission. Acts which cause death are referred to as active euthanasia, positive euthanasia, or mercy killing. Acts which allow a natural death to occur are referred to as passive euthanasia or negative euthanasia. There is debate about whether the withholding of "ordinary" means, such as nutrition, would constitute active or passive euthanasia (Capron 1984) and about whether it would ever be ethical to use a dose of a lethal drug to cause death directly. It appears that the bioethical mainstream and most clinicians now accept the notion of passive euthanasia; there is much controversy about the status of withholding nutrition. Although supported by a number of prominent ethicists (e.g. Rachaelis 1975; Kuhse 1981), it appears that most bioethicists see direct killing as unethical.2 (Pres. Comm. 1983:60-88; Veatch 1976; Steinbock 1976).

The Clinical Literature on Withholding Treatment

Clinicians have written numerous articles about when to give or withhold certain treatments; most have concerned the care of terminally ill patients and/or cardiac resuscitation (stimulation to the heart if it stops or is about to stop). For example in 1976, the Clinical Care Committee suggested a four category classification system for hopelessly

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2 This is differentiated from a decision by a terminally ill competent patient to choose to take a lethal drug. It appears to be more acceptable than active euthanasia for an incompetent patient; whether it should be socially sanctioned is very controversial.
ill patients in the intensive care unit. The physician in charge was to make classifications, to be based on prognosis: A) Maximal therapeutic effort; B) Maximal therapeutic effort with daily evaluation; C) Selective limitation of measures (with a detailed care plan and resuscitation status recorded); D) All therapy can be discontinued (comfort measures given).

More recently, Wanzer and his associates (1984) issued a statement about the physician's responsibility toward hopelessly ill patients. They wrote "the patient's role in decision making is paramount, and a decrease in aggressive treatment of the hopelessly ill patient is advisable when such treatment would only prolong a difficult and uncomfortable process of dying" (p. 955). They differentiated four levels of care to be considered and discussed by the clinicians, and the patient and/or patient's family: (1) emergency resuscitation; (2) intensive care and advanced life support; (3) general medical care, including antibiotics, drugs, and surgery, cancer chemotherapy, and artificial hydration and nutrition; and (4) general nursing care and efforts to make the patient comfortable, including pain relief and hydration and nutrition as dictated by the patient's thirst and hunger. (p. 958)

Numerous articles have also been written on establishing guidelines for issuing "Do-Not-Resuscitate Orders" (e.g. Miles, Cranford and Shultz 1982). (Such orders are also frequently referred to as DNR, no code, or no arrest page.) Many clinicians have stated that DNR is not synonymous with no treatment, and that clinicians, patients,
and families should discuss both the DNR order and the appropriate level of care, and the level of care should be clearly documented in the chart and communicated to other clinicians.

There are often problems in implementing guidelines (Lo and Steinbrook 1983). Resuscitation may be withheld without consulting the patient or family; older patients, those with functional impairments, (especially the senile, demented or mentally retarded), those transferred from a nursing home, and those with chronic-obstructive pulmonary disease or malignancy, are less likely to be resuscitated (Lee and Cassel 1984; Farber, Bowman Major and Green 1984). Physicians who are taking care of another physician's patient, sometimes misinterpret the intention of the orders (Uhlmann, Cassel and McDonald 1984). In addition, decisions are sometimes made to do a "slow code," that is delay an attempt to resuscitate and/or do it in a slow or inefficient manner for patients who have a poor prognosis but have not been officially classified as "no code." (Basson, Dantzker, and Benjamin 1981).

Recently there have been a few studies in which series of actual cases have been reviewed to investigate the factors involved in decisions not to resuscitate. Younger and his associates found that 14% of the patients admitted to one medical ICU were designated DNR, 9% survived hospitalization. Severity of illness, age and prior health were associated with DNR designation while race and socioeconomic factors were not (1985). Levy, Lambe and Shear also found that age, sex, ethnicity and pay status were not associated, while residence in a
nursing home, and not being alert and oriented on admission were associated with DNR orders (1984). Such factors as patients having cancer, dementia, incontinence, being non-ambulatory, divorced, separated and unemployed were all more likely to be associated with DNR orders. (Ulmann, McDonald and Inui 1984).

Centers differ in how long patients have been the the ICU before DNR orders are issued (Zimmerman et al. 1984). Lo and his associates found that 4% of all patients admitted to medical services at three teaching hospitals were designated DNR. In most cases consultations with patients and/or their families took place. Sometimes, however, when patients or families did not agree, "limited DNR" orders were issued (1985). At another center, in many cases, there was no documentation of discussions with families; this was attributed to fear of litigation (Ireland and Puri 1984) although the clinicians wish to avoid confronting the issue directly with the family may also have been a factor.

There have been even fewer studies to document the withholding of other life saving treatments beside resuscitation. There are some reports that discuss examples of the withholding of more ordinary treatments, such as blood transfusions (e.g. Lo and Jonsen). As far as I know, there is only one systematic study that reports the association of non-physiological factors with the withholding of less aggressive treatments. In that study, Brown and Thompson report that decisions not to give active treatments (e.g. antibiotics) to residents of nine extended-care facilities showed a significant relation to diagnosis,
mental status, mobility, pain, narcotics prescribed, size of the facility, relation of the physician to the patient and medical-record statements documenting the patient's deterioration or plans for non-treatment in general. 59% of the patients, who were not actively treated, died.

Surveys and Sociological Studies of Decisions to Withhold Life Saving Treatments

Although there has been much written by social scientists on aspects of care of the critically ill (e.g. Glaser and Strauss 1965; 1968; Sudnow 1967; Bluebond-Langer 1978), on the use of high technology in medicine (e.g. Fox 1976; Reiser 1978), and on social factors affecting medical care (e.g. Gaines and Hahn, 1985; Wright and Treacher 1982; Atkinson and Heath 1981) social scientists have done few in depth, observational studies on decision making about the aggressiveness of treatment. Studies on decision making about the care of newborns (Anspach forthcoming; Guillemin and Holmstrom 1986), the only in depth observational studies I know of (beside this study), will be reviewed in Chapter III).

In an address entitled "Reflections and Opportunities in the Sociology of Medicine," Renee Fox (1985) lamented the fact that, unlike the 1950s and 1960s, there have been few recent ethnographic studies of hospitalized patients or of physicians or nurses working in hospital settings. She also noted the limited participation of social scientists
in the field of bioethics. She quoted from her own recent article with Judith Swazey (1984), comparing "medical morality" in China and "Bioethics" in the United States, and called for more social science research on issues in bioethics. Beside the work of Fox and Swazey, there has been little work by social scientists which has looked at the field of bioethics in its broad societal context.

Numerous surveys have been conducted to investigate clinicians attitudes and behavior regarding the withholding of treatment from critically ill patients using survey research methodology. As early as 1961, Levinsohn, who conducted a survey at a medical convention, found that 61% of the physicians present believed that euthanasia was being practiced by members of the profession. Another survey, conducted in 1968, found that 72% physicians polled would not perform dialysis on all patients with chronic uremia. Williams (1969) found that among "leaders of medicine" 87% favored negative euthanasia, and 80% had practiced it, while 15% favored "institution of therapy that is hoped will promote death sooner than otherwise."

One of the most quoted surveys was conducted by Travis, Noyes, and Brightwell (1974). Their 1971 survey of Iowa physicians indicated that nearly half of the respondents frequently omitted life-prolonging procedures or medications in the care of terminally ill patients but most objected to a change in social attitudes which would permit physicians to hasten death. A follow-up survey (Noyes et al 1977) revealed that support for the omission of life-prolonging treatments
was increasing; opposition to the use of death hastening measures remained strong.

More recent surveys of clinician attitudes found that clinicians distinguish between ordinary and extraordinary treatments (Carey and Posavac 1978; Micetich, Steinecker and Thomasma 1983) and there is variation in beliefs about prognosis, information felt to be important as well as in treatment recommendations (Pearlman, Inui and Carter 1982). Farber and his associates found patient's social as well as physiological factors to be important in decisions about cardiopulmonary resuscitation (1984; 1985). In making decisions to withhold treatment, some physicians state that they would override the wishes of patient, family, hospital or community (Blum 1982).

A survey in Nursing Life found that 97% of nurse respondents favored "withholding all life-sustaining treatment for dying patients who don't want it" and 61% had "seen a slow code." Younger, Jackson and Allen found that professional role (physician or nurse) was more important than gender or religion for attitudes about the decision making process, but, in general, there was more variation among physicians and nurses than between professional groups (1979).

In studying attitudes of non-clinicians, Jorgenson and Neubecker, who conducted a national survey of attitudes found a general favorable attitude toward euthanasia. 64% of respondents approved of "termination of life" for a patient with an "incurable disease." Pro-euthanasia attitudes were found to be associated with being white and being male,
while strong religiousity and living in a rural environment was associated with anti-euthanasia attitudes (1981). A Gallup Poll, conducted shortly after the Conroy decision in 1985, found 81% supporting a "right to die," 13% were opposed (New York Times 3/17/85).

The most comprehensive study of physicians decision making is the study by Crane, The Sanctity of Social Life: Physicians Treatment of Critically Ill Patients (1975). In her study, based primarily on a survey of physicians, Crane elucidated criteria used by physicians in making treatment decisions. She found that physicians no longer used a purely physiological definition of life. Instead, physicians used a social definition. First the physician attempted to decide if the patient is "salvageable." Second, the physician considers the patient's future quality of life - the extent of physical or mental damage. Together, the salvageability of the patient and the degree of irreversible damage indicates the capacity to resume social roles. Crane found that a norm is evolving to guide treatment decisions based on the capacity to resume social roles and to interact meaningfully with others.

In general, Crane found there was most agreement to treat salvageable patients with physical impairment and not to treat unsalvageable patients with severe mental impairments. There was more controversy surrounding treatment decisions about unsalvageable patients with physical damage and salvageable patients with severe brain damage (Crane 1975; 1975a).
Crane also reviews the general issues involved in decision making about the critically ill and terminal patients and explores institutional and background factors associated with variations in physician attitudes.

Crane's study was based on a survey composed primarily of hypothetical vignettes and questions about whether the respondent would be likely to perform a number of tests and treatments. Among others, there are items which asked physicians "how actively" they would treat a patient with a particular condition. The marginal responses to the questionnaires indicated that in many situations, physicians would provide some treatments while withholding others (personal communication 1981 - see Chapter III) In some of the analysis, Crane distinguished types of treatments (e.g. "comfort therapy", "diagnostic" or "minor treatment", "heroic treatment", and "resuscitation". She notes:

A continuum ranging from comfort therapy to diagnostic procedures to emergency surgery to resuscitation can be discerned with physicians being least likely to withdraw the first and most likely to refuse to perform the last." (1975:70)

In most of the analysis, responses concerning a number of treatments were combined into a "scale of activism," which was then used to examine variations associated with characteristics of patients and respondents. Differences between characteristics of treatments was not a main focus of Crane's study. Crane also did not seek respondents' attitudes concerning the social prognosis for the patients in the vignettes;
rather, the categorizations about the capacity of patient's to resume social roles were made by the analyst.

Finally, Benoliel conducted a retrospective chart review study of the care of patients in three teaching hospitals on the day of death. She compared data collected for 2,879 patients who died in 1966 and 1971 and concluded that "shifting medical norms were shown by increases in heavy recovery and life support treatments. Influence of technology was shown by increases in critical care wards and increases in work effort activity for all types of dying" (n.d.:v, also see 1977).

Further analysis was conducted on data from the charts of 184 adults who died in one urban teaching hospital. A "work effort index" was devised using points for medical consultations, surgical procedures, medications, medical treatments in identified categories, and cardiopulmonary resuscitation. The analysis showed that "the medical treatment orientation was overwhelmingly toward the cure end of the care/cure continuum, despite the fact that the majority of patients had been designated no code (non-use of cardiopulmonary resuscitation) and had conditions labeled by their physicians as either grim prognosis or terminal" (Mumma and Benoliel 1984).
As with questions about the aggressiveness of treatment for patients in general, questions about the aggressiveness of treatment for infants has a long history. Many of the issues have always been similar to the issues raised for adults. In addition, however, because of the unique feature of being newborn and the degree of dependence on adults some issues arise in the care of infants which are different from those raised in the care of older patients. As with adults, the dramatic recent advances in technological medical capacity has led to a new focus on questions about the aggressiveness of medical treatment. Perhaps because of the complexity of related ethical issues and because of the perceived relationship to the abortion issue, questions related to treatment for newborns have been debated and politicized even more extensively than similar decisions for older patients.
Cross Cultural and Historic Perspectives on

Infanticide and Non-treatment Decisions

Some people see non-treatment of newborns in the NICU as the modern day version of infanticide, the intentional killing of infants.¹ For example, Robert Weir starts his book, Selective Nontreatment of Handicapped Newborns, with a chapter on infanticide. It begins:

The contemporary practice of selective nontreatment of handicapped newborns is, in many aspects, a continuation of historical practices of infanticide. The settings and circumstances vary from historical patterns, but infant deaths brought about in neonatal intensive care units (NICUs) often provide parallels to acts of infanticide in earlier times and places.

(1984:3)

A number of other recent books on non-treatment of newborns have either approached the issues primarily as the same as those of infanticide, or, at least included a chapter drawing links to practices of infanticide in other cultures and/or the history of Western Civilization (Kohl 1978; Horan and Delahoyde 1982; Tooley 1983; Kuhse and Singer 1985; Lyons 1985).

In some cases, there are parallels with infanticide as it was practiced at other times and in other places. What characterizes infanticide generally is that it entails killing of newborns who are not

¹ Infanticide can also refer to death caused by neglect or less support than the family might be able to provide, and less than family members know should be provided (Scrimshaw 1982).
seen as an acceptable addition to the social group. The infant's lack of acceptability may be due to one or more of a number of factors. These factors may be identified as attributes pertaining to the infant - such as gender or appearance, to the birth - such as twins (Williamson 1978) or breech (Sargent 1982), to the social situation of the mother - such as illegitimacy (Cohen n.d.; Langer 1974) or age (Tsing 1986), or to the social group - such as captive populations (e.g. first born sons of Jewish children in Egypt at the time of Moses) or population control (Scrimshaw 1982; Hausfater and Hrdy 1984). In most cases, infanticide takes place at a point of time earlier than that when the child is recognized as a member of the social group (Morgan 1983). The theme of rejecting the baby as a potential member of the social group is the dominant theme in some decisions to withhold treatment from infants with impairments in the NICU.

In most cases of non-treatment, however, there is no question that the family wants to accept the baby as a new member into the social group. The child is considered to be a member of the family. Decisions about care involve other issues, more similar to those involved in making treatment choices for critically ill older people. These are fundamentally different from infanticide decisions for they are focused on the presumed value of treatment for the benefit of the patient, not for the benefit of others. As will be discussed below, some decisions involve elements of both themes.
Many authors have claimed that infanticide of newborns with disabilities was the norm in "primitive societies." For example, Williamson concludes:

Infanticide may be widespread in a society or happen only occasionally, but it has very few, if any, exceptions with one class of infants, that is, deformed infants. The reasons for eugenic infanticide seem obvious; unwillingness or inability to assume the burden of caring for such an infant, whose future at best would be unsure. The same is true of infants who are clearly "different," as, for instance, those with unusual skin color, too light or too dark."

(1978:64-65)

Such statements reflect our ethnocentric assumptions about disability. As Scheer and Groce state in their paper on "Impairment as a human constant:"

...the category 'the disabled' is a cultural artifact which varies cross-culturally ...

As ethnographers of the disabled, we have observed that given the cultural latitude to do so, the vast majority of individuals with impairments can contribute and function in a much wider variety of ways than would be expected by American social norms. It is our position that the cultural expectations and social arrangements which accompany the category 'disability' circumscribe the life of each disabled individual to a greater extent than an individual's particular physical or mental impairment. Furthermore, we suggest that throughout human history, culture has defined what does and does not constitute a handicap or impairment and that these definitions have changed from one society to the next, from one historic period to another, and of course vary to a degree within subcultures and socioeconomic classes.

(1985:1)

They cite a study by Weiss, who used the HRAF (Human Relations Area File) to review the 47 groups where disabled individuals were mentioned. Of these, 13 groups practiced infanticide of disabled infants. Eight of
the 13 practiced infanticide on other newborns as well. They conclude, "It is our impression that societies in which disabled infants are put to death and those where they are not exist in equal proportion" (Scheer and Groce 1985). The fact that groups that practice infanticide have members with congenital impairments that would have been obvious at birth, proves the fact that the "deformed" were not always killed (Jessica Scheer, personal communication, 1986).

All cultures develop customs to care for pregnant women, and for mothers and infants at the time of birth. These include means to care for infants born not breathing, sick or premature (Jordan 1978; Kay 1982). Mothers, other family members, and/or other birth attendants assessed the physical condition of infants and made judgments about how to care for infants. In general, decisions were made to care for infants in such as way as to maximize chances for survival, but in some situations, the assessment led to decisions not to try to promote survival or even to take actions which might bring about death.

For example, Soranus, an ancient Greek physician who wrote a text, *Gynecology*, describes how a midwife may recognize an infant "worth rearing:"

...the infant which is suited by nature for rearing will be distinguished by the fact that its mother has spent the period of pregnancy in good health, for conditions which require medical care, especially those of the body, also harm the fetus and enfeeble the foundations of its life. Second, by the fact that it has been born at the due time, best at the end of nine months, and if it so happens, later; but also after only seven months. Furthermore by the fact that when put on the earth it immediately cries with proper vigor; for one that lives some length of time without crying, or cries but weakly, is suspected of behaving so on account of some unfavorable condition. Also by the fact that
it is perfect in all its parts, members and senses; that its ducts, namely of the ears, nose, pharynx, urethra, anus are free from obstruction; that the natural functions of every member are neither sluggish nor weak; that the joints bend and stretch; that it has due size and shape and is properly sensitive in every respect. This we may recognize from pressing the fingers against the surface of the body, for it is natural to suffer pain from everything that pricks or squeezes. And by conditions contrary to those mentioned, the infant is not worth rearing.

(1956 ed.: 79-80)

Cohen, in her paper on the treatment on impaired newborn in American history, documents how, as the medical profession developed, physicians gained the authority to determine whether anomalous infants were monsters who should be killed or infants who were entitled to the same careful treatment as other infants (n.d).

Until the recent developments leading to the practice of giving birth and special care to infants with problems in hospitals, most birth attendants and physicians would have encountered relatively few infants with congenital impairments in the course of their life's work. Rather than a well defined class to be treated in a culturally prescribed manner, physicians and family would make decisions about the care of each child.

**Development of Medical Treatment Capabilities for Newborns**

Until recently, in the United States, there was relatively little that could be done for babies who were born more than a few weeks premature or for those who were born with severe abnormalities. Most
babies were born at home, and sick infants were generally cared for and/or died at home into the beginning of this century. There was a high child mortality rate both immediately following birth and later in the first years of life. For example, in 1885, for every 1000 live births, 273 infants died (Pawluch 1983). Most were the result of high rates of infectious disease reflecting both the undeveloped state of the medical sciences (including lack of preventative methods such as immunizations), and poor nutrition and sanitary conditions. Deaths of premature infants were seen as part of high reproductive wastage (MacMullen and Bruckner 1986). While the rate of newborns who were born critically ill because of prematurity [rate of prematurity estimated at 16 - 20% in 1900 (Kretchmer 1964)] or congenital impairments was probably high, in general, it was not seen as a separately identified social problem.

The Beginnings of the Development of Modern Technology to Care for Critically Ill Newborns

As recounted by W. A. Silverman (1979), the beginnings of modern attempts to improve the survival of prematurely born infants can be traced to France, following the great loss of life resulting from both military action during and famine following the Seige of Paris in the Franco-Prussian War (1870-71). In 1878, Dr. E. R. Tarnier, a leading Paris obstetrician observed a warming chamber for the rearing of poultry devised by Odile Martin of the Paris Zoo. At his request, Mr. Martin
built an incubator which was the first warm air incubator. It was used at the Paris Maternity Hospital in 1880.

A former pupil of Tarnier, Pierre Budin, wrote about the care of premature infants in 1888. Influenced by Madame Henry, a midwife, Budin established a special department for "weaklings" in 1893, which became the first center in the world to specialize in the care of premature infants. In 1900, Budin established basic protocols for the care of the prematurely born. This included instructions 1) to maintain an appropriate, warm environment by use of an incubator, 2) to provide human milk feedings (if the baby was unable to suckle, milk was expressed in a trickle into the mouth), fed by spoon into the mouth or nose, or introduced directly into the stomach by intermittent gavage, 3) to take precautions against infection by use of such techniques such as isolation, sterilization and cold storage of milk. Over time, other nurseries adopted these techniques.

While incubators and other aspects of special care may have slowly spread in medical circles, the early use of incubators for the care of premature babies became best known through their exhibition by Dr. Martin A. Couney. He exhibited first at the Berlin Exposition of 1896, and later at Earl court in the United Kingdom in 1897. He was probably the first to use incubators to care for premature infants in America when he brought his exhibit to Omaha, Nebraska in 1898 and Buffalo in 1901. He was unhappy that his exhibit was placed in the amusement section in Omaha, but was pleased when it was placed in the scientific section in Buffalo and received serious attention from such journals as
the Scientific American. Following the show, the Children's Hospital of Buffalo purchased incubators by the same manufacturer. Couney immigrated to America, settled on Coney Island, and exhibited premature infants there each summer for almost forty years. He was respected by New York obstetricians, who sent their babies to Coney Island for skilled care. In 1937, he was honored by the New York Medical Society. Silverman writes that the reasons that no one else established a center to care for infants commercially was the great expense of such care - $15.00 a day. Couney charged admission for spectators, and did not charge parents for the care of their infants.

Julius H. Hess, who later became the leading American expert on the subject of prematurity, paid tribute to Couney when he wrote his text, Premature and Congenitally Diseased Infants. (Silverman 1979). Hess organized the U.S. first hospital-based specialized premature infant center at Michael Reese Hospital in Chicago in 1920. After Couney exhibited in Chicago in 1933-34, he donated his equipment to Hess and gave his ambulance to the City of Chicago, which became the first U.S. metropolitan infant transport vehicle (Silverman 1979).

Couney returned to New York and exhibited premature babies at the World's Fair in 1939. Vital Statistics from the babies cared for at the Fair were published in the Journal of the American Medical Association in 1940. Arnold Gesell, a contemporary authority on infant behavior, studied the infants at the Fair. (Silverman 1979). The show, however, was a financial disaster. After the fair, Couney returned to Coney Island, but soon after, when the first premature station in New York
City opened at Cornell's New York Hospital, Couney closed his show for good.

Maternal and Child Health Care Before 1945

In the early part of the 20th century, as scientific medicine began to develop, hospitals came to be seen as an appropriate place for others, beside the destitute, to receive care. In addition to the care of the sick, the hospital came to be seen as the appropriate place to give birth.

Before 1900, less than 5% of American Women delivered in hospitals, but the percentage increased greatly during the first half of the century. More than half the births in large cities took place in hospitals by 1921 (Cone 1983). [By 1950, 93% of white births and 58% of non-white births took place in hospitals (Cone 1983).] Rather than receiving care at home, sick babies began to be cared for in hospitals. Most care to newborns, however, was still delivered by the general practitioners, midwives, or obstetricians who delivered the babies. During the first three decades of the twentieth century, there were few American specialists in Pediatrics. In the 1930s, many pediatric training programs started; in 1933 the American Board of Pediatrics introduced certification (Thompson 1984).

Hess, in his 1922 text, *Premature and Congenitally Diseased Infants* stated
Hippocrates, in his writings of 460 B.C. ... [wrote] 'No fetus coming into the world before the seventh month of pregnancy can be saved.' We note that the literature of our day records only a limited number of exceptions to these conclusions that infants born before the end of the twenty-eighth week are viable.

(p.205)

Hess, and other pediatricians, worked on developing safe methods to artificially feed infants. They also started to apply medical interventions originally developed for the care of older patients, to the care of infants. It is very easy for us to take for granted very basic medical interventions which were not in use even a comparatively short time age. For example, in the 1920s and 1930s, for the first time, infants were given blood transfusions (without knowledge of blood typing) and supplemental oxygen. By the 1940s, techniques were developed enabling surgery for some congenital impairments (such as a TE fistula - see Baby Doe, below). The general philosophy guiding the care of premature infants was to protect them from infection and support them with as little interference as possible. Parents were generally not allowed to enter the nursery. The major efforts of the time to reduce infant mortality, however, did not concern premature or sick infants, but rather concerned the care of normal babies in the community and the care of mothers at birth.

At the end of the nineteenth century and the first decades of the twentieth century efforts were made to decrease the rates of infant mortality and improve the health of young children. Most of the programs focused on preventative public health rather than acute care measures. There were major reduction in the infant mortality rate which
fell from almost 30% in cities like New York in the 1880s to less than 4% in the 1940s (Rosen 1958; Lesser 1985).

In the 1930s, the first major move towards improving maternal and child health measures focused on the safety of mothers. In 1935, maternal mortality was almost 6 per thousand. With the war time development of antibiotics which enabled treatment of puerperal infection and blood banking which enabled treatment of hemorrhage, and improvements in training in obstetrical techniques and anesthesia, maternal mortality fell sharply to less than 1 per thousand by 1949 (Divitt 1977). This reduction of risk for the mothers and changes in the medical care system which took place after World War II led to a shift in focus to more concern with the care of infants.

Post World War II Changes in the American Medical Care System which Affected the Care of Infants.

Following World War II, efforts to improve the nation's health was seen as an important component of the the Cold War strategy because it would build up America's strength and would demonstrate humanitarian concern. Proposals for a National Health Insurance Program were seriously considered, but were then defeated by a campaign which labeled them as "socialistic" (Starr 1982). Instead, the "war against disease" used the same means that had brought America's victory in war, the "massive mobilization of enormous material assets and a rapid increase
in technological development" (Silverman 1980). Science was "the new frontier."

Previously, the federal government had spent little on health expenditures; after World War II, the government began to invest millions and then billions in the health field. The 1946 Hill-Burton Act provided money for hospital capital expenses and encouraged investment in expensive hospital equipment (Richmond 1969; Starr 1982). Some of the federal money was spent on preventive health programs and the delivery of primary health services, but the major thrust of the funding furthered the emphasis on technologically oriented acute care and research. It primarily stimulated research on hospitalized, critically ill patients. The size and significance of teaching hospitals and medical schools within the medical care system increased. (Starr 1982: Richmond 1969). There were much greater rewards for developing technologies which produced new solutions to unsolved problems than to develop less costly methods to solve problems with existing solutions (Warner 1978).

With the success of the polio vaccine in the 1950s and the technological advances such as life support techniques in the 1960s, the general public optimism toward the benefit of the application of scientific research in medicine grew even further. With this public support and the medical research lobby, the federal medical research budget became the fastest growing component of national health expenditures reaching 1.5 billion by 1965 (Richmond 1969) [exceeding 4 billion dollars annually by 1983 (Science 1983)]. As will be discussed
below, research on catastrophically ill newborns, about which little was previously known, flourished (Silverman 1980).

Trends in Efforts to Reduce Infant Mortality - 1945-1965

During the first half of the twentieth century, there had been dramatic reductions in infant mortality rates. In New York City, for example, deaths under one year fell from 136.7 per thousand in 1898-1900 to 26 per thousand in 1946-50 (New York City Dept. of Health 1982). Despite the great reductions, however, people realized that infant mortality was still a major cause of death. A study at the time noted that for every two soldiers who had been killed overseas during World War II, three babies under one year had died at home. Studies were conducted to identify causes of mortality and programs were initiated in efforts to reduce mortality rates (Corwin 1952).

After the war, a new system of record-keeping was initiated in which both length of gestation and birthweight were recorded. This led to the realization that although deaths in children above one month had been sharply reduced, deaths in newborns under one month had hardly changed at all (Corwin 1952), and most of the deaths occurred in premature, low birthweight babies (under 5 1/2 pounds). The development of glass walled incubators, which allowed clinicians to observe the troubled respiratory efforts of unswaddled premature infants, and the new statistical awareness, led to both a literal and statistical
visibility of the problem of prematurity (Silverman 1980:70-71; Wallace, et. al. 1949).

The problem was addressed by efforts to centralize the care of such babies in special premature centers, some built with the help of Hill Burton funding. Some cities, such as New York, organized infant transport systems and subsidized care that then averaged $400.00 for each infant to discharge. Although premature babies had been cared for earlier at the Columbia University Medical Center, the first special center for the care of premature infants, a 23 crib unit, opened at Babies Hospital in 1949, the forerunner of the unit in which participant observation research was conducted for this study. Daily costs for New York City to take care of premies were $14 - 17 a day (Wallace, et al. 1950).

Previously, most newborn care was delivered by general practitioners, obstetricians, and general pediatricians (Budetti et al. 1981). At the premature centers, some pediatricians started to specialize in the care of the newborn. Along with funding from the federal and municipal governments and the growth of academic medicine, the concentration of babies with similar problems encouraged research both to improve the treatment techniques and to gain understanding of basic physiological processes. Efforts were made to improve treatment by the application of advances from other fields of contemporary medicine, such as antibiotics. In addition, there were applications derived from research in chemistry, physics, and engineering, such as the use of plastics (Graham 1981) that had an important impact on the ability to
deliver care. While overall, there were major improvements in treatment during that period, some interventions had disastrous consequences.

The non-interventionist philosophy which had dominated the care of sick newborns changed as physicians tried to apply newly developed techniques. For example, during the late 1940s and 50s, babies were regularly fed with indwelling tubes, newly discovered antibiotics were used, infants were given high concentrations of oxygen for the first time and new surgical techniques were developed to shunt fluid from the ventricles of infants who had hydrocephalus.

Iatrogenic Diseases of the 1940s and 1950s

Some of the treatment choices had drastic effects. For example, physicians acted on a theory that infants should be fed nothing by mouth for several days after birth. The smallest babies (under 2 lbs.) were not fed for 4-5 days, 3 days for 3 lb. babies, 1-2 days for babies over four pounds. Although it was debated, the first detailed clinical study of the delayed feeding did not occur until the 1960s. Drillien showed that during the delayed feeding period, three-quarters of infants weighing less than 1,367 grams at birth (3 pounds) developed severe neurological handicaps, while infants born earlier or later had a much lower (about 30%) rate (Cone 1983:19-20).

Cone quotes a lead article in the Lancet (1974) "the years when modern neonatal iatrogenesis reached a peak when almost every major
error in newborn care was widely practiced for at least a time." Many infants who were given high concentrations of oxygen were blinded by retrolental fibroplasia (RLF). By 1945, 12% of premature infants born 3 pounds or less were blind - primarily in the larger, better equipped hospitals. Other iatrogenic diseases included kernicterus (brain damage) as a result of sulfisoxazole given to prevent bacterial infections and "gray syndrome," a lethal condition, caused by excessive doses of chloramphenicol (Cone 1983:24-26). Other interventions included keeping the infants body temperature low and restricting fluids (Cone 1983:24-26; Silverman 1980).

Although clinicians were concerned about each complication, these problems did not appear to have been perceived as part of a more general social issue about the iatrogenic consequences of aggressive treatment. When studies were suggested to test the effects of various interventions, many clinicians objected that it would be unethical to deprive infants in the control group of their benefits (Silverman 1980). According to Dr. James, a young researcher at the time (now director of the Division of Perinatology at Columbia) during the 1950s, as clinicians were getting more aggressive in treatment, they thought that the chance of cerebral palsy, blindness or deafness was greater than 70%, which had been the statistics shown by studies of the effects of treatment for infants under 2500 grams (about 5 1/2 pounds). The impairment rates for those less than 1000 grams he reported at 90%, those under 1500, 85% during 1948-52. He said that the "driving force" for neonatologists at that time was to improve care.
Even as the beneficial treatments were separated from those with serious iatrogenic effects, the capabilities were still very limited by today's standards. For example, Patrick Bouvier Kennedy, 2100 grams (4 1/2 pounds), delivered by Caesarean section five and one half weeks before his due date, in 1963 (the only child of a US President born in office this century) died on the second day of life of respiratory distress syndrome (Cohen and Stevenson 1983:13).

Despite the developments in treatment practices, during the 1950s and 1960s there was little decline in rates of infant mortality. The infant mortality rate of industrialized societies is largely determined by the birth rate of premature babies (Lee et al. 1980) which, in turn, is highly correlated with measures of social class. Premature babies continued to be born at a high rate and most did not receive special care. The U.S. infant mortality rate fell to sixteenth among industrialized nations, 24.7 in 1965.\(^2\) This was seen as an indication of problems in the health care system, since infant mortality rates had become a popular indicator of the quality of a nation's medical care and the health of a society (Richmond 1969; Newland 1981; Miller 1985).

President Kennedy and other members of his family, concerned about preventable mental retardation and better services for the retarded, and President Johnson, citing the embarrassingly high rates of infant

\(^2\) Infant mortality rates are indicated by a number of deaths per 1000 live births unless otherwise noted.
mortality, called for efforts to improve the care of infants as part of their "Great Society" programs in the 1960s.

Trends in Efforts to Reduce Infant Mortality - 1965-Present

Since the mid-1960s, there has been a dramatic improvements in the care of critically ill infants. This has resulted in a significant decrease in the overall infant mortality rate and reductions in the level of physical and mental impairment for many surviving infants. This is due to a number of factors including biomedical advances, changes in the organization of services, such as "regionalization," and an increase in third party coverage. However, there has been little change in the rate of birth of premature infants, so that the U.S. infant mortality rate remains higher than that of many other nations.

Organizational and Technological Changes: the Development of Neonatal Intensive Care

The association of poverty and infant mortality had long been acknowledged (Baird 1952; Antonovsky and Bernstein 1977) as well as regional variation in facilities. The solution to these problems was sought in improvements in the accessibility of medical services through medicaid and regionalization. Little was done to identify and remedy the factors associated with poverty which lead to more premature births. The programs had relatively little impact on the rate of babies born at
risk. Both the medicaid program and regionalization were intended to and did provide both primary and acute services, their greatest impact was in improving access to acute services (Starr 1982).

Changes in third-party (from sources other than the patient or the patient's family, or the provider) payments from Medicaid, Blue Cross and other private companies were very important for the development of neonatal intensive care. They provided funds that allowed the development of sophisticated and expensive equipment and methods to treat catastrophically ill infants. In the past, health insurance programs often did not cover the costs of newborn care. Pediatricians lobbied and, in the 1970s, obtained law to require plans to cover care from the first day of life (Thompson 1984:805). The costs of care were not limited to what the family could afford to pay.

From 1940 to 1980, the percentage of the medical expenses paid by third-party plans increased from under 20% to over 70% of which more than half came from government sources (National Center for Health Statistics 1984). In some states, Medicaid subsidized neonatal care for others beside the poor because infants can become Medicaid eligible without their families having to deplete their resources to poverty level in order to qualify. The structure of third-party payments has provided relatively little for preventative services, and moderate amounts for ambulatory care, but has been most comprehensive for acute, hospitalized care, such as intensive care. One study found that third-party payers covered 85% of the costs for neonatal care, hospitals
absorbed an additional 11%, and individual families paid only 4% of the costs (Budetti 1981).

Intensive care units developed when the organizational and technological innovations of post-surgical recovery rooms and respiratory care units were combined with the capacities of the special care nurseries in the early to mid-1960s. The use of respirators, electronic monitoring, analysis of small blood samples, and the training of specialized staff of highly trained nurses, that characterize intensive care, all contributed to the survival of small infants.

In addition, other life saving developments of the period included the development of techniques of cardiac surgery for infants, the availability of chromosome tests for clinical use, intravenous feeding for premature infants, other improvements in the ability to deliver and monitor oxygen, better ability to regulate temperature, and application of pharmacological advances to the care of the NICU patients. Physicians, nurses, respiratory therapists, and social workers and others coordinated their efforts.

Regional networks were organized to coordinate services for obstetrical and newborn care. Regional centers developed services specializing in high risk births and the care of sick infants. Mothers and infants were transferred to these centers for tertiary care. These centers were also responsible for training clinicians from community hospitals and specialists in neonatology (Committee on Perinatal Health
1976). Some centers developed special expertise in the care of infants with certain conditions such as cardiac lesions or spina bifida.

Neonatology became a Board Certified Subspecialty in 1975. By 1981, 200 neonatal training programs were established nationwide (Budetti 1981). Neonatologists developed and used even more sophisticated technology. Some physicians sought further specialized training in both neonatology and other specialties such as neurology or surgery. Private companies selling specialized equipment and supplies began to aggressively market products for use in the NICU. Because Americans have traditionally looked toward technological solutions to problems, hospitals which had the latest equipment were able to attract staff and patients who wanted the "best" facilities.

Current capabilities of neonatal intensive care

The vast majority of infants admitted to NICUs are premature babies. The capacity to treat infants with birth injuries and congenital anomalies have developed along with care for the premature infant.

Premature Infants

Premature infants are defined as those infants who are born before completing the 37th week of gestation (of the normal 40 weeks).
Survival rates for premature infants rose dramatically as further development of respirators and other respiratory support devices, of new methods of feeding, and other techniques, revolutionized their care. The change was most striking for the treatment of very premature infants. Infants born after less than twenty-eight weeks used to be considered "non-viable fetuses" and were usually classified as miscarriages; now they are considered "live births" and many premature babies born between twenty-four and twenty-eight weeks have been successfully treated (Budetti 1981; Driscoll 1982; Stahlman 1984). (See Table III - 1, Infant Survival by Birth Weight Group.)

In 1985, at some of the major centers, over 50% of all infants 500-750 grams (1 - 1 1/3 pounds) survive, over 70% in the 750 - 1000 grams range and more than 90% of babies of 1000-1500 grams (Driscoll, n.d.).
### TABLE III - 1

**INFANT SURVIVAL (%) BY BIRTHWEIGHT GROUP**

New York City 1950 - 1980

<table>
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<tr>
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<tbody>
<tr>
<td>&lt;1000</td>
<td>&lt; 2 1/4</td>
<td>3.2</td>
<td>6.8</td>
<td>18.9</td>
<td>39.0</td>
</tr>
<tr>
<td>1001-1500</td>
<td>2 1/4 - 3 1/3</td>
<td>53.7</td>
<td>52.4</td>
<td>64.6</td>
<td>83.6</td>
</tr>
<tr>
<td>1501-2000</td>
<td>3 1/3 - 4 1/2</td>
<td>82.3</td>
<td>82.5</td>
<td>88.1</td>
<td>94.4</td>
</tr>
<tr>
<td>2000-2500</td>
<td>4 1/2 - 5 1/2</td>
<td>95.1</td>
<td>95.6</td>
<td>96.7</td>
<td>97.9</td>
</tr>
<tr>
<td>&gt; 2500</td>
<td>&gt; 5 1/2</td>
<td>98.9</td>
<td>98.9</td>
<td>99.2</td>
<td>99.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>97.5</td>
<td>97.4</td>
<td>97.8</td>
<td>98.4</td>
</tr>
</tbody>
</table>

**SOURCE:** Unpublished Statistics, NYC Dept. of Health n.d.
Although infants who are born very premature and survive have higher rates of impairment than infants who are not born at risk, most are healthy. For example, a follow-up study was conducted of the 25 infants who weighed less than 1000 grams who were cared for in the NICU at Columbia in 1977 and 1978. Two infants died after discharge, one of sudden infant death, the second due to BPD (a chronic lung condition associated with prolonged dependence on a respirator). At three years of age, 17% of the 23 survivors had neurological defects and 13% had intellectual defects. Of the four who were abnormal neurologically, two had spastic quadriaparesis, one static encephalopathy, and one hydrocephalus secondary to intraventricular hemorrhage (Driscoll et al. 1982).

A more recent study of 33 school-aged children, who had weighed 1250 grams or less at birth, three were in classes for children with major handicaps whereas 30 were found to be comparable to their classmates by teachers and/or test scores. About half of the thirty were receiving remedial instruction and/or specialized instruction, but with that help they were performing at grade level and were reported to "compare favorably with their peers" (Eilers et al. 1986).

With continued improvement in techniques to care for very premature infants, the rates of impairment for infants of a given birthweight can be expected to decrease. As new efforts are made to save yet smaller and smaller infants, these new NICU patients may have relatively high rates of impairments. Even at the lowest weight ranges,
however, well over half of the survivors do not appear to have serious impairments.

New medications to treat women who are threatening to deliver prematurely and other advances in neonatal care are likely to save more infants. Although some have suggested that medicine is approaching a theoretical limit beyond which developments in acute care may be unable to lower infant mortality, such a limit has not yet been demonstrated. The last 20 years have shown a continued ability to save premature infants formerly thought to be untreatable.

Treatment for Infants with Other Conditions

Surgical techniques were developed to enable treatment of babies born with many congenital anomalies. Open heart surgery and new drugs enabled treatment for infants with many cardiac defects. For babies born with severe spina bifida (a defect in the formation of the spinal column causing damage to the spinal cord and other anomalies), neurosurgical techniques were developed to close the spinal lesion and shunt excess fluid from the brain. There have been increased capabilities, in general, to perform surgical techniques for smaller and smaller infants. For example, surgery can be performed to repair many complex intestinal conditions.

Progress in respiratory therapy enables better treatment not only for infants who are premature but also for asphyxiated babies who have
suffered from lack of oxygen before, during or immediately after birth. Improvement in pharmacological techniques has led to a greater ability to handle infections, circulatory problems, and other conditions. Greater ability to support infants with total parenteral nutrition enables clinicians to sustain infants who cannot tolerate oral feeding for a long period of time.

A new, still experimental, technological apparatus, ECMO (extra-corporeal membrane oxygenation), enables treatment for some babies who formerly could not have been saved. It is a device which oxygenates the blood, by-passing the lungs and heart, in a manner somewhat similar to the heart/lung pumps used for shorter periods of time during open heart surgery. It can be used in the treatment of infants with a diaphragmatic hernia, persistent fetal circulation, or who are badly asphyxiated (who have suffered from lack of oxygen). A baby on ECMO needs at least 24 hours of care from both surgeons and nurses each day. Infants have been sustained on ECMO for as long as two weeks. Only a few centers in the country are now using this device; Columbia is the only center with ECMO between Boston and Washington, D. C.

In addition to saving the lives of many critically ill infants, NICU care has prevented impairments for many others who would have survived even without intensive care, but who would have had disabilities. Although infants who were in an NICU have an higher incidence of impairments than other children, the vast majority of NICU survivors have no lasting impairments (Shapiro, et al. 1983; McCormick 1985).
Over two billion dollars is spent each year on the provision of care for the six to seven percent of all babies born in the U.S. who are admitted to close to 600 NICUs each year (Budetti 1981; Institute of Medicine 1985). In 1983, there were 545 NICUs, with 8,067 beds, an average of 14.8 per unit (up from 413 units and 6,187 in 1980) (Richards 1985:67).

Recent information on infant mortality

The overall U.S. infant mortality rates have been sharply reduced from 24.7 in 1965 to 10.9 in 1983 (Miller 1985). Part of the reduction is due to greater availability of family planning and abortion services which have lowered the rate of birth to high risk mothers (Lee et al. 1976), but most of the reduction results from better treatment of premature and other acutely ill infants (Budetti 1981).

Despite the improvements in acute care which has led to tremendous strides in the ability to treat prematurely born infants, relatively little has been done to correct those factors which led to a high rate of birth of premature infants. 6.8% of all babies born in the U.S, in 1981 were low birth weight. Therefore, despite advances in technology, which greatly increased the rate of survival for low birth weight babies, the U.S. infant mortality rate still ranks 17th among industrialized nations (Miller 1985).
The association of socioeconomic factors, including race and social class, with the rate of birth of preterm and low birthweight infants has been well documented (Antonovsky and Bernstein 1977; Miller et al. 1985; Institute of Medicine 1985). Infant mortality rates among Blacks, at 19.6 per thousand, are nearly twice as high as among whites. In 1982, 124 of each 1000 black babies were of low birth weight while the rate for whites was only 56 per 1000. In some areas, the sociodemographic difference is even more striking. For the primarily poor residents of Central Harlem, the 1983 infant mortality rate was 21.2, while for the primarily prosperous residents of Manhattan's Upper East Side, the rate was only 7.2 (NYC Dept. of Health 1983).

Because of the primary thrust of expenditures for health care has been to cure rather than to prevent, less has been done to prevent the births of infants at risk than to cure them once they are born. While social and health services have not been adequate to significantly affect the risk of low birthweight associated with sociodemographic characteristics (Institute of Medicine 1985), high quality of neonatal intensive care has been made available to infants of all social classes. A study showed that in New York City, once a baby was born, the chance of surviving the neonatal period for babies in a given weight category did not vary significantly with socioeconomic factors (Paneth, et al. 1982).

Sociodemographic characteristics are strongly associated with post neonatal infant mortality rates. For example, the 1983 death rate of infants 1 month to 1 year was only 1 per 1000 on the Upper East Side,
but 11.7 in Central Harlem (New York City, Dept. of Health 1983). Recent increases in infant mortality rates in some areas have been shown to be associated with cut backs in programs for mothers and children and increased economic stresses (Newland 1981; Miller 1985; Miller et al. 1985).

Studies have shown that increased use of prenatal care would be cost effective by reducing later health care expenditures for low birthweight infants (Institute of Medicine 1985). Improvements in the standard of living and the provision of better primary health care services for babies would also decrease the infant mortality rate. ³

Mortality rates especially for small premature infants declined rapidly. Neonatal units became showcases for the power of modern medicine.

³ The clinicians who deliver neonatal intensive care do not usually have the choice of giving more preventative and other primary care. Rather, the resources available for different types of care are now determined primarily by public policy decisions governing the availability of medicaid and other third-party payments, and to a lesser extent, by funds for research, training, and social service programs. It is important to realize that acute interventions and preventative measures need not be conceptualized as mutually exclusive choices. Further reductions in infant mortality would probably result from more investment in each of these area.
Concerns About the Aggressiveness of Treatment for Catastrophically Ill Newborns

Despite the overall feelings of pride, new concerns began to emerge. For the first time, large numbers of infants with similar problems were brought together and cared for by specialists. Many centers provided post-neonatal care for children with impairments. Some specialists came to see severely impaired babies not as isolated cases, but as part of a group of cases for which newly developed techniques were doing more harm than good. Whereas previously, an isolated practitioner and/or family might have privately decided to allow an individual baby to die, practitioners at some regional centers now began to discuss some treatment decisions as part of a new problem brought on by technological advances.

The concern with the ethics of neonatal decision making arose in the context of a growing concern with biomedical ethics in a number of arenas. These included concern with the protection of human subjects, with abortion, and with decisions about the cessation of treatment prompted, in part, by questions about the use of cardiac resuscitation, respirators and organ transplantation (Pres. Comm. 1981) and the increased interest in "death and dying" (Kubler-Ross 1969). These led to a questioning of the major assumption guiding medicine in the preceding period -- that death should be "fought" with aggressive treatment. It also occurred, in part, because of wider social trends in American Society which involved questioning of professional authority, not only in the health arena (exemplified by IRBs and the natural
childbirth and women's health movements) but in such areas as educational reform and the peace movement (Barber 1978; Rothman, lecture at Columbia 1984). The ecology movement was growing, with fear about the inappropriate use of technology. In addition, there was increased concern with mental retardation and disability rights. The late 1960s and early 1970s was also a time of much public debate about over population, birth control and abortion.

The Beginning of the Debate About Selective Non-treatment

Those who write about withholding medical treatment from newborns often assume that the debate on the issue began in the early 1970s with the publication of articles by Lorber (1971), and Duff and Campbell (1973). There is evidence from multiple sources, however, that even when there was the capacity to do so, infants were not always given maximum treatment to prolong life. For example, in 1921 an opponent of euthanasia quoted an advocate as writing:

In one instance, in the case of a child suffering from hydrocephalus and beyond hope of cure, only the most constant attention could keep him alive; the matron finally somewhat relaxed her vigilance in seeing that he was cared for, and indigestion carried him off. ... death is brought on by neglect rather than by administering a drug.

(Spaulding 1921:235-6)

The extent to which clinicians intentionally allowed death to occur through withholding treatment is unclear since physicians rarely
wrote about such practices. Even during the beginning of the aggressive period of neonatal treatment such practices and discussion about them evidently continued. In a 1961 editorial in the *Journal of Pediatrics*, Veeder wrote:

> One of the present day medical "ethical conflicts" revolves [around] ... the "prolongation of death" by the use of recently developed techniques, such as transfusion, intravenous feeding, fluid therapy, and the cardiac pacemaker, along with the development of such drugs as the antibiotics.

(p. 604)

He goes on to discuss the treatment of a condition he refers to as "mongolian idiocy" noting that the causative mechanism was only discovered within the last two years. He states that "nature" had provided a "compensating abnormality ... low resistance to infection" which usually led to death but that with the use of "modern techniques and the newer drugs ... the Mongol continues a vegetative existence, worthless to himself and a burden to his family and society." He asks if "the use of 'miracles of modern medical science'' and "interference with the process of nature [is] justified in this condition?" He states that "the brilliant development of cardiac surgery" during the last few years, adds to the problem.

In reference to attitudes towards use of these treatments, he states "opinion is divided. There is one group with a decided 'yes' answer and another with a decided "no." A third group believes in selective judgement." He concludes that ethical problems are matters which cannot be decided by majority vote, rather, each physician "has to decide for himself [sic.]"
In 1963, a group of physicians agreed to withhold treatment when a mother (who was a nurse) and father refused to give consent for corrective intestinal surgery for an infant with Down's syndrome. The physicians felt that the Courts would not order the surgery over the objections of parents (Gustafson 1973).  

Although many authors assert that aggressive treatment for infants born with Spina Bifida became the norm only after modern neurosurgical techniques were developed in the late 1950s, some surgeons advocated aggressive treatment even earlier (Ingraham and Hamlin 1943; Bluestone and Deaver 1953). Even some of the early supporters of aggressive treatment felt that it was sometimes appropriate to withhold treatment for medical or social reasons. For example, in 1961, two British physicians wrote:

In deciding his attitude to the problem of spina bifida cystica, the neurosurgeon must obviously consider first the conflicting claims of all the various types of disorder, both congenital and acquired, in adults as well as in infants and children, with which he is called upon to deal, together with the resources in terms of hospital beds, operating time and the like, to which he has access. There is also the question of whether it is likely that adequate after-care, both from the medical and from the social point of view, can be provided for children with varying degrees of physical, and possibly mental, handicap. The prospects of this will undoubtedly vary considerably between countries, perhaps from industrial to rural areas in the same country, according to the attitudes and financial status of the parents, and to some extent to the size and potential helpfulness of the family unit.

(Doran and Guthkelch 1961:342)

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4 This case, which has come to be known as "The John Hopkins Case" has been widely discussed in the debate on the treatment of newborns (see below).
Some physicians in the United States (Bucy 1960, Matson 1968), England (Hide, Williams and Ellis 1972), Scotland (Stark and Drummond 1973) and Australia (Medical Journal of Australia 1971) practiced selective non-treatment throughout the 1960s.

Commonly, people who write about the issue of withholding treatment from newborns, date the beginning of the debate with articles by Lorber and Duff and Campbell in the early 1970s. There were, however, many early articles and letters in the clinical literature about withholding neurosurgery from some infants with Spina Bifida. (Forrest 1964, 1965, 1967; Sweetnam 1965; Eckstein 1965; Sharrard, Zachary and Lorber 1967; Zachary 1968a, 1968b; Sanders 1968; Wickes 1968; Fernandez-Serrats, Guthkelch and Parker 1968; Matson 1968; Zachary 1969; Bluestone 1969; McCann 1969; Shillito 1969; Katzen 1971; Lightowler 1971; MacKeith 1971; Lorber 1971; Medical Journal of Australia 1971; Slater 1971; Freeman 1972; Cooke 1972; Hide, Williams and Ellis 1972; Eckstein, Hatcher and Slater 1973; Hunt, Lewin, Gleave and Gairdner 1973; Lorber 1973; and Freeman 1973) withholding surgery from infants with other conditions, (Rickham 1969; Hesse 1971; Shaw 1973), withholding resuscitation (Véghelyi 1970) and/or other treatments (Crocker and Cushna 1972; Engelhardt 1973; Gustafson 1973; Harris 1973; Duff and Campbell 1973) from some infants with impairments (see Chapter VIII for a more detailed examination of the published debate on the issue following an article by Zachary (1968).)
In October of 1971, the Joseph P Kennedy Jr. Foundation held an International Symposium on Human Rights, Retardation and Research. The symposium began with a film, Who Shall Survive?, about the John Hopkins case. The case was discussed by prominent ethicists, lawyers, and social scientists, as well as clinicians. The symposium was written up in the Boston Globe (Crocker and Cushna 1972). An article by pediatric surgeon Anthony Shaw, appeared in the New York Times Magazine Section on withholding surgery from infants. Another article about a case in which a hospital obtained a Court order to treat an infant with Down's syndrome after parents refused surgery appeared in Life magazine (Harris 1973).

Despite over twenty-five articles, including a few in the popular press, published by 1973, many date the inception of the debate on non-treatment of newborns to the publication of two articles in the early 1970s. The first article was published in England by Lorber in 1971; the second was published in the United States by Duff and Campbell in 1973. One can speculate as to why these are seen as the landmark articles. Although Lorber, and Duff and Campbell, might have advocated withholding treatment in more cases than many other clinicians would have, it appears that selective non-treatment per se did not run contra to professional norms. Rather, it might be suggested that what was most controversial about their approaches was the manner that each advocated for making selective non-treatment decisions.

It appears that most clinicians at the time saw non-treatment decisions as essentially medical decisions to be made by physicians on a
case by case basis. Both Lorber's and Duff and Campbell's positions ran
counter to these norms, though in radically different ways. Lorber
advocated the use of explicit standardized criteria to be used in all
cases. Duff and Campbell advocated parental decision making which could
be expected to vary from case to case. Perhaps it was these positions
which were most controversial. Or, perhaps, political or personality
factors may have influenced the reactions.

Ethical and Social Concerns About the Treatment
for Catastrophically Ill Newborns, 1973 - 1982

For the following decade, clinicians and bioethicists continued to
debate questions about the care of newborns. The debate had two main
dimensions 1) Should all babies be treated? If not, which babies shall
live?, 2) Who should decide? Starting in the mid-1970s, there were
numerous articles, conferences, and research groups both in clinical and
academic settings; the papers presented at some of the conferences were
published as edited volumes (Jonsen and Garland 1976; Roy 1978; Swinyard
1978). Selective non-treatment of infants with impairments became one
of the most prominent issues to be addressed by philosophers, lawyers,
clinicians and others interested in bioethical issues.5 Virtually all

5 Robert Weir, in his monograph Selective nontreatment of
handicapped newborns (1984) and the chapter on newborns in the
President's Commission Report (1983) both provide excellent overall
reviews of clinical, legal, and ethical perspectives on the issues
involved in decision making about the treatment of newborns.
of the issues of 1973-1982 continue to be debated. (Some additional issues are now part of the debate as well, as will be discussed below).

An article entitled "Infants" from the Encyclopedia of Bioethics (Infants 1978) provided one the best contemporary reviews of the issues. Hempill and Freeman began their section on "Medical aspects and ethical dilemmas:"

The ethical dilemmas in the medical care of infants are primarily the consequences of several developments: an increased ability to save the lives of infants who formerly would have died ... directing concern toward their future quality of life; improved capability in diagnosing disease and disability in advance of their manifestations; and an attitude which takes seriously the dilemma of decision making by others on behalf of the infant.

This article will delineate the highly complex issues involved in decision making in infant care as seen from a medical perspective, including birth defects; problems when the outcome is unpredictable, experimentation with infants; and the management of infants selected for nontreatment.

(Infants 1978:717)

Similar to the issues in the care of the critically ill adults (see Chapter II), clinicians and bioethicists discussing the care of the newborn considered the type of problems -- mental or physical, progressive or static, terminal or not terminal. In addition, unpredictability of the outcome, which is even more common for newborns than for older adults was seen as an issue. Options in the management of children who were not to be treated were also discussed. Differentiations were made between active and passive euthanasia. The goals of "preserving life" and "doing no harm" were seen to conflict (Infants 1978:717-722).
The roles of possible conflicting interests of the infant (interests in both sanctity of life and quality of life), of the family, of the health personnel and of society were considered. Since infants cannot make decisions about their own care, and they have no personal history on which to base decisions, there was debate about who should be empowered to make decisions on behalf of the patient. Decision making by parents, by physicians, joint decision by parents and physicians, and decision making by committees was advocated by various parties. Questions were raised about the appropriateness of court review, or a priority of responsibilities in decision making (Infants 1978:722-724, 738-39).

Also in the Encyclopedia of Bioethics, Reich and Ost wrote a section on ethical perspectives on the care of infants. In outlining the ethical theories applied by philosophers and theologians, they listed the following:

... (a) traditional deontological positions: (b) contemporary positions emphasizing a rethinking of the concept of "person"; (c) consequentialist; and (d) approaches rejecting the "humanhood" standard and proposing either an ethic of care or an ethic of avoiding harm (a negative formulation of the consequentialist positions).

(1978:724)

Deontological or rule based principles for decision making included views of human life as a sacred trust, to be protected, both by not deliberately killing an innocent human being, and an obligation to sustain human life, especially on the part of those who have the...
responsibility of caring relationships (Infants 1978:726-727). In addition, as for adults, distinctions were made between ordinary and extraordinary means, omission and commission, and prolonging life and prolonging dying. Some philosophers advanced consequentialist, or utilitarian positions, challenged those distinctions, advocating instead, consideration of the effects of choices both for the baby and for society. Some philosophers advocated active euthanasia, in order to spare infants the pain and suffering which could result from the withholding of treatment (Infants 1978:726-735).

While consideration of the meaning of life and the definition of personhood or humanhood have been an element in discussion of care of critically ill adults, it has been an even more important issue in discussions about treatment for infants. For example, Joseph Fletcher proposed 20 elements of "humanhood," including cerebration, self-awareness, intelligence, self-control, control of existence, and communication." He felt that babies who did not possess these elements (e.g. infants with Down's syndrome and/or IQ below 40 - questionable, below 20 - not a person). Others have supported a much more inclusive definition of infants who should be treated. For example, McCormick suggested as a criterion, the potential for human relationships (Infants 1978:732-735).

Another concern of those discussing ethical issues pertaining to neonatal decision making was the high cost of care and the allocation of health care resources (Infants 1978:739-40). Frequently, comparisons were made between the high cost of intensive care and the benefits that
could result from an equal investment in preventative and primary care. A Hastings Center research group formed to examine issues related to NICU care; allocation of resources was a major issue.

Throughout the 1970s and early 80s occasional articles or stories appeared in the popular media on decision making in neonatology. One that was widely cited by clinicians "On the death of a baby." It appeared in the Atlantic Monthly in 1979. It was written by Peggy and Robert Stinson, parents of a very premature infant. Their son, Andrew, had been treated for months in an intensive care unit and died after suffering many iatrogenic complications.

Many of the clinicians who worked in neonatal intensive care were familiar with the perspectives of bioethicists and other clinicians; they were aware of the feelings of parents, such as the Stinsons, who had objected to NICU care for their children. Some neonatal units established ethics rounds or had discussions about ethics in regular teaching rounds. Courses on ethics and values were established in many medical schools, schools of nursing and other health sciences programs. Most included discussion of the issues involved in decision making about catastrophically ill newborns.

Another area of social concern, which did not appear to have much salience with clinicians until the 1980s, was the linking of neonatal decision making with the issues surrounding abortion and the "right to life." Some anti-abortion activists saw non-treatments of infants as a
second step on a path from abortion, through infanticide to euthanasia and genocide. For example, one activist said:

Speaking as the official American witness at the Nuremberg doctors trials, Dr. Leo Alexander commented on the genesis of the medical atrocities revealed during the proceedings. "What ever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitudes of physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived."\(^6\) Today we can see the same shift in attitude occurring in American medicine. We can see the substitution of a "quality of life" ethic for a "sanctity of life" ethic and a discarding of our Hippocratic traditions in favor of the cost-benefit morality of the new technology.

(Diamond 1982:55)

One strong proponent of such a position was Everett C. Koop, later to become Surgeon General of the United States. In 1982, he wrote:

Infanticide is the killing of a born infant by direct means or by withholding something necessary for its survival. This practice in the United States is extraordinarily important to those who are interested in the sanctity of human life because infanticide might never have come about had it not been for abortion on demand. When I read, in the months following the January 22, 1973 decision of the Supreme Court in Roe v Wade, various references to Justice Blackmun's majority opinion in that case, my blood ran cold. You will remember that he considered the Hippocratic Oath which forbids abortion to be irrelevant. He spurned whatever morality he might have gleaned from the Judeo- Christian heritage of this country and turned instead to the pagan religions of Rome, of Greece, and of Persia. Although those countries practiced abortion, it was infanticide and euthanasia which were more important inhumanities in their cultures.

(Koop 1982:90)

In the 1980s, Disability Rights activists also began to be concerned about neonatal decision making, both for the sake of the newborns, and also a concern with the implications of selective non-treatment for social value setting concerning society's attitudes for people with disabilities (Anne B. Swanson, personal communication 1984). For example, Asch and Fine state:

Unacknowledged by those who deny treatment is ... discrimination against people with disabilities. Such prejudice is found throughout the population and thus it is no surprise although quite dismaying to see people who decry discrimination on the basis of race, ethnicity, gender, sexual orientation or social class urging that public policy embody their fears, terrors, revulsion and ignorance of disability and people with disabilities. Millions of citizens with biological limitations would assert that their main obstacles to fulfilling lives stem not from these limitations but from a society which stresses mental and physical perfection and rugged individualism, that often rejects, isolates and segregates them, assuming that disabled people are unpleasant, unhappy, helpless, hopeless and burdensome.

Such stereotypes lead inevitably to the first of three major arguments given for non-treatment: that the child's quality of life will be intolerable. We ask: intolerable to whom? How do we know? And, if that child's quality of life is less than someone else's, how much do we as a society contribute to its impoverishment by denying needed health care, education, independent living, rehabilitation and social supports to ensure a better life? We do not know what the lives of any children will be when they are born. People who decide that Down's Syndrome or spina bifida automatically renders the children or adults "vegetables" or "better off dead" simply know nothing about the lives of such people today -- much less what those lives could be in a more inclusive, person oriented society.

(Asch and Fine 1984:52-53)

Over the past two decades, the debates by clinicians and bioethicists on issues of neonatal decision making have only become more intense.
The Law and Legal Cases Concerning the
Withholding of Treatment From Newborns

The applicability of various laws to the treatment of catastrophically ill newborns has never been clear. A number of different bodies of law have been seen as appropriate to the regulation of treatment decisions by various legal scholars. These include states laws pertaining to child abuse and neglect (Shatten and Chabon 1982), civil liability (Ellis 1982) and criminal law pertaining to murder (Ellis 1982). In addition, some have asserted that federal law proscribing discrimination against the handicapped (DHHS 1983) and constitutional law pertaining to the rights to privacy, equal protection and due process are applicable to decision making about the care of newborns.

At the time that I did the majority of the field work on which this study is based, as well as during the time since then, the clinicians whom I studied, like many others who sought a sophisticated understanding of the law, were not sure about the legal status of various clinical decisions to withhold treatment. In this section, I will briefly review some of the more important cases and events pertaining to the law and non-treatment of newborns. No attempt will be made here to reach conclusions about the constitutionality of any of the decisions or the legal basis of the laws. More thorough reviews of the law pertaining to newborns have been written by Shatten and Chabon
Some legal scholars assert that decisions to withhold treatment from catastrophically ill newborns fit the legal definition of murder; they believe parents and clinicians could face charges ranging from manslaughter to murder. Murder is the "deliberate killing of one person by another." First degree murder is "willful, deliberate and premeditated killing" (Ellis 1982:402). Ellis asserts that such factors as good motives, active or passive euthanasia, and/or the terminal illness of the infant would not provide a defense against a charge of first degree murder. Although theoretically possible, no parents or physicians have ever been found guilty of criminal charges because they withheld or withdrew treatment from a catastrophically ill newborn.

In one case in Danville, Illinois, parents and a physician were charged with attempted murder and thirteen other charges when they were accused of withholding treatment from conjoined (Siamese) twins who were born in May of 1981. The mother of the twins, Pam Mueller, was a registered nurse; the father was an emergency room physician in the hospital where the twins were delivered. When the twins were delivered, joined with a single trunk below the waist, and sharing three legs (and internal organs), the obstetrician decided not to resuscitate; the parents concurred. The twins started to breathe spontaneously. An order -- "Do not feed in accordance with the parents' wishes" -- was written on the medical chart.
An anonymous caller reported the case to the Illinois Department of Children and Family Services. The department filed a petition of neglect against the parents, temporary custody was granted to Family Services, and the children were moved to another hospital for evaluation. On June 11th, when the infants were five days old, the parents and the attending physician were charged with conspiracy to commit murder. When a hearing was held, no witnesses were willing to give testimony linking the parents and physician directly to the order to withhold food from the twins. The charges were dismissed. Four months later, custody of the twins (who could not be separated) was returned to the parents. They were brought home. Although they were only expected to live for a few months, five years later they are still alive. (Material on this case derived from Taub 1982; Weir 1984).

The case in Danville received much national publicity. Although criminal charges have been threatened in other cases, I believe that the case in Danville remains the only one in which criminal charges have actually been made. Some clinicians and parents fear that decisions to withhold treatment will lead to criminal charges.

The body of law that has more regularly been applied to cases involving non-treatment of newborns has been the child abuse and neglect statutes. According to Shatten and Chabon (1982), in general, the law has granted deference to the rights of parents to make decisions for their children, including medical decisions. Parents have a legal duty to care for their children. There is a legal presumption toward giving life saving treatment. If the parents refuse consent for treatment, and
the child is found to be dependent or neglected, the Court can order treatment. Shatten and Chabon state:

Resolution of dependency and neglect cases requires more than mere factual findings; in all but the most obvious cases it required the court to balance competing interests. This balancing reveals an effort by the courts to refrain from interfering in socially, emotionally, medically, and legally private matters, yet to ensure that children, whose parents really are not acting in their best interests, will not remain uncared for. The line between matters reasonably subject to state intervention and private family matters is often difficult to draw.

(1982:63)

There have been a number of cases in which physicians have gone to Court when parents have refused to give consent to treatment. Decisions have been made both to require treatment and to permit parents to refuse treatment. Therefore, there seems to be no clear legal precedent on the basis of state law pertaining to child abuse and neglect.

For example, in 1974, a baby boy named Houle was born at the Maine Medical Center. He had no left eye, a rudimentary left ear, and a tracheoesophageal fistula (necessitating IV feedings and allowing fluid to enter the lungs, bringing about pneumonia) among other defects. Brain damage was suspected. One physician stated that he didn't think that the baby should be treated, but the attending physicians and pediatric surgeon did. When the parents refused to give consent for surgery, the physicians initiated a neglect case. The judge ordered surgery saying "the existence of the child herein gives the court equitable jurisdiction to fulfill the responsibility of government in its character as parens patriae to care for infants and protect them from neglect." Despite the surgery, the baby died the next day (Weir
Similarly, the Court ordered surgery for a baby girl who was born with meningomyelocele in New York City in 1979 (Taub 1982).

In other cases, however, the Courts have upheld the parents' decisions to refuse consent for medical treatment. For example, in 1972, physicians from John Hopkins were unsuccessful when they sought to obtain a Court order for corrective surgery for a child with Down's syndrome and an intestinal obstruction (Ellis 1982). Physicians were also unsuccessful in obtaining orders for treatment in what was to become the most famous non-treatment case concerning the infant who became known as "Baby Doe."

Baby Doe was born in Bloomington, Indiana on April 9, 1982. He had Down's syndrome and an esophageal atresia with associated tracheoesophageal (TE) fistula. At the time of his birth, he was also thought to have an enlarged heart. His physicians were divided about his care. Without surgery, he could not take nutrition by mouth. Some of his doctors argued that surgery to correct the defect had an 85–90% chance of success, while others argued that the chances of success were only 50–50. His parents refused consent and surgery was not performed. He was not given IV nutrition or fluids; he was given sedatives.

The administrators of Bloomington Hospital sought legal advice on the possibility of legal intervention to require surgery. In an emergency hearing, a circuit judge ruled that the parents had the right to withhold treatment. The judge appointed the Monroe County Welfare Department as guardian ad litem; they decided not to appeal the judge's
ruling. The next day, the county prosecutors intervened and the judge encouraged an appeal of his own ruling by appointing one of the prosecutors as guardian ad litem. He filed an emergency petition with the circuit court which failed. The prosecutors then appealed to the Indiana Supreme Court which conducted an informal hearing. The justices voted three to one not to intervene. According to Weir, they were apparently concerned about second-guessing physicians on medical matters.

After the Supreme Court decision, the prosecutors flew to Washington in an attempt to bring the case to the Supreme Court. They planned to raise the issues of whether the child had a right to continue living under the 14th amendment, was denied Due Process, and/or if the child was denied Equal Protection because of his handicap. While they were en route to Washington, Baby Doe died. (Material on Baby Doe is derived from Pless 1983; Weir 1984; Lyon 1985.)

This case received much national publicity. In response to the case, President Reagan instructed Richard Schweiker, Secretary of the Department of Health and Human Services to notify health care providers that recipients of federal funds are forbidden "from withholding from handicapped citizens, simply because they are handicapped, any benefit or services that would ordinarily be provided to persons without handicaps" (Weir 1984:131). Such a notice was sent in May of 1982. It informed health care providers that they risked losing federal funds if they did not comply. Other efforts were begun to pass laws in Congress
to involve the federal government in selective non-treatment decisions; that year, the efforts were unsuccessful (Weir 1984:132).

When I did the most intense period of observation in the neonatal unit in the Fall of 1982, federal efforts at intervention had little visibility. Most of the clinicians had been aware of the Baby Doe and Danville decisions. Many were aware of other neonatal cases. There was growing public awareness of neonatology because of these cases, and occasional TV shows and articles in the popular press. The issue of neonatal decision making was primarily conceptualized as an ethical issue of concern to bioethicists, clinicians, and the parents of catastrophically ill newborns. In the following year the public awareness of the issue of neonatal decision making was to rise dramatically.

In the Spring of 1983, President Reagan announced plans to enforce the 1982 regulations issued by the Department of Health and Human Services by requiring signs to be hung in every nursery, obstetrical unit, and pediatric unit, installing a toll free hotline for reporting cases to the federal government, and establishing mechanisms to investigate reported cases. The regulations, opposition from the major health organizations and others, and related court decisions and revisions received much national publicity.

Also in the Spring of 1983, the President's Commission for the Study of Ethical Problems in Biomedicine and Behavioral Research published an influential report, Decisions to Forego Life-sustaining
Treatment. It promoted the use of a standard based on "the best interests of the baby" for making neonatal decisions. The Commissioners believed that in some cases, those interests were best served by decisions to forego life saving treatment. They recommended review of such decisions by hospital-based ethics committees (Pres. Comm. 1983). The report received much attention from the media.

In 1983 decision making for catastrophically ill newborns had become a public issue. The issue remained prominent in the Press throughout 1983 when there was extensive media coverage concerning court cases about the care of a child with spina bifida, known as "Jane Doe," who was born in New York that Fall. The case of Jane Doe is discussed in Chapter VII; the Baby Doe Regulations, including federal child abuse regulations, are discussed in Chapter VIII.

Research on Neonatal Decision Making

Although there has been much written on clinical decision making about neonates, especially during the past two years (including such books as Frohock 1986; Gustaitis and Young 1986; Kuhse and Singer 1985; Lyon 1985; Magnet and Kluge 1985; Murray and Caplan 1985; Weil and Benjamin forthcoming; Weir 1984) there has been little systematic social science research on the topic. There have been a number of surveys of attitudes of clinicians. Social scientists have conducted research on neonatology, including two in depth observational research studies on
neonatal decision making (Anspach forthcoming; Guillemin and Holmstrom 1986), which will be reviewed briefly in the following section.

Surveys

Between 1970 and 1982, there have been at least eight surveys of pediatricians' and other clinicians' attitudes about treatment for catastrophically ill newborns (Crane 1975; McKilligin 1976; Johnson and Garland 1976; Shaw, et al. 1977; Todres et al. 1977; Singer, et al. 1983; Levin 1985). An additional study is currently nearing completion (Guillemin 1985).

I will try to draw some general conclusions, although it is difficult to make comparisons because there were major differences in the design and phrasing of questions on the surveys. On each of the surveys, most clinicians expressed support of selective non-treatment for some cases. On the three surveys where clinicians were specifically asked if there were circumstances in which it is appropriate not to sustain life, 83% to 100% of the respondents agreed that for some infants, some aggressive treatments are not mandatory (Jonsen and Garland 1976; Shaw et al. 1977; Singer et al. 1983).

Respondents expressed less consensus when asked about treatment in specific cases. For example, when asked about treatment for infants with Downs syndrome and other complicating conditions, which would be routinely treated for newborns without impairments, four of the surveys
from the 1970s indicated that approximately half the clinicians would
treat aggressively (Crane 1975 [based on combined data on two
vignettes]; McKilligin 1976; Todres et al. 1977; Shaw et al. 1977). On
a survey conducted shortly after the announcement of the first "Baby Doe
Directives" in 1983, almost 90% of the respondents said they would
recommend intestinal surgery for a baby with Down's syndrome (Levin
1985).

On those surveys which asked about treatment of infants with
meningomyeloceles at various levels and with various social and medical
complications, 33% to 73% responded that that would recommend
neurosurgery (Crane personal communication; Shaw et al. 1977; Todres et
al. 1977).

Although selective non-treatment is often thought of in terms of
"giving treatment" or "withholding treatment," in a modern hospital, a
patient is virtually never "not treated" in the sense that no treatments
are given. Rather, decisions about both giving and withholding
treatment involve decisions about which treatments to give and which to
withhold from the range of possibilities. Therefore, the important
questions include not only: "Who should be treated?" and "Who should
decide?" but "Which treatment should be given and which should be
withheld?"

Since clinicians give patients some treatments while they withhold
others from the same patients, they make distinctions based on
characteristics of the treatments as well as characteristics of the
patients. Such distinctions have been made for a long time and characterize decision making at least in the English speaking medical community. When Singer and his associates surveyed Australian pediatricians in 1981-82, more than three-quarters responded that they felt that it was important to distinguish between ordinary and extraordinary means of preserving life.

Variations in the rate at which clinicians would recommend withholding different treatments was reflected in the marginal data from Crane's survey, conducted in 1970-71 (see table III - 2).
**TABLE III - 2**

TREATMENT OF CONGENITAL ANOMALIES AND SEVERE BIRTH DEFECTS IN NEWBORNS

<table>
<thead>
<tr>
<th>% who would give each treatment</th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
</table>

1. INFANT WITH HYPOPLASTIC LEFT HEART

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intravenous fluids for maintenance</td>
<td>63</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Medical management of congestive heart failure (i.e. digitalis, diuretics, oxygen)</td>
<td>77</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Catheterization for diagnosis</td>
<td>60</td>
<td>17</td>
<td>21</td>
</tr>
<tr>
<td>Antibiotics for infection</td>
<td>52</td>
<td>20</td>
<td>25</td>
</tr>
<tr>
<td>Bag-breathing for respiratory distress</td>
<td>22</td>
<td>29</td>
<td>46</td>
</tr>
<tr>
<td>Respirator for respiratory distress</td>
<td>16</td>
<td>24</td>
<td>58</td>
</tr>
<tr>
<td>Resuscitation for cardio-respiratory arrest</td>
<td>17</td>
<td>13</td>
<td>66</td>
</tr>
</tbody>
</table>

2. INFANT WITH HIGH LUMBAR MYELOMENINGOCŒLE
   (20 y.o. parents, not H.S. grads)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local antibiotic for myelomeningocele</td>
<td>41</td>
<td>14</td>
<td>40</td>
</tr>
<tr>
<td>Operation - early closure of defect</td>
<td>53</td>
<td>22</td>
<td>23</td>
</tr>
<tr>
<td>Manage urinary tract infection</td>
<td>72</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Perform crede massage on the bladder</td>
<td>44</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Shunt if hydrocephalus developed</td>
<td>47</td>
<td>21</td>
<td>28</td>
</tr>
<tr>
<td>If meningitis developed, would you treat?</td>
<td>60</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>If cardiac arrest, resuscitate?</td>
<td>20</td>
<td>15</td>
<td>62</td>
</tr>
</tbody>
</table>
TABLE III - 2 (cont.)

% who would give each treatment

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. 1500 gm. INFANT WITH DOWNS' AND RESPIRATORY DISTRESS (35 y.o. Mom wants child, limited financial resources)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perform appropriate cultures (blood, CS</td>
<td>73</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Treat with antibiotics</td>
<td>72</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Correct acidosis</td>
<td>83</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Pneumothorax, aspirate chest?</td>
<td>65</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Stops breathing 2 min., bag breathe 2-3 hrs?</td>
<td>20</td>
<td>22</td>
<td>58</td>
</tr>
<tr>
<td>Respirator if apneic spells continue?</td>
<td>21</td>
<td>26</td>
<td>53</td>
</tr>
<tr>
<td>Resuscitate if cardiac arrest?</td>
<td>19</td>
<td>14</td>
<td>66</td>
</tr>
</tbody>
</table>

Based on responses from national sample of 232 pediatricians. Unpublished data from a larger study (Crane 1975).
Observational Studies of Neonatal Intensive Care

A number of social scientists have conducted studies in neonatal intensive care units. Some have focused on the reactions of parents (Barnett et al. 1970) or their perceptions of their infants, on communication and interactions between staff and parents (Bogden, Brown and Foster 1982; Sosnowitz 1984), or on ethical issues involving families from different subcultures (Clausen 1985). Two social scientists reported their own experiences, and those of their older daughter, following the birth of their catastrophically ill newborn (Scrimshaw and March 1984). Some have examined the environment for infants (Newman 1980; Glass 1985). Other have looked at social factors pertaining to staff interactions with other staff members and patients (Weiner et al. 1979; Brody and Klein 1980).

There have been two major studies of neonatal care based primarily on participant observation. The first, by Renée Anspach, examined life and death decisions in two neonatal intensive care nurseries. She examined decisions from the standpoint of the sociology of knowledge, relating decision to the social context in which they took place. A major finding is that attending physicians, residents and nurses, because of their experiences in the intensive care nursery, differ systematically in their views of infants' prognosis. She also discusses such issues as uncertainty in medical decision making, negotiations between parents and practitioners and negotiations among staff (Anspach forthcoming).
Guillemin and Holmstrom (1986), in a new study just published on neonatal intensive care, report on their participant observation research in a neonatal intensive care unit and visits at fourteen other units in the U.S. and six other countries. They report on professional roles and responsibilities, the process of clinical decision making, and on the family in the NICU. They situate decisions within the larger context of the national organization of health care. They were struck by the similarities in organization and behavior from unit to unit in all of the NICUs they studied.

Although there are some differences between the units studied by Guillemin and Holmstrom and Anspach and the unit at Columbia, much of the process of decision making they describe is similar to that which I observed. Accounts in both studies reflect the importance of clinicians' conceptualizations of characteristics of patients and treatment. As I found at Columbia, there is variation in the categorizations of particular patients and/or treatments; overall the categorizations are similar. The decision making appears to be guided by the same norms and goals as those that will be discussed below.
CHAPTER FOUR

CHOICE THOUGHTS:
CULTURAL CATEGORIES AND DECISION MAKING

The choices concerning the aggressiveness of treatment for a catastrophically ill newborn involve (1) the evaluation of characteristics of the patient condition and characteristics of the treatment options (2) in relation to the goals of treatment (3) guided by norms about clinical decision making. In order to make such choices, information about the patient, treatments and goals are evaluated according to culturally relevant categories. Disagreements about appropriate treatment decisions may result from differences between clinicians about the categorization of particular patients and treatments into the culturally relevant categories, variation concerning the goals of treatment, or differences in the norms to guide decision making.

In this chapter, I will briefly discuss some of the literature on decision making. Then I will present discussion of a cognitive model for decision making. Finally, I will present a model for making decisions about the care of catastrophically ill newborns. I do this to set the ground work for a discussion of how clinicians themselves think about the factors they find relevant in decision making. Much of what has been written on clinical decision making uses abstract categories defined outside the clinical context. These discussions often miss much
of the complexity of actual clinical decision making. The complexity of
categorization of patient condition, treatments and goals as well as the
norms for decision making will be discussed in more detail in Chapters V
through VII.

Review of the Medical Decision Making Literature

The model of decision making presented here draws primarily on
work in the anthropological literature on decision making in natural
settings. It is based on work done by cultural anthropologists and
cognitive psychologists. Most of the work on medical decision making
has been focused on developing formal analytic models of how clinicians
should made decisions, the aim of this research, however, is to explore
the concepts clinicians themselves use in decision making and to place
those conceptualizations within the larger economic, political and
social environment.

Most research on medical decision making has used quantitative
methods. Much is prescriptive, intended for use by clinicians in making
more rational diagnoses or treatment choices (Lusted, 1968; McNeil,
Keeler and Adelstein 1975; Pauker 1982). For example, Kassirer
developed a model for use in determining if a patient suspected of
having a particular condition, subphrenic abscess, should have surgery.
He builds a decision tree based on probability values and assigned
utility values for the value of various outcomes (100 for no surgery and
spontaneous recovery, 65 for correction after serious surgical complications, and 0 for death) (Kassirer 1976).

Other quantitative work investigates the impact of various sociological factors on decision making by clinicians including characteristics of the patient, characteristics of the clinician, the clinician's interaction with his profession and the health care system and the clinician's relationship with the patient (Eisenberg 1979). Such factors as the number of physicians in a geographic area (Wennberg and Gittelsohn 1982), the nature of the practice setting (Fink, Colombotos and Barr 1984) and the medical specialty (Greenwald et al. 1984) have been shown to affect medical decision making.

Some of the research on clinical decision making has focused on psychological factors (Elstein et al. 1982). For example, Elstein and his colleagues have sought to discover the cognitive processes used by clinicians in making decisions. They have examined the steps used by experienced and novice clinicians in diagnosis (Elstein, Shulman and Sprafka 1978). Wallstein examined sources of bias in decision making (1981).

Although there are exceptions, almost all of the research on clinical decision making assumes that the usual goals of treatment, cure and the preservation of life, are the goals of the decision makers. While they are the primary goals in most medical decisions, decision making about the aggressiveness of treatment for catastrophically ill infants involves decision making in those situations in which cure is
not felt to be possible or probable and the value of the continuation of life is brought into question.

Studies on decision making in those situations where the value of preserving life is questioned was reviewed in Chapters II and III. In sum, there has been relatively little social science research in this area. The major work remains the study by Crane (1975) based primarily on a large scale sample survey of physician attitudes. A recent study examined what treatments residents intended to have withheld when they wrote no-code (do no resuscitate) orders for actual patients, and compared them with the interpretation of other residents who took care of the same patients. They found "both the intention and interpretation of no-code orders were characterized by variability, and interpretation of the orders was characterized by uncertainty as well" (Uhlmann, Cassel and McDonald 1984).

There is some work which has endeavored to devise models to incorporate value considerations into formal, prescriptive models for decision making. Some of the research has looked at differences in the way people value various types of risks (Pochin 1982; McClain 1983). Studies have also examined preferences for various outcomes (Eraker and Sox 1981; Berwick and Weinstein 1985) including some in which the benefits of survival are weighed against other values (McNeil, Weichselbaum, and Pauker 1981; McNeil and Pauker 1979). However, there has been little work on this area. Most of it has, out of necessity, had to delimit the factors examined which might influence decision making in order to use quantitative methods.
Most of the work on clinical decision making has been based on chart review or consolidated quantitative data about treatment decision, procedures, admissions, discharge data etc. or the use of surveys or formal interview schedules. While informed by the current research on clinical decision making, the methods and aim of the research reported in this dissertation lies closer to the work of medical anthropologists and sociologists who have used participant observation, historical and document analysis and interview techniques.

The purpose of the work is to explore the complexity of factors influencing clinical behavior. In some ways, it was inspired by and builds on the work of those who used participant observation to study clinicians' behavior towards the critically ill, such as Glaser and Strauss (1965; 1968), Sudnow (1967), Fox and Swazey (1974) and Bluebond-Langer (1978), and on the work of others who have done participant observation research in clinical settings such as Bosk (1979). It is also related to research on the social construction of medical work (Foucault 1975; Hahn and Gaines 1985; Wright and Treacher 1982; Atkinson and Heath 1981). A few qualitative studies have examined clinical decision making. These include decision making pertaining to prenatal diagnosis (Rapp 1986; Rothman 1986), a study of decision making by surgeons (Katz 1985), and a study of differences in decision making in different specialties (Burkett and Knafl 1974).

As reviewed in Chapter III, there have been two major participant observation studies of neonatal intensive care (Anspach forthcoming;
Guillemin and Holmstrom 1986). While Anspach examined clinician's conceptualization of prognosis, neither has utilized the frameworks developed by cognitive anthropologists who have worked on decision making in natural settings.

Work of anthropologists working on decision making in natural settings has been useful in providing a framework with which to research clinical decision making. Their work had dealt with decision making in a variety of settings. Some of it has concerned decision making in relation to economic activities such as agricultural decision making (Barlett 1980) and shopping decisions (Murtaugh 1984) and conflict resolution (Quinn 1976). There has been research on medical decision making in natural settings but it has generally concerned choice between medical systems or within a traditional medical system (Kleinman 1980; Young 1981). Some of the understandings of cognitive anthropologists about categorizations, goals, and norms and their use in the process of decision making will be presented in the course of this chapter.

A Decision Making Model

The model that I will later use to describe clinical decision making about the aggressiveness of treatment in intensive care is based on a more general model of decision making (see Figure IV - 1). This model is based in part on work by Spradley (1972) and other cognitive anthropologists. According to that model, in order to act, an
individual must organize information about factors relevant to the problem being addressed. Cultural knowledge systems function to "(1) provide a scheme for the storage of knowledge in memory, (2) to select appropriate knowledge for problem solving; and (3) to supply a logic for solution of a problem" (Nardi 1983:697-98). Sensory stimuli which are perceived by the individual are cognitively organized into categories. Categorization involves deciding how a particular case fits into a class of similar entities. Norms (or cultural rules) indicate relationships between categories and provide prescriptive guides about behavior on a cognitive level which are then translated into concrete behavioral acts and performed. The categorization of stimuli, the norms, and translation from categories to acts are all influenced by the context -- political, economic, social, technological and ideological factors from the environment at both microsocial and macrosocial levels.
MODEL OF DECISION MAKING

Political, Economic, Social, Ideological, and Technological Environment

Collect data → Translate data into categories → Make decision → Translate categories into action → Act

Perception ↔ Cognition ↔ Behavior

Norms
Perception and Categorization

When humans behave, they make choices (conscious or unconscious) between possible behavioral options based on categorizations of perceived phenomena. While perceptions are in part determined by the physical stimuli, perception also depends on the interpretation of the observer and are, in part, culturally determined. (Berlin and Kay, 1969) In order to be acted upon, such perceptions must be organized cognitively. One way the quantity of stimuli is simplified is by division of aspects of the perceptual stream into categories. For example, rather than differentiating each shade, a variety of shades may be referred to as "red" in some circumstances. Sometimes there may be finer distinctions reflected in more differentiation within categories. For example, tones such as "crimson," "wine," and "rose," may be differentiated within the "red" category. Criteria for categorization may be physical traits alone, or may involve subjective dimensions.

Multifactorial Categorization

While some categorizations are made on single traits, others involve many dimensions. Categorizations may be based on emotional quality such as "scary" versus "comical" to categorize movies, or may involve complex moral evaluation of behavior such as "forthright" versus "underhanded" acts. Multifactorial categorization may be used to simplify very complex phenomena. Such categorization is used in clinical settings. For example, a judgment may be made that an infant
is "at risk" for neurological impairment on the basis of results of ultrasound data, electronic tests of brain activity, lab tests, as well as "soft signs" of tone, activity, etc.

Discrete and Overlapping Categories

Much of the ethnoscientific work in anthropology has concerned the explication or classification of biological species and diseases that are presumed to form discrete categories, often hierarchically arranged (Casson 1981:75-91). For example, Frake studied the diagnosis of disease among the Subanun of Mindanao. He found that disease terms formed a taxonomic hierarchy comprised of different sets of contrasting categories. The categories of any one level were included in the category at the next level. For example, at one level a "sore" was distinguished from a "bite," while at the next level they were both categorized together as "skin disease" (1961:117-118). Similarly, much of the clinical decision making literature has focused on discrete choices such as making a diagnosis (assumed to be a discrete entity) or whether to order a test or do a procedure such as surgery.

Ranked and Relational Categories

Beside models based on hierarchically arranged, discrete categories, however, other model of categorizations can be designed. Rather than simply discrete categories, categories may refer to a
collection of points on a ranked or continuous dimension. For example, Galdwin and Murtaugh, in a study of car choice, used four "transportation requirement" categories: (1) cars for a large family, (2) cars for a small family, (3) limited family use car, and (4) single person car (1984:218).

Relative as well as absolute features can also be used to form categories (Casson 1981:86). For example, in some situations a color - "color A" - may not be categorized as "purple" but as "more blue" or "less blue" than another color, "color B". The fact that such a categorization is relative, is illustrated by the fact that (the less blue) "color A" shade may be considered "more blue" than yet another color, "color C". On an ordered dimension, there may be clear, operationalized, breaking points between categories or there may be no clear divisions.

Most of the cognitive anthropological work on categorization may be seen as pertaining to noun categories (e.g. disease categories, species, color names). These are seen as discrete entities. A number of features may be used to define each category having to do with form, function etc. Criteria are used to determine which category an entity belongs in and theoretically, each entity would only belong in one such category at the same hierarchical level. There may be variation in how an item is categorized because individuals may use different criteria for categorization (Kempton 1978).
Other categories may be thought of more as adjectival or adverbial. They are used to identify characteristics of things or actions. While color terms can be looked at as "nouns" themselves, they can also be used to refer to aspects of other things - for example, they can be used to describe furniture. A red chair, a blue chair, etc. Other categorical judgments can be made about the same entities in another domain. For example, in describing the appearance of a chair, one could talk about them as hard or soft. One could also look at another domain, for example, having to do with value. One could make judgments about price, about whether it was a name brand or not, etc. In trying to make a decision about which chair to buy, one could consider characteristics of chairs in two domains, "Appearance" and "Value":

**CHAIRS**

**CHARACTERISTICS OF APPEARANCE**
- color
- texture
- material

**CHARACTERISTICS OF VALUE**
- price
- workmanship
- brand

Some elements significant in determining the category in one domain may be relevant in making categorization in another. For example, the material that a chair is made of (if it has gold trim), may be part of what determines price. Likewise, workmanship, in part, is related to appearance, as well as value. But, if one wanted to discuss how people think about making a decision about which chair to buy, you could discuss considerations about characteristics in each of these two
domains. Entities can be categorized on all characteristics from each domain (although all may not be relevant for a particular decision).

Some categorizations describe a relationship between attributes. For example, one could refer to a purchase as extravagant. This categorization would depend not only on the price of the chair, but would also depend on the relationship of the price to other domains, like the purchaser's budget, which could be seen as forming part of the context of the decision.

Some of the categories that I will refer to as characteristics of patient condition and treatment are relational categories. For example, I will discuss categorizations of treatments as ordinary and extraordinary. These are defined by clinicians both by characteristics of the treatments and by their benefits to patients. Categorization of blood pressure provides a clinical illustration of such categorizations. Blood pressure is sometimes discussed as "high," "normal" or "low" blood pressure as if it fell in discrete categories (although it is based on a continuous dimension). A patient whose blood pressure measures a given amount may be seen as having "high blood pressure" or "low blood pressure." The categorization does not depend on the value of the blood pressure measurement alone, however. Such factors as age, whether or not the patient is pregnant, will affect how the blood pressure is categorized. Therefore, a value which is seen as "high" blood pressure for one patient, may be seen as "normal," or even "low" for another.
Variations in Categorizations Between Individuals

Categorization about some phenomena may be universally shared by all members of a culture. Sometimes, however, categorizations vary among individuals of different social groups or even between individuals within a social group (Mervis and Rosch 1981). This may occur because of differences in the perceptions about the stimuli which are considered in making the categorization (either because of physical differences - one person may see red while someone who is partially red/green color blind may see black, or because one person may have learned to discriminate shocking pink from coral while another has not), because there are differences in opinions about what is important in defining the category (one may discriminate more on brightness while another on hue when categorizing as purple or pink), or differences concerning the cut off points between categories (some may define aqua as green while another may see it as blue).

Returning to a clinical example, clinicians may vary in how they interpret an X-ray. A number of physicians may examine the same x-ray but may come to different conclusions about the diagnosis of the patient because of differences in equipment or eye sight, differences in training or differences in criteria used in making a diagnosis. (For fuller discussion of physician variation see Eddy 1984.)

There also may be differences because clinicians disagree about the criteria to use. For example, one clinician may feel that for an adult male, a diastolic blood pressure of 95 is normal, while another
clinician may feel that it is abnormal and prescribe antihypertensive medication.

Categorizations in Cultural Contexts

Categorizations may also vary for the same individuals when asked to make categorizations in different contexts. For example, in many indigenous medical systems, foods are categorized as "hot" or "cold". A food which is considered hot in one context, such as healing, may not be considered "hot" in another (Mathews 1983). This is true as well in the clinical situation; a heart rate which may be high at rest, may be normal after exercise.

Attentive and Preattentive Categorizations

Categorizations may be made consciously by an individual when confronted with a new situation or a categorization may be preattentive - made unconsciously according to previously learned criteria (Murtaugh 1980). For example, if shopping for dining room chairs, one might categorize a number of chair as falling in the category of dining room chairs preattentively, without consciously thinking about whether they were the appropriate height, material, etc. If one encountered one, however, that wasn't clearly a member of the category, one might consciously consider whether or not it was a member of the category "dining room chairs."
Similarly, in the clinical context, a nurse in the emergency room screening incoming patients could make a preattentive categorization that a patient who was bleeding heavily from a gun shot wound was a "seriously ill patient," while she might have to consciously evaluate the criteria to decide if a child who arrive with abdominal pain was "seriously ill."

Norms

Norms have been defined a number of ways by anthropologists and sociologists. According to Cancian, a typical definition of norms is a combination of "two elements (1) shared rules or beliefs about how a person should behave (2) that are backed by sanctions, or are the criteria for reward and punishment" (Cancian 1976:357). Social scientists have varied in the extent to which they use "norm" to refer to the ideal prescription about how people should behave as opposed to using "norm" as a behavior rule that provides guidance for real behavior. In this dissertation, I am using the concept of norm to refer to cultural rules that guide behavior, or provide "patterns for action" (Schneider 1976). More abstract ideals providing prescriptive guides about how people should behave, as well as other types of desirable ends, will be discussed in terms of "goals" (see below).

An example of a behavioral norm is "Stop at the corner when you see a red light. When the light turns green, drive through
"intersection and wait until the light turns green." Norms guide clinical behavior as well. For example, clinicians are explicitly told to do a throat culture before giving antibiotics for a mild sore throat. If it is a protocol they follow, then for them it is a behavioral norm. Other physicians follow a norm which dictates that they should let the patient feel they are "doing something" when they come for an office visit. Guided by that norm, a physician may order antibiotics without a throat culture. There are other informal norms to orient clinical practice. For example, Scheff (1963) identified a norm that guides physician behavior that it is better to judge a well person sick, than a sick person well. Bosk (1979) identified a norm in relation to surgical mistakes - "To forgive and remember."

Changes in Norms by Context

Cultural rules may vary by context (Wallace 1972). For example, the rules about stopping at a red light may be generally true, but may vary by context. For example, it may apply in most circumstances, however, it may not guide the behavior of some individuals if the light has just turned red. For others, who generally obey the rule, the rule may be modified late at night if there is no policeman present. In that context, they may follow a rule such as, "drive up to the intersection, look both ways, then drive through." Or, the rule may not apply if the actor is in a particular role, for example, an ambulance driver in an emergency situation. In the clinical situation, as the cultural norm to treat may be modified in the situation in which the treatment itself is
very risky and the likelihood of lasting problems from the condition is small. As will be discussed in Chapter VIII, both norms and the meaning of norms for decision making about newborns have varied as conditions from the larger context have changed.

Goals

Behavior may vary according to the goal. "Goals comprise the aims and aspiration, whether object or actions, that a person values and strives after" (Nardi 1983:689). For example, if one's goal is to go straight ahead, one may have to stop at a red light before going through an intersection. If, however, one want to turn right, in some contexts, one may be able to turn after a full stop.

Actors act in order to achieve certain goals. One can look at a set of goals at a number of levels of abstraction. For example, at one level, the usual goal of driving a car is to get somewhere. A subsidiary goal may be to exhibit one's new sports car. At another level of abstraction, one can look at goals in terms of the desire to earn money; driving to work contributes towards that goal. At yet more

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1 One can use the concept of goals to encompass the concepts sometimes referred to as norms, when norm is used for ideal prescriptive statements. For example, in some models "Honor thy mother and father" would be considered a norm. In this model, it would be a goal. "Don't use foul language in front of your parents," or would be an example of a norm, a prescriptive statement about behavior oriented toward achieving the abstract, ideal goal. "Don't use language in front of your parents that they wouldn't use" would be an example of a norm that changed, although the underlying goal of respect for parents could remain the same.
abstract levels, one can look at such goal as satisfying basic needs (e.g. hunger, thirst) or to achieve sense of self esteem. An individual may be able to achieve the same goal a number of different ways in the same context, or there may be constraints on options.

One can look at goals at different levels of abstraction in the clinical context too. For example, at a low level of abstraction, one may want to increase the level of oxygen in the blood and therefore increase the rate, pressure or concentration of oxygen on respirator settings. At a higher level, the same behavior can be seen as working toward the goal of preserving the life of the patient. At a still more abstract level, the goal may be to continue the existence of a socially active member of a family.

Sometimes goals may come into conflict. For example, the desire to show off a new sports car may come into conflict with the goal of driving safely. Similarly, the goal of trying to minimize the chance of brain damage (from too little oxygen) may conflict with the goal of trying to minimize the chance of eye damage (from too much oxygen). At other times, goals from different levels of abstraction may conflict. For example, the goal of minimizing the chance of infection may conflict with the goal of maximizing the chance of an older sibling to establish a good relationship with a newborn.
The Process of Decision Making

In making a decision, one considers what to do about a situation, based on perceptions, by categorizing phenomena, and acting according to norms in order to satisfy goals.

Some parts of the decision making process take place consciously, however, much of the decision making process may take place at an unconscious or preattentive level. For example, in making a choice about what to eat for lunch, an individual may unconsciously eliminate foods which are culturally defined as inappropriate food choices (cat food) and those which are inappropriate in a given context (e.g. cheerios which is a "breakfast food" or filet mignon which is a "dinner food."). One can think of these in terms of choices governed by norms about the appropriate categories of food choices: "Eat food which is appropriate for human consumption" and "Eat food appropriate to the time of day."

In the clinical context, there are many potential options which are never consciously considered. For example, artificial insemination provides an opportunity for a woman to give birth to a healthy child even if both she and her husband carry a rare recessive gene with a one in four risk of occurrence. Although her husband would be the child's social father, he would not be the biological father. Some genetic counselors do not routinely raise the possibility of donor insemination to the carriers of genetic diseases presumably because they don't think
that the couple would find it an acceptable option (Barbara Katz Rothman, personal communication).

Next the actor may preattentively or unconsciously consider which culturally appropriately options are alternatives by an approach known as elimination by aspects. (Tversky 1972) First, a set of criteria are generated to use in making choices. Possibilities may be reviewed in a hierarchical fashion (Galdwin et al. 1984). They may be judged on one criteria first, and only those that rate as acceptable on that criteria may be considered in relation to the next. Those possibilities which do not meet certain criteria, such as easy availability (no tuna in the cupboard) are eliminated. There may be a number of criteria by which alternatives are serially evaluated. After one criterion, availability, the actor may consider others one at a time, or the advantages and disadvantages of a number of possibilities may be considered at once according to a number of criteria (e.g. baloney, salmon, fried eggs may all be considered at once in terms of utility values such as cost, ease of preparation and taste). Each possibility is also considered in relation to larger goals (to satisfy hunger, to have a pleasant experience, to return quickly to work).

Similar processes take place in a clinical context as well. For example, suppose a patient presents in the clinic complaining of abdominal pain. The clinician hopes to discover the diagnosis. Certain types of diagnostic procedures are ruled out as inappropriate preattentively in a Western medical setting, such as divination. Other potential methods of diagnosis, such as those that are very costly.
and/or involve the use of sophisticated technology, such as use of a CAT scan or NMR that may be appropriate in some contexts, would not be for first presentation with mild abdominal pain. Such alternatives are eliminated without conscious thought. Other alternatives such as ultrasound, a lower GI series, liver function tests or an IVP may be evaluated in terms of such criteria as staff time, cost, availability of equipment, discomfort for patient, future risks, etc.) The utility values of various choices in relation to various goals will be considered. The goals of trying to cure the patient, bringing relief from pain to the patient, educating the student, finishing quickly in order to help as many other clinic patients as possible or leave early, or discovering a patient with an unusual condition, may all be considered in evaluating diagnostic procedures. Such decision making, or parts of the decision making process, may be 1) standardized by use of a protocol, 2) may be learned in the process or socialization or through repetition, or 3) may take place consciously in a particular case. Through an elimination of aspects, a decision might be made that a liver scan is too expensive, an IVP is too risky, and a few particular tests, such as a lower GI series and an ultrasound may be ordered.

The Context of Decision Making

Numerous factors from the larger social, political, economic and technological environment affect the process of decision making. They both enable choices and establish constraints on behavior. For example, consider clinicians in an emergency room. Options are determined in
part by the level of technological development of the society, and also
by equipment available at the institution. The costs of use of the
equipment, determined by factors outside of the institution, and the
policies concerning use of the equipment within the institution affect
it's use. The sanctions exerted for over or under utilizing tests, the
possibility of a malpractice suit as well as the relationships
established with patients, the patients' past history and current living
situation, and clinicians' training and personality may affect decisions
made. Although the cognitive approach can help in understanding the
meaning of factors from the larger environment to the actors involved -
how they are perceived, interpreted and utilized - the factors
themselves must be taken as given.

Decision Making About the Aggressiveness of Treatment

The model of decision making has proven useful in studying how
decisions are made about the aggressiveness of treatment for
catastrophically ill newborns. In order to make choices concerning
treatment behavior, clinicians must evaluate the suitability of various
possible treatment options for particular patients. Such decisions
involve the categorization of characteristics of patient conditions and
treatments and also involve evaluations about which choices would
further the achievement of desired goals.

For example, a decision might be made that a patient should have
heart surgery because she would be able to enjoy a good quality of life.
In another case, a decision might be made that a patient should not be put on a respirator because such extraordinary treatment would be undesirable for a patient who is terminally ill. Such decisions cannot be reduced and made on the basis of physiological criteria alone but involve categorizations into culturally defined categories such as "good quality of life," "terminal illness" and "extraordinary treatment." For example, categorizations about the "quality of life" depend not only on the physiological findings but also on ideas concerning the stigmatization of those with disability and the societal circumstances which facilitate or impede realizing satisfactions with a disability.

Treatment decisions also depend on value judgments about what types of behaviors and outcomes are desirable -- these clinical norms and goals are also culturally defined. For example, one goal may be the preservation of life. The cultural definition of life and death (see Chapter II) will, in part, determine the meaning of the goal.

In making treatment decisions, I have found the following model useful for understanding how clinicians make decisions and how clinicians categorize patient condition and treatment characteristics. (This is not a model that is consciously used by clinicians. While it can be used to represent the dimensions discussed by clinicians, it does not purport to be the only model, or necessarily an actual model, used by clinicians for conceptualizing this issue.)

As I will discuss below, although categorizations of particular patient conditions or treatments may be described as if each category
was dichotomous, each of these dimensions of patient condition and treatment characteristics can be seen as forming a continuum.

While, on the whole, there is agreement among clinicians that each of these dimensions are relevant in decisions making, there is variation in how particular patient conditions and treatments are categorized on a given dimension and on the importance of each dimension.

In the following chapters, I will discuss each of these characteristics of patient condition and treatment and illustrate the ways in which they are culturally determined. I will describe each, discuss the dimensions involved in defining the characteristics, and present areas of consensus and variability among clinicians. I will explain how these relate to elements of the wider clinical and societal context of decision making.

Although each of these dimensions may be discussed separately for analytical purposes, they are, in the context of neonatal decision making, interrelated. In some cases, the categorizations on one dimension may be heavily influenced by categorizations on other dimensions. Examples of this will also be discussed below. (Please see Figure IV - 2, next page.)
MODEL OF DECISION MAKING ABOUT THE AGGRESSIVENESS OF TREATMENT

The context of decision making including:
Medical technology; bioethical traditions; laws pertaining to treatment;
funding of health care; attitudes toward impairment, reproduction,
roles of parents, professionals, and the state; links to other issues.
MODEL OF DECISION MAKING

START WITH COLLECTION OF DATA

"Data" are collected about the condition of the infant. Information consists of perceptions collected through the senses (physical features, skin color, tone) and through such means as lab test, radiographic exams, electronic monitoring. Information on the patient's history, social situation, etc.

Information is also selected that is culturally defined as relevant about the patient's condition and treatment options from previous clinical studies and past experience (e.g. natural history of disease, outcome, equipment and staff time involved in treatment, pain etc).

Selective collection and attention to data are informed by socialization and cultural norms. While some of the data collection is consciously done, some is preattentive.

CATEGORIZE INFORMATION INTO CULTURALLY RELEVANT CATEGORIES

Information is translated into culturally meaningful terms by organizing data in relation to characteristics of patient conditions and treatments. The following categories can be used to represent the culturally meaningful categories.

**PATIENT CONDITION CHARACTERISTICS**

- Quality of life
- Uncertainty
- Nature of the Critical Condition
- Social Value

**TREATMENT CHARACTERISTICS**

- Aggressiveness
- Ordinary/Extraordinary
- Withholding/Withdrawing Treatment
- Active/Passive Euthanasia

These categorization are, in part, based on the data collected above but also involve subjective evaluations informed by the socially determined values of the decision makers.
CONSIDERATION OF THE GOALS OF TREATMENT

The condition of the patient and the treatment options are considered in terms of the goals of treatment:

GOALS
To cure
To Care
To Preserve Life
To do no harm

DECISION MAKING ABOUT HOW AGGRESSIVE TO BE IN TREATMENT GUIDED BY CLINICAL NORMS

It is this step in the decision making process which is usually thought of as THE DECISION. It involves making the principle decision about how aggressive to be in treatment. A decision is made about which goal(s) will be maximized and how they will be achieved in a manner which is appropriate given the patient and treatment characteristics. The decision is guided by the norms of clinical decision making.

TRANSLATION OF DECISION FROM CATEGORIES TO BEHAVIOR

The decision is meaningful in cultural terms but does not specify behavioral acts. The decision has to be translated from a decision at an abstract level to "preserve life," or to "give ordinary treatments but not extraordinary ones" into a decision about what specific treatments to give and which to withhold.

TREATMENT BEHAVIOR

Actions are performed to provide treatment to the infants.

CONTEXT

The entire decision making process occurs within the context of technological, ideological, social, economic, and political factors. Technological factors include the high technology of neonatal intensive care. Ideological factors include the traditions of medical ethics and societal values related to children, death, and impairment. The social factors include the attitudes and relationships of families and caregivers, and the health care system. Economic factors include the systems of third party supports and the larger capitalist system which supports the NICU. Political factors include larger political issues concerned with the rights and duties of families and the state, and legal definitions of life and death. All of these, plus many other aspects of the larger environment shape norms and categorizations and help determine the decisions which take place.
Summary

After a brief review of the literature on decision making, a model was outlined for use in examining decision making in natural settings. The importance of cultural factors in perception, was discussed. Multifactorial, discrete and overlapping, and ranked and relational categories were explicated as well as variation in categorizations between individuals, categorizations in cultural contexts and attentive and preattentive categorization. Norms, goals and the process of decision making was discussed. Finally, a model for the examination of treatment decisions in neonatology was introduced.
As discussed in the previous chapter, decision making about the aggressiveness of treatment for newborns involves the evaluation of characteristics of patient conditions and treatments and classification into culturally defined categories. In this chapter the cultural categorizations of characteristics of patient conditions will be discussed. The main dimensions to be discussed are quality of life, uncertainty, nature of the critical condition, and social value. Other patient condition characteristics categories sometimes used by clinicians are discussed under these main headings.

Quality of Life

Quality of life has been defined a number of ways. (Pres. Comm. 1983:299; Njaman and Levine 1981; Van Dam, Sommers and Van Beck-Couzijn 1981; Arras forthcoming).

According to Wenger, Mattson, Furberg and Elinson:

Quality of life may be defined in terms of 3 major components: functional capacity, perceptions and symptoms and their consequences. Functional capacity has 5 subcomponents: the ability to perform activities of daily life, social function, intellectual function, emotional function and the often-resultant economic status. Perceptions are a person's views and value judgment of the
components; of concern are perceptions of general health status, level of well-being and satisfaction with life. Symptoms of the disease, whether induced by treatment or concurrent illness, or reduced or abolished by the intervention are the third major component. They may influence functional capacity and perceptions; in fact, all 3 are interrelated.

(1984:908)

A working definition of quality of life may be taken to be the overall balance of positives (pleasure, satisfaction, etc.) versus negatives (pain, sadness, etc.) experienced by an individual over a period of time. In the present study, when not otherwise specified, "quality of life" is used only to refer to considerations of the quality of life as judged from the perspective of the individual patient. Considerations pertaining to the future quality of life for others, such as family members, will be referred to as "social value" considerations (these will be discussed below, at the end of this chapter).

In addition to quality of life, a variety of terms have been used when referring to considerations along this dimension. These include: "prognosis" (Crane 1975), a "best interest standard," (Arras 1985) or the "amount of pain and suffering" (Murray, 1984). Each of these domains will be discussed here in the section on quality of life.

Quality of life is the first dimension usually considered by clinicians in decision making concerning the possibility of withholding treatment. In the neonatal intensive care unit, if a clinician feels that a baby has a significant chance of enjoying an acceptable quality of life, then a decision will usually be made to provide all treatment
necessary in order to maximize the probability of survival. The only major exceptions occur in situations which involve very experimental and/or expensive treatments including those which involve a very rare resource (e.g. a liver or heart transplant) (see Chapter VII).

The vast majority of infants admitted to NICUs, are felt to have a significant chance of having at least an acceptable quality of life. Most are expected to be "normal" and have a good capacity to have a good quality of life. Usually this evaluation is made without conscious consideration; for most babies, the possibility of limiting treatment is not considered. ¹

The next largest category of babies admitted to an NICU is comprised of those babies who are terminally ill, and who could not survive for long no matter what treatment decisions were made. While decisions are often made to withhold treatments from such babies, such decisions are not usually seen as ethically problematic or as involving quality of life considerations. (For a discussion of the complexity of such decisions and the way in which they do involve quality of life considerations, see below, section on the critical condition).

¹ Murphy (1966) has written about the fact that "normal" entails more than a notion of a statistical norm. It must also encompass philosophical dimensions about the meaning of deviations from a statistical norm. "Normal" as used by the clinicians in the NICU usually refers to an infant who will have no, or only minor, impairments. Clinicians vary in where they draw the line between "normal" and "abnormal."
When clinicians think about ethically problematic decisions to withhold treatments, they are usually thinking about decisions for a third category of infants -- those who could survive with certain treatments but who would be expected to have a very poor quality of life. It is in these cases that clinicians may consciously consider withholding treatment.

Quality of life involves a number of components. In making decisions in the NICU, quality of life is usually thought of primarily in terms of the degree of physical and/or mental impairment. Quality of life is also sometimes discussed in terms of the amount of pain and suffering experienced by the baby. Clinicians also sometimes talk about a quality of life worth living as one in which a person can interact meaningfully with others, sometimes described as having the capacity to give or receive love.

In the survey I conducted in 1983 on attitude about neonatal decisions (see appendix), the respondents, the majority of whom were clinicians working in neonatal intensive care or other health care professionals, were asked to express their opinions about the basis for decisions by indicating which of 21 factors they felt should be important when deciding about the care of individual newborns. About two thirds of the respondents indicated that they felt one of the quality of life considerations - severity of intellectual impairment, severity of physical impairment, amount of prolonged pain and suffering, or capacity to give and receive love - should be the most important factor. Among respondents, there was consensus that severity of
intellectual impairment and amount of prolonged pain and suffering should be among the important factors considered in decision making. In addition, parents' wishes, which some clinicians used to indicate that parents should be able to make quality of life decisions, and uncertainty about the extent of impairment, which also relates to quality of life, were circled as most important by an additional sixth of respondents (see Table V-1).
TABLE V - 1

IMPORTANCE OF SPECIFIC FACTORS FOR DECISION MAKING

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percent who thought it should be the most important factor</th>
<th>Percent who thought it should be an important factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of intellectual impairment</td>
<td>29</td>
<td>87</td>
</tr>
<tr>
<td>Amount of prolonged pain and suffering</td>
<td>20</td>
<td>77</td>
</tr>
<tr>
<td>Severity of physical impairment</td>
<td>15</td>
<td>72</td>
</tr>
<tr>
<td>Parents' wishes</td>
<td>15</td>
<td>69</td>
</tr>
<tr>
<td>Capacity to give and receive love</td>
<td>4</td>
<td>30</td>
</tr>
<tr>
<td>If chance of successful treatment is small</td>
<td>3</td>
<td>47</td>
</tr>
<tr>
<td>Uncertainty about extent of impairment</td>
<td>3</td>
<td>42</td>
</tr>
<tr>
<td>If non-treatment would be active euthanasia</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Impact on parents</td>
<td>2</td>
<td>49</td>
</tr>
<tr>
<td>If treatments are heroic</td>
<td>2</td>
<td>33</td>
</tr>
<tr>
<td>Danger of lessening the &quot;value of life&quot;</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>If treatments are already started</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Long term cost of caring for disabled child and adult</td>
<td>0</td>
<td>38</td>
</tr>
<tr>
<td>Financial burden to the family</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td>Impact on siblings</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>Availability of resources for other sick children</td>
<td>0</td>
<td>26</td>
</tr>
<tr>
<td>Ability of the parents to have other healthy children</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Cost of neonatal intensive care</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Availability of resources for other medical care</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Availability of resources for other, non-medical social needs</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Feelings of staff caring for baby</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>Other factors</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>
Although both physicians and nurses indicated that they felt that quality of life considerations should be the most important, they differed in the rates at which they cited individual factors. More neonatologists cited the amount of intellectual impairment (45% vs 25%), whereas more neonatal nurses thought that the amount of prolonged pain and suffering should be the most important factor (28% vs 3%).

Prognosis related to degree of impairment

The elements described above which are seen as indicating future quality of life all have to do with the physical and intellectual capacity of the infant. The impairment alone does not determine quality of life, for it is also determined by the meaning of the impairment for the individual in a given social environment.

In general, clinicians feel that the type of impairment that would have the most devastating impact on the future quality of life is mental impairment, especially if it is severe. In most cases where the withholding of treatment is considered, there is thought to be a significant neurological impairment. In the survey, about a quarter of the respondents, (almost half the neonatologists) felt that the severity of intellectual impairment should be the most important factor in decision making. In addition, a few respondents indicated that the capacity to give and receive love should be most important, which is also related to the degree of neurological impairment. There was a
clear consensus with almost nine out of ten respondents indicating intellectual impairment as one of three most important factors.

Some of the infants who are cared for in an NICU have devastating mental impairments that leave them unaware of their surrounding. Almost all clinicians would agree that such infants should not be treated aggressively. Some others are left minimally aware of their environment, including the attention of caretakers. While a few clinicians feel that even minimal awareness (being able to enjoy rocking and attention from parents, for example) does provide a quality of life worth living, it appears that most do not.

Others babies, of course, have more moderate or even mild impairments. In talking about intellectual impairments as a factor to consider in decision making, most clinicians are concerned about severe impairments. Some clinicians would consider non-treatment for an infant with more moderate impairments, such as someone who as an adult would have the intellectual capacity of a baby, toddler, or preschool child. Other clinicians would not consider non-treatment for such infants. Most clinicians are disturbed at the thought that someone would withhold treatment because of mild mental retardation. A number of the children who leave the NICU have mild mental impairments including learning disabilities. Many clinicians believe that the majority of their critically ill infants could be considered at risk for such problems (although only a minority develop significant ones). They are not considered grounds for non-treatment.
About a seventh of the respondents listed the severity of physical impairment as the most important factor, while almost three quarters reported that it should be an important factor in decision making. Even if a physical impairment is fairly severe, if there is not thought to also be intellectual impairment, treatment will usually be aggressive. An exception may occur in the most extreme cases. For example, in the case of the Danville Twins (see Chapter III) treatment was withheld from Siamese twins even though there was no suggestion of retardation.

Quality of life may be discussed as if it formed a dichotomy (a "good quality of life" versus a "bad quality of life," but it is often conceptualized by clinicians as if it formed a continuum. At one end of the continuum are cases of permanently comatose and anencephalic babies (babies born without a brain). Such babies may even be thought to lack those qualities which define a human existence (see discussion, Arras 1985). The only time that I heard clinicians who worked regularly in the NICU refer to a patient as "it", (rather than "he" or "she") was in reference to an baby who was thought to be anencephalic.

Philosophers have written a great deal about the concept of personhood; there is debate about whether a newborn, especially a severely impaired one, does or does not have the same claims as older individuals, or is actually a "person" with all the rights which come with personhood (Khuse and Singer 1985). Clinicians don't appear to think about it at all in these terms. With the possible exception of an anencephalic baby, they seem to see each infant as fully
human - their questions concern appropriate treatment choices for their human patients.

Another issue related to personhood, however, that is relevant to clinicians, concerns the beginning of life. While some people who do not work regularly in the NICU, may see very small premature babies as less than human - living fetuses - that is not true for the people who do work with them regularly. All babies in the unit are seen as people. However, there is a point of division between live birth and non-viable fetus. The dividing line has changed during the past 10 - 20 years. It used to be generally though to be at about 28 weeks. When I started field work, in 1977, about 25-6 weeks was considered to indicate the divide between miscarriage (not a person) and newborn (a full person). Now it is lower. There are indications that new technology may be pushing the divide still lower so that some people seem to consider the fetus/patient still in utero who can be monitored, visualized with ultrasound, and treated with fetal therapy to be a person.

In the case of anencephalic babies, there is consensus about withholding aggressive treatment by virtually all clinicians including such staunch "right to life" advocates as Surgeon General Koop. In response to questions on the survey, there was clear consensus to withhold most treatments from the anencephalic baby (see Table V - 2).
<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>% WHO WOULD RECOMMEND</th>
</tr>
</thead>
<tbody>
<tr>
<td>BABY WHO IS ANENCEPHALIC</td>
<td></td>
</tr>
<tr>
<td>Feedings by mouth</td>
<td>76</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>56</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>32</td>
</tr>
<tr>
<td>Resuscitation in the delivery room</td>
<td>13</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>3</td>
</tr>
<tr>
<td>Arrest page</td>
<td>2</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>2</td>
</tr>
<tr>
<td>BABY WHO HAS MULTIPLE ANOMALIES (BEFORE CHROMOSOMAL ANALYSIS)</td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>90</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>81</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>76</td>
</tr>
<tr>
<td>Respirator</td>
<td>65</td>
</tr>
<tr>
<td>BABY WHO HAS MULTIPLE ANOMALIES (AFTER CHROMOSOMAL ANALYSIS INDICATES TRISOMY 13)</td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>85</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>60</td>
</tr>
<tr>
<td>Respirator</td>
<td>24</td>
</tr>
<tr>
<td>Surgery for cleft palate</td>
<td>14</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>13</td>
</tr>
<tr>
<td>Arrest page</td>
<td>10</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>8</td>
</tr>
</tbody>
</table>

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2 For the Baby with trisomy 13, and for questions on resuscitation in the delivery room and an arrest page for the anencephalic baby, n = 119; actual base varies slightly depending on the number of ineligible answers (in all cases, ineligible answers less than 5% of total n.).
TABLE V - 2 (cont.)

<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>% WHO WOULD RECOMMEND</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A SMALL PREMATURE BABY WITH AN IVH</strong></td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>93</td>
</tr>
<tr>
<td>Suctioning</td>
<td>92</td>
</tr>
<tr>
<td>resuscitation in delivery room</td>
<td>64</td>
</tr>
<tr>
<td>Increased respiratory settings</td>
<td>53</td>
</tr>
<tr>
<td>Pressors</td>
<td>39</td>
</tr>
<tr>
<td>Arrest page</td>
<td>26</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>13</td>
</tr>
<tr>
<td><strong>A BABY WITH DOWN'S SYNDROME AND DUODENAL ATRESIA</strong></td>
<td></td>
</tr>
<tr>
<td>Intravenous feedings</td>
<td>91</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>88</td>
</tr>
<tr>
<td>Surgery for intestinal defect</td>
<td>87</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>71</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>59</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>28</td>
</tr>
</tbody>
</table>
Many clinicians also believe that aggressive treatment would not be appropriate for other infants who would also be expected to have an extremely poor quality of life such as those with intracranial bleeds and some very premature babies. These categories were given as examples of babies who did not require treatment under the first revised version of the Baby Doe Regulations (DHHS 1983b).

Sometimes, when it is suggested that treatment should only be withheld in such circumstances, it is said that such decisions are made because treatment would be "futile;" it is claimed that such decisions are not being made on the basis of quality of life. (DHHS 1983b) Such decisions, however, do reflect a consideration of quality of life, even if at an extreme. As long as it is possible to prolong physiological life, and a decision is made that the condition of the person or the short span of time before death does not warrant treatment, treatment is being withheld on the basis of a quality of life consideration (For a discussion of this point, see Rhodan and Arras 1985).

There are also other conditions for which there is general agreement against aggressive treatment by most clinicians including situations where there is profound brain damage and genetic anomalies such as trisomy 13 or 18 (which are usually associated with a short life span and always associated with numerous physical defects and severe retardation). For example, on my survey, three quarters of the respondents answered that they would not recommend aggressive respiratory support for a baby who was diagnosed as having trisomy 13 (see Table V - 2).
At the other end of the spectrum lie those cases with the smallest amount of impairment thought significant enough to raise the question of withholding treatment. There is much controversy surrounding this end of the continuum. Indeed, among clinicians, as among other members of society, there is much variation in opinion concerning what constitutes handicap and concerning the implications of particular physiological conditions for quality of life. The Disability Rights Movement has done much to challenge prevalent assumptions about the quality of life of those with disabilities. Almost nine out of ten clinicians would recommend intestinal surgery for an infant with Down's syndrome and an intestinal defect. (see Table V-2)

It is not deviations from physiological norms, in and of themselves, which determine quality of life. Rather, the interdependence of cultural factors (such as the degree of stigma and architectural barriers) which interact with individual background characteristics of the person who has impairments, which determines the quality of life.

There is debate about the extent to which factors pertaining to the future environment of the newborn should be considered in making treatment decisions. The significance of factors in the general social environment for all people with certain disabilities, such as financial assistance to provide mobility aides or the quality of care in long term care institutions, is one set of issues under debate. There is also
controversy about the relevance of the financial and emotional resources for an individual infant from his or her family.

One article which has become a focus of the debate on the relevance of family characteristics is a report of an Oklahoma study in the October, 1984 issue of *Pediatrics*. It reported on the use of a formula to determine the future quality of life of infants with spina bifida which included contributions from the family and from society (Gross et al. 1984). Both this group, and Shaw (1977), who wrote the article from which the formula was derived, used the formula in a schematic way as a model of factors to consider in decision making. Many, however, interpreted the article as if the formula was used to determine a numerical estimate of the "quality of life."

The degree to which family and societal contributions determine quality of life is a very controversial area. While some people believe that having a loving family who is able to accept the child is the most important factor, others believe that such social factors should not be considered in decision making.

The role of the economic resources of the family and society is even more controversial. Some have argued that consideration of the financial contribution of the family could lead to double discrimination against the poor, since poor mothers have higher rates of prematurity and other factors associated with risk factors for disabilities. Referring to consideration of economic resources from society, others have argued against considering such factors as the quality of care in
institutions because such decisions would serve as a disincentives for improving the quality of care in such institutions. (Arras, 1985)

There is a high degree of agreement among clinicians that certain deviations from the norm do not significantly alter a baby's chances of a good quality of life. In one case in which a decision about complex heart surgery was being discussed, it was noted that the infant, Maria, also had features which are associated with Turner's Syndrome, an XO deletion syndrome which is associated with mild retardation, short stature, certain physical stigmata and infertility. A senior neonatologist, Peter, noted that Turner's syndrome is not something that affects "quality of life" and is not relevant in making non-treatment decisions.

When clinicians feel that a condition will clearly not prevent an infant from enjoying an acceptable quality of life, even if the parents objected to certain treatments, all treatments thought necessary to preserve life will be given. If necessary, clinicians will seek a court order to obtain custody in order to be able to make decisions. Frequently, upon threat of losing custody, parents agree to treatment.

For example, upon seeing his child who had a cleft palate, a father said "shouldn't a monster like that be killed." The clinicians would not allow consideration of non-treatment in such a case. They felt that their role as caregivers was to provide counselling to help the parents adjust after an emotional reaction to an unexpected outcome.
Within hours, the father was able to begin to relate positively to his new baby.

In a 1982 interview, Dr. Raymond Duff, one of the most outspoken proponents of parental decision making, spoke about a baby who was born with cosmetic deformities of the hands and face. The baby's parents wanted to withhold treatment and allow the child to die. Dr. Duff said that they couldn't do that and, if necessary, he would go to Court in order to obtain permission to treat. After discussions with the staff, the parents agreed to treatment.

Norms have developed among clinicians which lead to a high degree of consensus that some conditions lead to such a bad quality of life that treatment is futile and that other conditions enable a good quality of life so that non-treatment decisions are out of the question. For other conditions, such consensus has not developed and there is disagreement about future quality of life.

For example, the spina bifida task force of the Project on Ethics and Values in Health Care (see appendix) interviewed two physicians who had very different views of the quality of life of Ellen, a child with spina bifida. Her lesion had caused her to be paralyzed and to lack feeling from approximately her umbilicus (belly button) down.

Her urologist believed that she would have a good quality of life. He believed that she was bright and capable and would be able to handle such things as catheterization for urinary incontinence necessitated by
her condition. Although she would never have genital sensation, he said she was a bright girl with an active imagination, so she could have an active sex life. He thought, perhaps, she would become a mother and would be able to be employed.

Her neurosurgeon, on the other hand, felt that because she would be unable to learn to walk, unable to control bladder and stool, (he characterized her as "sitting in her own urine and feces,"), she would face social stigma. Although she was a happy child at 6, he felt that as an adult "she would regret that she survived."

Not all clinicians agree about which cases are clear-cut and, therefore, to them, involve medical criteria alone, and which involve ethical dilemmas. This is due to at least three factors. First, based on personal background characteristics and experiences, clinicians differ about which impairments they believe can be compatible or incompatible with a good quality of life. Second, differences exist because of uncertainty about outcome (see section on uncertainty). Finally, some variation in decision making reflects differences in assessment of prognosis based on differences in attention to various types of information about the infants. Anspach found systematic variation in assessment of prognosis among nurses, house staff, and attending physicians. This occurred because the work environment differentially structured access to information for each professional group.
To parents who are not socialized in the clinical subculture, with inadequate understanding of the medical situation, and/or who have very different values than the clinicians, a judgment may be made which differs radically from clinician assessments. In such situations clinicians often see their role as one of educating parents, since decisions they see as clear-cut are conceptualized as "medical decisions." This differs from those situations that they do not see as clear-cut that they conceptualize as "ethical decisions." They also may define cases as involving "ethical decisions" in which they acknowledge that differences of opinion may reflect valid variations in values rather than lack of information or irrational thinking on the part of parents.

Pain and Suffering

Another component which people often consider in relation to quality of life is the amount of pain and suffering. For example, in response to the question on my survey concerning factors considered important in making treatment decisions, about three quarters of the respondents indicated that they thought the amount of prolonged pain and suffering should be an important factor and a fifth responded that it should be the most important factor.

Neonatal nurses (28%) were significantly more likely to consider the amount of pain and suffering to be the most important factor as opposed to neonatologists (3%). Some of the nursing leadership were
surprised and upset that so many nurses felt that this should be the most important factor. It may have been more characteristic of newer nurses who had not yet been socialized to share the philosophy of the unit. Some people have hypothesized that nursing has traditionally been more concerned with providing "comfort" and attracts individuals more concerning this nurturing, while medicine, has been more focused on cure, and attracts individuals more concerned with the capacity for intellectual achievement.

Although the amount of pain and suffering is a frequently mentioned factor, especially by non-clinicians, there are relatively few neonatal conditions which themselves lead to long range physical pain. Most of the pain and suffering which would diminish quality of life comes from two sources: emotional or psychological pain from limitation of function and/or stigmatization, or, pain engendered as part of medical treatments to correct congenital problems or treat subsequent complications.

Assessments of clinicians about future pain and suffering probably vary even more than about prognosis for degree of future impairment. For example, some physicians have said that children with spina bifida who have mental impairments suffer more because they cannot learn to use crutches and other aides. Others feel that children with spina bifida who are not retarded suffer more because they are aware of what they cannot do because of their condition.
Some non-clinicians are so disturbed about the pain and suffering experienced by babies during an NICU admission, that they sometimes feel that infants should not be subjected to painful treatments. For example, some of the strongest advocates of "natural childbirth" would prefer a less intensive level of care to NICU care even if it there is more risk to survival. Clinicians who work in NICUs, on the other hand, virtually never consider the pain and suffering associated with a treatment to be severe enough to justify non-treatment in an infant who can be saved and enjoy a good quality of life. Usually this is also true for those situations for which a good outcome is uncertain or unlikely.

For example, some non-clinicians may be concerned about such issues as the suffering of an infant because of separation from the mother. Some fear that the experience of hospitalization and separation may cause a significant diminution in quality of life. Clinicians, however, because of their familiarity with hospitalization, are rarely concerned with separation per se. Clinicians rarely seem to acknowledge the pain associated with routine procedure, perhaps because of its familiarity, and perhaps a need to build defenses in order to work in the environment. The pain associated with procedures appears to be seen as an accepted part of a beneficial intervention rather than as a focus of concern. Clinicians may not even appear very concerned about pain associated with more invasive procedures, such as insertion of chest tubes or cardiac catheterization (which is sometimes done without anesthesia), and very invasive procedures (such as open heart surgery).
Many clinicians believe that newborns don't suffer with pain the same way that older people do (Murray 1985).

While the pain of routine procedures is rarely considered significant for any patient, pain from the more invasive procedures is considered important for patients when there is felt to be little hope of benefit from treatment. For example, if a baby is dying, efforts may be made to minimize procedures which would cause discomfort. Opinions vary about the degree to which pain and suffering should be considered in making treatment decisions for infants who have little chance for long range survival.

For example, many clinicians believe that an infant with a heart defect which can probably not be corrected should not be subject to the pain of open heart surgery. Clinicians expressed mixed opinions about the care of Andrew Stinson, a premature baby whose parent wrote a book about his treatment. He suffered many complications (some iatrogenic) and died after 6 months in a NICU. (Stinson and Stinson 1979) Some believed that it was appropriate that his physicians continued to try to treat him as long as they felt he had a chance at survival. Others believed that he was treated much too long after it seemed likely that he would die and that treatment should have been stopped earlier to ease his suffering.

While clinicians in neonatology rarely consider the pain and suffering involved in treatment during the newborn period, they do sometimes consider the pain and suffering associated with repeated
medical treatments throughout childhood. For example, the need for repeated surgery will often be mentioned as a significant problem associated with severe spina bifida or very severe, complex cardiac lesions. They are even more likely to consider pain and suffering associated with permanent dependence on life support equipment such as a respirator or TPN (total chronic intravenous feeding) or kidney dialysis (which are also associated with a shorter life span).

While most clinicians do not seem as concerned with the pain or suffering associated with treatment, as non-clinicians, they often seem to be even more sensitive to pain and suffering associated with non-treatment. For example, non-clinicians may be more likely to feel that an infant with a lethal condition should not receive treatments such as intravenous fluids which may cause pain while many clinicians are more likely to feel that discomfort will be associated with the lack of fluids.

Diana's care provides another example. Diana was a child who had already been in the NICU for over a year, chronically dependent on a respirator. She had very bad lung disease leading to virtually no hope of long term survival and had been classified as no arrest page (she was not to be given emergency treatment if her heart stopped). One day she had and received vigorous aggressive treatment for what was characterized as a "respiratory arrest" (bronchial spasms), including numerous emergency drugs and was "bagged" or given artificial respirator by hand for over an hour. Without the treatment, she probably would have died in minutes. It appeared that the clinicians felt that they...
had to treat the respiratory arrest, otherwise she would suffocate which "would be a horrible way to go."

In the case of an infant who could survive, clinicians often find the pain and suffering associated with non-treatment to be all the more disturbing. In at least some of the "non-treatment" cases involving babies with Down's syndrome, surgery was not performed and therefore the infants could not eat but they were given fluids by IV and sometimes sedated (see John Hopkins case, Chapter III). While it prolonged the dying process, it was considered to lead to a more humane death. In the 1982 case of Baby Doe of Bloomington, Indiana, fluids were not given (Lyons 1985). To most clinicians, especially nurses, the thought of not giving fluids is extremely disturbing. Beyond the concern about the original non-treatment decision, upset caused by withholding fluids may have been part of what compelled the nurses to report the case of Baby Doe to the authorities.

Uncertainty

The concept of uncertainty has received a considerable amount of attention in the literature on Medical sociology (e.g. Fox 1957; 1980; Light 1979; Atkins 1984), and in the literature on decision making (e.g. Tversky and Kahneman 1974; McNeil, Keeler and Adelstein 1975; Eddy 1984) Chibnik, in discussing agricultural decision making, cites Cancian's distinction between risk and uncertainty. In risky situations decision makers can form intelligent guesses about the odds for or against
desirable outcomes from a given course of action while in uncertain situations they have difficulty making these estimations. Chibnik points out that risk/uncertainty can be thought of as a continuum rather than as a dichotomy as presented by Cancian.

Decision makers in neonatology face both risky situations in which statistics are available for infants who had a similar condition, and other situations in which there is uncertainty because it is a rare condition and the risks or not known, or because there is a new treatment and there has not yet been time for follow-up.

There are at least two components of uncertainty which are important in neonatal decision making. The first concerns uncertainty about the severity of the impairment. The second concerns uncertainty about the existence of impairment. In considering how aggressive to be in neonatal treatment, there is consideration of both the existence and severity of impairment. When the probability is high that the patient will not be "normal", then there may be consideration of withholding treatment. Then the severity of the impairment is considered. However, a high probability of severe impairment alone is not usually thought to be grounds for withholding treatment in the NICU, if there is also a chance that the baby could be "normal." (See note on "normal," in section on quality of life.)

This contrasts to the concern in prenatal diagnosis where possibility of severe impairment is often thought enough to justify a selective abortion even if the probability of impairment may not be
high. For example, in cases of fetal exposure to Rubella, many clinicians would counsel a selective abortion even when the risk of anomalies is only 25% because the defects could be very severe. After birth, most clinicians would never consider non-treatment in a situation in which there was a only a 25% chance of severe impairment if there was also a good chance that there would be no impairment. For example, there are cases in which infants have had bleeding in the brain which would be expected to result in severe damage but if there is also thought to be a significant chance of the child being normal, the child will receive aggressive treatment.

How much chance of being normal is necessary to justify aggressive treatment in the face of a high probability of severe impairment varies from clinician to clinician. Some clinicians will say even if there is a 5% or a 10% chance that the baby will be normal, the baby should be treated aggressively. Others will say things like "even if the chances are one in a million" the baby should be treated. Some clinicians will say, "this baby could be another Einstein or Beethoven" to explain the rationale for treatment in those cases where treatment seems futile.

I believe that it is the emphasis on the uncertainty that a baby could be normal that has led to a focus in the literature on ethical issues in neonatology on treatment decisions concerning infants with Down's syndrome and Spina Bifida. These are conditions where the level of impairment is often not likely to be as severe as in some other NICU patients but the existence of at least a minimal level of impairment is certain.
In some neonatal cases, such as trisomy 13 or short bowel syndrome, there is no uncertainty that a child will not be normal and will in fact have severe defects. In some such cases, even advocates of aggressive treatment, such as Surgeon General Koop, will sanction the withholding of aggressive treatments. In many other cases, however, critics of withholding treatment will cite examples of children with spina bifida or very small premature babies who turned out to have much greater capacity than predicted, even when limits were thought to be known.

The Critical Condition

The third factor which clinicians consider is the nature of the condition which, if untreated, could lead to death. The severity of the condition, if the condition is acute or chronic, if it involves a unique discrete episode or will have repeated critical episodes, can all affect treatment decisions.

Crane, in The Sanctity of Social Life, examined the implications of "salvageability" (1975). Crane treats salvageability as a dichotomous category. In the clinical context, I think it may be more useful to think in terms of "the critical condition." It can be seen as forming a continuum. At one end of the continuum, one can identify patients who by old criteria could have been said to be "dead" (because they have no heart beat or because they have stopped breathing) (see
Chapter III). Others at the most critical extreme are premature babies born at the border or viability and "fresh still born" babies, born without a heart beat but possibly able to be resuscitated. Close to this end of the continuum are patients with terminal conditions, conditions which despite treatment will lead to death.

At the other end of the continuum, one can say that everything that is alive is in a critical condition for all life will end in death. While the concept that life is a critical condition has become almost trite, it is useful in this context to think of everyone as having a potentially critical condition. Life as a critical condition usually refers to acknowledging that life does not last an unlimited time. In this context, it is also useful to think about life as being a critical state if certain needs are not met, such as the needs for nutrition, fluids, oxygen, warmth. While we usually do not question provisions for these needs, in certain circumstances, choices about giving or withholding treatments pertain to these needs. Relevance to medical decision making will be discussed below.

Virtually all of the infants admitted to the neonatal unit fall in between the two ends of the continuum. They need some treatment beyond that necessary to sustain most newborns. Some have very serious, life-threatening conditions, some of which are terminal. In general, all other things being equal, the more critical the condition, the more likely that questions about the aggressiveness of treatment will arise. In this section, the role of the nature of the critical condition for treatment decisions will be discussed.
Unsalvageability and Non-treatment

Although the debate concerning non-treatment has focused primarily on those infants who are considered salvageable, non-treatment decisions are also very important concerning babies who are considered unsalvageable. This is true for two reasons. First, some of those babies who are expected to die, live if they are given particular treatments. Second, the choice of treatments may affect the timing of death and the nature of death.

Patients in a modern hospital virtually never receive no treatment. Even if a patient is felt to be dying, that patient will generally be fed, open lesions will be kept sterile, etc. Even more aggressive treatments may also be given for a baby for whom "nothing more can be done." For example, a baby may be given antibiotics and the acid/base balance may be aggressively managed (requiring frequent blood tests and injections), a baby may be given powerful drugs to maintain blood pressure, chest tubes may be inserted through the chest wall, a baby may be given massive blood transfusions, and/or may be on a respirator even when "nothing more can be done." In some cases, with this support, despite the expectation of death, the patient may survive. Whereas, if such support had been withheld, the patient would have died. In some cases, this may be clearly beneficial, as when a baby with serious cardiac lesions, who is felt to be unsalvageable, is given experimental surgery and is successfully treated. However, in other
cases, it is sometimes felt to be a tragedy when treatment prolongs
dying or a very poor quality of life. This will be illustrated by a
discussion about the treatment for Devon in Chapter VI.

A second way that decisions about withholding care from
"unsalvageable" babies becomes important is in terms of the timing of
death and the costs (financial and emotional) of care. Even though the
care provided may not lead to long term survival, it may lead to
survival for a period of time - it may be only minutes or it may be
weeks, or months after the patient is classified as "unsalvageable."

In some cases, the timing of death may be "managed" consciously by
clinicians. For example, a decision may be made to remove a baby who is
unsalvageable from the respirator, but the actual act of taking the baby
off the respirator may be delayed to give the parents an opportunity to
deal with the fact that the baby is about to die and to give the parents
an opportunity to hold their baby while he or she dies if they want to.
If parents do not want to be there when life support is discontinued,
such actions may be postponed until after they leave.

Sometimes there is conscious management of the timing of death for
the benefit of health care professionals. For example, a particular
person may want to examine a baby before the baby dies or they may want
to wait until a quiet time in the unit before discontinuing life
supports. There are reports that on some occasions, terminally ill
babies may have been removed from life supports when there was a
shortage of space or equipment in the NICU.

While the "last bed in the ICU" is a problem frequently discussed in the ethics literature, I never saw life supports removed from a terminally ill infant because of equipment shortage during the course of my observations. Such actions, if they occur at all, are very rare events. Such problems may be rarer in neonatal intensive care than in other types of intensive care. Since NICUs frequently have a less acute section, and the service may include facilities in the labor and delivery area, it provides an opportunity to care for a greater number of critically ill children than the theoretical capacity of the unit. For example, at Columbia, when the unit was full, critically ill infants could be cared for in the transitional nursery until it was possible for a space to be made. Over the years, sicker and sicker children were cared for in the semi-acute unit.

In many units, the critical resource is not beds, or respirators, but staff time, particularly nursing time. On occasion, when a unit is extremely busy and staff time is short, there may be tension between trying to give adequate attention to the infants who are unsalvageable, and those who are terminally ill. The staff members may feel that not enough time is being spent devoted to the care of critically ill infants who are salvageable, but such "competing needs" issues are likely to affect micro-allocation issues, not life and death decisions about discontinuing care.
Although sometimes the timing of death is consciously managed to achieve certain goals. More often treatment decisions are made which also affect the timing of death, but the management of the timing of death is not consciously addressed. For example, a baby might be sent for cardiac catheterization for diagnosis of a cardiac lesion. If the lesion is found to be incurable, the baby may be removed from respiratory support, or such support may be continued; powerful heart medications may or may not be continued, if there is an arrest, there may or may not be resuscitation. Different decisions about these treatment options might mean the difference in days of survival; sometimes value questions relating to the timing are addressed, other times such decisions are seen as technical "medical" decisions and the goals of treatment, when cure is no longer the goal, are not consciously addressed. (See Chapter VII, discussion on norms for decision making.)

There is a norm that it is better to see infants as salvageable who are unsalvageable, than to see infants who are salvageable as unsalvageable. In some ways this seems to be the reverse of the norm discussed by Sheff that it is better to define a well person as sick than a sick person as well (1963). Sheff's norm assumes that the patient is sicker, while this norm assumes that the patient is healthier. Yet, both norms support more treatment, and more chance for physician activism.
Social Value

The last dimension involved primarily with patient condition characteristics, for lack of a better term, I will label Social Value. This term is sometimes used to refer to aspects which I have referred to as quality of life. Some people speak of the social value of life for the baby. I use this term, however, only to refer to the value of treatment or non-treatment to persons other than the baby.

Some would argue that considerations concerning this dimension are unacceptable because every human life is uniquely sacred and of equal value; no other values may be weighed against the value of a single human life (Koop 1983). Some state that all decisions must be made only in the best interests of the child (e.g. Pres. Comm. 1983). Others, however, feel that the net costs and benefits of survival and continued treatment to others beside the baby may also be considered (Khuse and Singer 1985). Most, though not all, who take this position feel that the interests of the baby in life are great, and the quality of the baby's life would have to be very poor, and the costs to others would have to be very great, to outweigh the baby's interest in survival.

The social value connected to treatment decisions may be thought of not only in terms of the benefits to others of the death of the baby despite the baby's interest in survival, but also the benefits to others of the survival of the baby, despite the potential that the baby's death might be in the babies best interest. The social value of treatment or non-treatment can be looked at from at least three perspectives - those
of the family, the health care professionals involved in caring for the baby, and society at large.

Social Value to the Family

Many clinicians believe that impact on the family should be considered in making decisions and even more feel that the parents' wishes should be considered. In the survey, almost half said that the impact on the family should be considered and almost three quarters thought that the parents' wishes should be important in decision making. Sometimes the clinician's assessments of the implications of treatment for the family are based on extensive, open conversations with the family. At other times, however, clinicians' judgments may be based on general or stereotyped assumptions about the parents' wishes.

For example, clinicians sometimes assume that upper middle class, educated parents would be less likely to want a mentally retarded child to survive than working class parents. While this may be true in many cases, it is not true for all parents. Sometimes such basic beliefs are taught through stories that become legends of the unit. One story, repeated many times, recounted the case of a doctor, who upon learning that his child was born quite premature, said that he didn't want the child treated unless the doctors caring for her could guarantee that she would be normal. (Despite persistent objections from the father, they

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3 As noted in the introduction, I did not interview family members. Here I report primarily on clinicians' view of social value for the family.
stalled for time, continued treating, and the child survived with no
major problems.) On the other hand, other educated, articulate parents
have expressed anger about the assumptions that clinicians have made
that they would not want their children to survive, when they very much
wanted everything possible done.

While some people have said that working class families are more
upset about impairments which affect physical ability and educated
parents are more disturbed by impairments which affect mental ability
others feel such statements are based on prejudicial attitudes and that
working class parents have as much concern about the mental ability of
their children as more educated parents (personal communication, Raymond
Duff 1982).

The degree to which clinicians can accurately perceive the social
value of the infant to the family is dependent on a number of factors.
One is the degree to which the beliefs and values of the family are
similar to those of the physicians. Similarities and differences in
social class, religion or ethnic background, education, or socialization
in the medical subculture may affect the degree to which the clinicians
can understand the beliefs and values of the parent.

Such background characteristics also indirectly affect
communication. The degree to which the clinician feels he or she can
communicate with the parents may influence what information is imparted,
and how information is shared. Those parents who are felt to be
"medically sophisticated," usually the more educated, may be given more
information. It is probably no coincidence that a number of well known cases, such as the "John Hopkins case" and the case of the Danville Twins, both involved children of doctors/and or nurses who were familiar with the options as defined by the medical subculture and were able to get clinicians to act on their wishes.

Clinicians sometimes feel that a baby has special value to a family because of the family's reproductive history. Referred to as a "premium" baby because of the advanced age of the mother, infertility problems, multiple miscarriages or neonatal deaths, such an infant is assumed be especially wanted. It is felt that if such a baby were to die, it might not be possible to "replace" the baby by another pregnancy. For example, extra efforts may be made to resuscitate an extremely premature baby born close to the edge of viability (around 24 weeks of gestational age) to a mother who had 5 previous pregnancy loses and no living children, while such vigorous efforts might not be made for the third child of a young woman with no previous losses.

In part this occurs because of a perspective focused not on the neonate about whom one is making a decision as unique individual but rather as a constituent piece of a family. One area of concern is whether, if this child dies, can he or she be "replaced" in the family. In some cases clinicians may talk about whether the family had to be concerned with reoccurrence of the same problem or, if they are likely to have a healthy baby if this baby dies.
I have heard clinicians talk of a child as a "replacement" for one who died, and talk about babies who were not born because of the survival of a child with impairments. They believe that if an impaired baby dies, the parents will have another child, while if a baby survives, and is severely impaired, the parents will not have another child because they will be so distressed and/or burdened by the handicapped child (Khuse and Singer 1985). It is as if the goal of reproduction was the production of healthy "children." A child with an impairment doesn't count as a "successful pregnancy outcome." In some cases, however, the reverse may be true. Rather than preventing a subsequent pregnancy, parents may choose to have an additional child if one or more of their children has a handicap.

One concern expressed by clinicians is about the impact of severely impaired child on the functioning of the family. The studies are inconclusive, some showing a higher divorce rate, others showing no increase, and still other studies showing a higher divorce rate following neonatal death. In addition to concern for family integration, there is also concern about emotional impact on both parents and siblings. Although rarely, one also hears concern about members of the extended family as well. For example, the reproductive choices of an aunt or uncle may be affected by a bad neonatal experience.

Some people speak of how meaningful raising a handicapped child has been for some families, others speak of how stressful and still others talk about both joys and hardships. Many clinicians
believe that the impact on the family is dependent to a great extent on the nature of the society and available resources. In most places in the U.S. today, information and referral systems, and coordination of services for children with disabilities and not as well developed as clinicians think they should be. Clinicians express anger at federal government regulations that require treatment at the same time that the federal government has been cutting support services.

In opposition to all the negatives, clinicians often recognize the value of these babies to their parents and believe parents are firmly committed to their well being. I have heard clinicians comment on the fact that even for a child who is dying or who has major visible anomalies, parents will notice and get pleasure from features like their own or like members of their families. While some parents have trouble becoming attached to a child with problems, others are able to bond immediately, or are able to continue bonds which formed before birth.

Sometimes, especially when the child has very serious problems, clinicians are more able to perceive the distress and do not fully recognize the positive attachments of a family to a baby nor how great the loss would be from the child's death. Other times, especially when the baby has a problem which is minor by NICU standards, some clinicians are unable to understand why the family is having trouble adjusting.

Both parents and clinicians generally feel that they are genuine advocates for the babies. Parents sometimes mistrust the motives of the clinicians, and clinicians sometimes mistrust the motives of parents.
Both find it hard to understand how the other could feel that they could not be interested in the well being of the baby.

Diana Crane, in *The Sanctity of Social Life*, writes that the capacity to perform social roles is an important determinant of treatment. Since even a severely impaired neonate has the capacity to perform the social role of being a baby, it may be more likely that such an infant will be treated than an older person with a similar condition, if the focus is on the ability to perform immediate social roles. For example, incontinence may not be thought of as a very serious problem for a baby who would not be expected to be toilet trained for 2 or 3 years anyway, while it is a very difficult problem for families to handle for the elderly.

If the focus is on the ability to perform social roles through life, however, then the infant may not be treated for the newborn with impairments may not be able to carry out social roles of adulthood, such as reproduction or employment, may not be able to take care of parents or care for him or her self after the parents have died, and may therefore, be less likely to be treated.

Sometimes parents desire treatment choices that differ from those of the clinicians. Sometimes the parents want more aggressive treatments than the clinicians would recommend because they want the baby's life sustained despite the chance of severe handicap. Other times they are not ready to accept the fact that the baby is dying or they feel that the baby's life should be sustained for as long as...
possible, even if the baby is dying. If the parents want a baby to get treatments, then the clinicians will give them, while sometimes also trying to persuade the parents to accept their recommendations.

In other cases, parents don't want treatments to be given that the clinicians believe the baby should have. Most often the reasons for non-treatment are not seen as acceptable to the clinicians. Sometimes parents' beliefs are seen as determined by religious convictions that the clinicians do not feel should determine treatment choice. For example, Jehovah's Witnesses believe that having a blood transfusion will prevent a person from going to heaven. They may therefore refuse permission for a blood transfusion. In such a case, clinicians will go to court to obtain permission for transfusions, even if the chances for saving the baby's life are small.

In other cases, clinicians see parents' refusal as resulting from the parents' emotional problems or inability to understand the risks to the baby. In one case, a father wanted to take him still very sick baby home from the acute unit; the clinicians called security to prevent him from doing so. Clinicians see such cases as problems, but not as ethically problematic. They try to manage what they see as irrational behavior on the part of parents, and go to court, if necessary, to obtain authority to treat.

Sometimes parents want to have treatment withheld from infants because they feel that the quality of the life for their baby will be so poor that treatment shouldn't be given, while the baby's clinicians feel
that treatment is in the baby's best interests. At Columbia, these cases have been managed through discussions between the parents and clinicians. When decisions have not been seen to clearly violate in the best interests of the baby, parents have been able to make choices to withhold treatment. There seems to be recognition of a fairly wide range of treatment choices as not being clear-cut, which may reflect a fairly wide range of beliefs among the physicians who work in the unit. It may also result from the persuasive powers of the clinicians who were able to convince hesitant parents to continue treatment. As far as I know, neither clinicians nor parents have seriously thought about bringing such a case to court from Columbia. At other centers, such cases have been brought to the courts, both by parents and by clinicians.

Social Value to Health Care Professionals

and the Health Care System

There are a number of ways in which variations in the treatment of patients may have particular costs and benefits to the health care professionals who care for that patient and to the health care system as a whole.

First, for doctors and nurses who care for a patient, the primary professional goal is usually to cure, or, if that is not possible, to provide care. The socialization of the practitioners in an intensive
care unit generally has rewarded the aggressive use of available medical technology.

Personal and professional satisfaction is usually derived from intervening and treating. (See further discussion under goals in Chapter VII.) Many doctors and nurses have spoken of how difficult it is not to treat aggressively because of the extent to which it goes against their socialization. Often health care practitioners have seen death as a "failure" and have trouble acknowledging its inevitability. On the other hand, some health care professionals, particularly some physicians, also often see chronic illness or disability as a failure and sometimes find dealing with chronic impairments as a continuing confrontation with failure. They may feel that continuing an activist role in prolonging a poor quality of life is worse than passively letting death occur.

Many clinicians and others, however, feel strongly that, in order to avoid undermining the morale of health care professionals and their value system, that they should continue to treat aggressively, or at least not play an active role in causing death.

On a crude level, "success" is often measured in terms of mortality statistics. The overall infant mortality rate, or the weight or disease class mortality rate may sometimes be taken as a measure of the success of a unit.
Often practitioners also derive satisfaction from being able to study an unusual case, sometimes referred to as a "fascinoma" (Shem 1971). They may derive status from describing a new clinical entity, gaining a new understanding of an existing one, or in performing new experimental procedures. Prestige often comes from being able to do something which was never done before, or by conducting a clinical trial. Fascinomas are also useful as teaching cases.

The benefits to the clinicians from being able to work with a fascinoma are generally seen as secondary to the benefits for the patient, and the patient's family. Occasionally, the benefits for the clinicians may assume priority. For example, a baby who is thought to be unsalvageable may be intubated (have a tube inserted in the respiratory passages) to allow a student to be able to practice intubation in a non-emergency situation. I was told about a case in which a baby who was believed to be unsalvageable was intubated "for practice" in the emergency room. To everybody's surprise, the baby survived as a result of the intubation and did very well.

In addition to benefits of aggressive treatment for professionals, however, there are also costs. For one, the intensive care unit is usually very busy. Staff members often feel that they do not have enough time to do all of what they should do for some of their patients. For example, clinicians often said that they would like to spend more time with the families of their patients. They sometimes feel frustrated if they think they are putting time and energy into a hopeless situation when the time and energy would be better spent for
other patients with a better prognosis. In some situations, staff members may find that they are making "triage" decisions about how to best utilize their time which may lead to less aggressive care for one patient in order to provide more care for another.

While one hears neonatal staff members express frustration at efforts to provide aggressive care for the terminally ill, when they have other critically ill infants to care for, they derive satisfaction from working with most of their NICU patients. Staff members who generally work in other settings, however, may express frustration at having to care for infants who have impairments when they could be providing care to other patients.

For example, a primary care pediatrician apologized for being late for a routine office visit explaining that he had to take care of an emergency situation for a baby who had just been born with hydrocephalus. He continued to complain about having to take care of "that kind of baby." In a similar situation Morgan, in her book, the making of a woman surgeon, complained about having to care for a child with hydrocephalus (1981). Neonatologists sometimes have trouble getting physicians from other specialties to perform procedures promptly for some of their patients, if those practitioners don't want to work with patients who may have severe lasting handicaps.

If clinicians feel that they are actually "doing harm" by treating, by prolonging the dying process or causing pain for the patient without compensating benefit, providing treatment is an
emotional burden for them as well. This situation can occur for a junior physician or nurse who must follow the orders of a more senior physician, or for any clinician who follows parents directives for aggressive treatment, although they feel it would be in the baby's best interest for treatment to be limited.

Space is also often at a premium in the ICU; aggressive treatment may keep an infant in an acute ICU bed when some staff may feel that such a bed would be better utilized by another patient. While the "classic," ethics hypothetical of an infant who is about to die, being denied emergency care because there are no more beds in the ICU virtually never occurs; babies are cared for in less intensive settings sometimes who could benefit from placement in a more acute setting, because the more acute setting is filled to capacity.

Sometimes the costs and benefits of particular treatments to different providers may vary. For example, traditionally doctors are more oriented towards "cure" and may find fewer rewards when "cure" is not possible, while nursing has be characterized by more concern with "care" and relief of suffering. Therefore, nurses may get more professional satisfaction out of treatments which provide "comfort care" while physicians may be frustrated by the fact that the same treatment is not going to lead to a cure.

Frequently, clinicians, particularly primary nurses who care for a baby daily, themselves develop emotional attachments to the baby. On occasion, it has appeared that some babies may have received more
aggressive care than they otherwise would have because of the attachment of a particular nurse who would have wanted treatment. Although I never heard of a case in which it appeared to lead to less aggressive treatment, sometimes, in the case of an infant who seems to be suffering, the clinicians who are most attached to the baby may be in favor of less aggressive treatment.

Finally, the costs and benefits of providing care for catastrophically ill newborns varies greatly depending on the particulars of the patient and treatments and on one's perspective in the system. For example, more utilization of certain diagnostic machinery and laboratory equipment may lead to greater profit for the hospital (in an era of retrospective payment) while labor intensive care of an "chronic" ICU patient may lead to greater costs than reimbursement (especially under prospective payment mechanisms). While financial considerations are important factors in the budgeting which determines the equipment and staffing for the NICU, considerations of the financial cost for the health care system appear to have little effect on the decisions made about the care of individual newborns.

One hears a position articulated which states that the clinicians caring for particular patients should only be advocates for their patients, and should not consider the costs of care. Clinicians, in fact, are often unaware of the costs of particular treatments. Many have said that the period of financial naivete may be ending with the end of retrospective payments.
Indirectly, financial factors do strongly affect decisions that are made. While they do not affect conscious choices made about the care of individual infants, they do set the options or context in which decisions are made. There may only be a limited number of particular pieces of equipment available for use. For example, when there was only one monitor capable of continuously measuring the level of oxygen in a baby's blood through the skin, only certain types of babies were seen as candidates for monitoring with such a system. When more such monitors were available, infants with a greater range of conditions were monitored with the equipment.

While for those directly involved in decision making the economic costs and benefits of treatment may not be considered important, clearly neonatal care helps to support aspects of the health care system including a large biomedical equipment and supply industry. Large amount of specialized equipment is developed and aggressively marketed for use in the NICU. Overall, intensive care units are often profit centers for hospitals and help to support less profitable services.

Social Value for Society

Much has been written about the implications of decisions making for catastrophically ill newborns for "society." The concept of "the society" in these discussions is vague; for the purposes of this study I will use it to mean anybody beside the neonate whose care is under
question, the neonates family, and those health care professional involved in the care of the baby.

Some discussions of "social value" refer to the need of society to maintain certain standards. For example, while it may be in the interest of a baby to die quickly and therefore put a quick end to suffering, it may be said that active euthanasia should not be performed in order to protect society from undermining a central value which forbids the direct killing of innocents. Arguments are also made that tolerance of and caring for dependent peoples is an important attribute for society (Fiedler 1985) and that not to do so would undermine the caring for other dependent peoples and/or others who are "different" in society (Horan and Delahoyde 1982). Although clinicians talk about the implications of neonatal decision for societal values, it does not appear that these concerns actually affect their decisions for individual newborns.

The presence of efforts for handicapped newborns may be very important ideologically in order to demonstrate the humanitarian concerns of society and technological expertise. On the other hand, some of those who object to the level of investment in NICU care, do so for they feel it diverts resources from other humanitarian concerns, including the prevention of the birth of low birth weight infants or the birth of infants with impairments. There is also concern about the overall costs to society of neonatal care. It is usually discussed in terms of two aspects. The economic costs of care and the burden caused
by treatment leading to the survival of people with impairments and/or severe impairments.

Neonatal care is very expensive. It has been estimated that the cost of neonatal care in 1981 was approximately 1.5 billion dollars a year (Budetti, et al. 1981), with both inflation and new technology, costs have undoubtedly increased. While non-neonatal clinicians sometimes talk about how some of the money could be better spent for other, non-medical needs, the neonatal staff rarely seemed to consider economic cost, except perhaps in terms of comparison with preventive health care to prevent the types of problems they were treating.

In the survey, some of the factors least likely to be considered important in making treatment consideration were the availability of funds for other medical care and for other, non-medical social needs, each of which was chosen by fewer than one fifth of respondents. (Many of the respondents who did indicated agreement, checked all of the other factors as well). Furthermore, although such factors might be mentioned in conversation, they appeared to play no part in actual decisions made about individual newborns.

There is concern among clinicians about the effect of NICU care on the prevalence of impairment. While risk of impairment for the individual is considered in making individual treatment decisions, clinicians focus on their own patients; the number of impaired individuals in the population is not considered an important factor in making decisions about individual newborns. Both economic costs for
society and the prevalence of impairment in the population may be important in determining the macro-allocation decisions determining the resources available to clinicians for treating individual newborns, but they are not consciously considered in decision making about individual cases.

Summary

Chapter V discussed characteristics of patient condition. Clinicians consider the quality of life (for the baby) to be a very important factor in decision making. Quality of life is influenced in part by physical and/or mental impairment, the capacity to give and receive love, and the amount of pain and suffering. There is debate about the degree to which the influence of family and societal factors about the quality of life should be considered. Clinicians also consider risks and uncertainty both about whether an infant will be normal, about the severity of impairment, and about the likelihood of success with a particular treatment. The critical condition -- what the infant needs to stay alive -- is also an important factor. Finally, clinicians talk about the social value of treatment or non-treatment for others -- family, clinicians and the health care system, and the larger society, the social costs and values to society seem to play a small role in the decision making process about individual newborns.
As discussed in Chapter IV, decision making about treatment for catastrophically ill newborns involves not only consideration of characteristics of patient condition, but also involves consideration of the characteristics of possible treatments. This is illustrated by the fact that clinicians give patients some treatments while withholding others from the same patient. For example, in the much publicized case of Baby Jane Doe, a child with spina bifida, her parents and clinicians chose to withhold neurosurgery to repair her spinal lesion, but they administered antibiotics when she developed meningitis. While each treatment could be considered a life saving intervention, the two treatments differed in a number of respects (See Chapter VII for a discussion of this case).

Decision making about which treatments to give and which to withhold involves the categorization of possible treatments along a number of culturally defined dimensions. In this chapter, I will discuss the dimensions of aggressiveness, ordinary/extraordinary treatment, withholding/withdrawing treatment and passive/active euthanasia. Although some of these dimensions may seem to be purely objective and/or dichotomous, in fact, like the patient condition
characteristics, each may be seen to form a continuum and each is, at least in part, culturally defined.

**Aggressiveness**

On the basis of observations of how clinicians talk about treatment options and make treatment choices, I concluded that clinicians categorize treatments according to what I refer to as a treatment's level of "aggressiveness." Treatments which have such attributes as a large physiological effect, which are experimental, which are not frequently done, which are invasive or involve the use of high technology, and/or which are costly in terms of staff time or monetary costs, and/or which are risky, are ranked as more aggressive than other treatments which do not share those attributes to the same degree.

At one end of the dimension of aggressiveness lie those treatments which are seen as the most aggressive. These include life support treatments that replace organ function such as chronic kidney dialysis, or the use of an artificial heart or a liver transplant. At the other end are procedures which may be considered so routine that they are not even usually considered "treatments" by clinicians. This would include such procedures as giving IV fluids, keeping an open lesion covered with a sterile dressing, wearing surgical gloves, or keeping a baby in an isolette. It is worth noting that some such procedures (such as IV fluids) are themselves relatively recent developments, and are not
routinely done in all parts of the world today; doing or not doing each of them can have life or death consequences in some circumstances.

Categorizations about treatments, in terms of their level of aggressiveness, are very basic to the way that clinicians think about treatments. Because they are so central, however, they are often made preattentively -- without conscious thought. Like many core cultural concepts for people socialized in a culture, to people socialized in the clinical subculture, differentiating on the basis of aggressiveness may form part of assumptions about the nature of their world; since the assumptions are so basic, they are often hard to articulate. To others, not socialized in the cultural system, behavior based on such distinctions may seem unintelligible.

I first became interested in what I was later to understand as the concept of aggressiveness in 1977 as I was observing treatment decisions which were made about the care of an infant whom I will call Sal. Sal was born three months premature and weighed two and one half pounds. He suffered from respiratory distress syndrome, a severe disease caused by lung immaturity. Soon after birth, he was put on a respirator which provides high levels of oxygen and can mechanically "breathe" for a patient. When I first saw him, he was on a respirator, receiving all that modern medicine had to offer to promote his survival.

As his respiratory status improved, he was weaned to CPAP (a sophisticated respiratory device which maintains air pressure to help keep the lungs inflated and can deliver a high concentration of oxygen
but, unlike a respirator, does not "breathe" for the baby by delivering bursts of air to the lungs). Soon after, his condition took a sudden turn for the worse. His muscle tone and movements decreased. Suspecting a problem, a spinal tap was done (which was the diagnostic test routinely used at that time to test for bleeding in the brain). Normally the fluid obtained was clear; Sal's fluid contained blood, indicating that he might have had bleeding in his brain.

This led to consideration of Sal's condition according to the patient condition characteristics discussed in the last chapter. Blood in the spinal fluid indicated that he might have suffered brain damage, resulting in serious impairment and a severely diminished quality of life. There was, however, a high degree of uncertainty because the test had low predictive value. (The test itself could have been traumatic and led to the blood, the bleeding could resolve leaving no serious deficit, or the bleeding could have caused damage in an area of the brain which would not have seriously impaired the future quality of life.)

The need for sophisticated respiratory support meant that the baby was seriously ill, but his condition was not seen to be as critical as if he had needed to be on a respirator. Social value, while not the central concern, may also have been considered. Potential very high costs of care and the impact for his family, could have been thought to be too high if, indeed, he did have severe impairments. For whatever combination of reasons, Sal's parents and clinicians decided that he might be so sick, it might be better if he was allowed to die.
The next time I returned to the nursery, I was told that a
decision was made to continue CPAP, but if his respiratory condition
deteriorated, the decision had been made that he would not be put back
on the respirator. If his heart stopped, he would not be given cardiac
resuscitation. Other treatment, such as intravenous feedings, anti-
seizure medications, and continuous monitoring of heart and respiratory
rate and other forms of intensive medical and nursing care, would be
continued.

I didn’t understand why he was on CPAP yet would not be put on a
respirator. At that time the treatments looked virtually the same to
me. Both meant that the baby was hooked up to sophisticated machines
and both involved tubes into the baby to deliver oxygen. It was
explained to me that the need for a respirator or cardiac resuscitation
bore no necessary relationship to his future quality of life. The baby
could have been severely impaired, yet have had no further respiratory
or cardiac problems and survived. On the other hand, his cardiac or
respiratory status might have temporarily been worse, yet he might not
have had any brain damage. Therefore, because treatments were withheld,
he might have died even though he could have survived without serious
impairment. Conversely, he might have survived with the current level
of treatment, yet have been severely impaired.

I had thought that decisions about treatment were all or nothing
decisions to "maintain life" or "pull the plug." The decision to
continue CPAP but not use a respirator didn’t seem to make any sense to
me because I thought that the use of CPAP did not differ in any significant way from the use of the respirator. However, for the clinicians involved, the use of the respirator, conceptualized by the clinicians as a more aggressive treatment, was significantly different. I asked repeatedly why he was on CPAP but wouldn't be put on the respirator. I was repeatedly told that "it wouldn't make sense to put him back on the respirator if his quality of life would be poor." Each time, I asked, "then why is he still on CPAP?" and was told that "that was different." Yet because the conceptualization of why there was a difference was felt to be due to variation in the aggressiveness of treatment, which reflected such a basic and unconscious assumption, the clinicians in the unit had difficulty understanding what I didn't understand.

Sal's condition did not deteriorate and he never had need for a respirator or resuscitation. At five years of age he had cerebral palsy which affected his lower limbs but he has no intellectual impairment.

When making decisions to withhold treatments, clinicians are more likely to recommend giving those treatments which are less aggressive while withholding those which are more aggressive. This notion of a ranking of treatments is widely shared among clinicians both in

\[1\] Another possible factor entering into the distinction between CPAP and the respirator was that stopping CPAP would be withdrawing treatment, while not putting the baby on a respirator was withholding treatment (see withdrawing/withholding, below). However, even in terms of withholding or withdrawing treatments, the level of aggressiveness makes a difference for I had been told that if he needed them, Sal would be given antibiotics, blood transfusions, and other, not very aggressive, types of treatment.
neonatology and in other clinical specialties. This is evidenced in the pattern of responses about treatment decisions on surveys of clinician decision making. For example, as part of her research on physicians' treatment of the critically ill, Diana Crane asked physicians if they would give or not give a series of specific treatments to patients described in hypothetical vignettes. The respondents indicated that they would give some less aggressive treatments, while withholding others which would be more aggressive from the same patients (Crane 1975; personal communication, 1981 -- see example of survey results in Chapter III).

I also found that clinicians were more likely to recommend less aggressive treatments and more likely to withhold more aggressive treatments in the survey I conducted in the Spring of 1983 (see appendix). I presented respondents with a series of hypothetical vignettes about catastrophically ill newborns and asked respondents if they would recommend or not recommend a series of treatments for each baby. In each case, the number of respondents who would recommend each treatment, varied from treatment to treatment (see Table VI - 1).
<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>% WHO WOULD RECOMMEND ORDINARY/EXTRAORDINARY</th>
<th>MEAN SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>BABY WHO IS ANENCEPHALIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedings by mouth</td>
<td>76</td>
<td>1.9</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>56</td>
<td>2.6</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>32</td>
<td>3.1</td>
</tr>
<tr>
<td>Resuscitation in the delivery room</td>
<td>13</td>
<td>4.0</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Arrest page</td>
<td>2</td>
<td>4.7</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>2</td>
<td>4.8</td>
</tr>
<tr>
<td>BABY WHO HAS MULTIPLE ANOMALIES (BEFORE CHROMOSOMAL ANALYSIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>90</td>
<td>1.6</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>81</td>
<td>1.9</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>76</td>
<td>2.0</td>
</tr>
<tr>
<td>Respirator</td>
<td>65</td>
<td>2.4</td>
</tr>
<tr>
<td>BABY WHO HAS MULTIPLE ANOMALIES (AFTER CHROMOSOMAL ANALYSIS INDICATES TRISOMY 13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>85</td>
<td>1.9</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>60</td>
<td>2.8</td>
</tr>
<tr>
<td>Respirator</td>
<td>24</td>
<td>4.1</td>
</tr>
<tr>
<td>Surgery for cleft palate</td>
<td>14</td>
<td>4.0</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>13</td>
<td>4.5</td>
</tr>
<tr>
<td>Arrest page</td>
<td>10</td>
<td>4.6</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>8</td>
<td>4.7</td>
</tr>
</tbody>
</table>

For the Baby with trisomy 13, and for questions on resuscitation in the delivery room and an arrest page for the anencephalic baby, n = 119; actual base varies slightly depending on the number of ineligible answers (in all cases, ineligible answers less than 5% of total n).
<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>% WHO WOULD RECOMMEND ORDINARY/EXTRAORDINARY</th>
<th>MEAN SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A SMALL PREMATURE BABY WITH AN IVH</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>93</td>
<td>1.6</td>
</tr>
<tr>
<td>Suctioning</td>
<td>92</td>
<td>1.7</td>
</tr>
<tr>
<td>Resuscitation in delivery room</td>
<td>64</td>
<td>2.3</td>
</tr>
<tr>
<td>Increased respiratory settings</td>
<td>53</td>
<td>2.3</td>
</tr>
<tr>
<td>Pressors</td>
<td>39</td>
<td>3.5</td>
</tr>
<tr>
<td>Arrest page</td>
<td>26</td>
<td>4.1</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>13</td>
<td>4.6</td>
</tr>
<tr>
<td><strong>A BABY WITH DOWN’S SYNDROME AND DUODENAL ATRESIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intravenous feedings</td>
<td>91</td>
<td>1.3</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>88</td>
<td>1.5</td>
</tr>
<tr>
<td>Surgery for intestinal defect</td>
<td>87</td>
<td>2.2</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>71</td>
<td>2.9</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>59</td>
<td>3.7</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>28</td>
<td>4.3</td>
</tr>
</tbody>
</table>
This variation can be seen to correspond to what clinicians would consider the aggressiveness of treatments. Less aggressive treatments were more often recommended while respondents less often recommended more aggressive treatments.

The pattern of responses on the survey indicated a high degree of consistency in the rank ordering of treatments to be given or withheld, reflecting consistency in categorizations. For each case, a Guttman scale analysis yielded a coefficient of reproducibility for the treatment recommendations exceeding 0.92. This indicates a high degree of correlation which corresponded to rankings along the dimension of aggressiveness.

There may be more consistency in the ranking of some treatments choices than others. For example, the most consistency in the ranking may occur for treatments alternatives that would be given in the same situation, the least in ranking treatments given in very different situations. To illustrate, responses to the survey indicated that when respondents were asked about their recommendations at two points in time (in the delivery room and in the ICU) the coefficient of reproducibility was lower than when all questions pertained only to treatments in the ICU. When only the responses about treatments to be recommended in the ICU were considered, the coefficient of reproducibility was above 0.97 in all cases, indicating a very strong degree of ordering according to aggressiveness.
When treatments are close to the same level of aggressiveness or involve treatments from different domains, such as diagnostic tests and surgical procedures, ranking may also be less consistent. For example, while in general, diagnostic tests are seen as less aggressive than surgery, very invasive tests like cardiac catheterization or expensive tests like CAT scans may be considered more aggressive than minor skin surgery.

Although clinicians may speak of questions about which treatment to give and which to withhold as questions of "how aggressive to be in treatment," it is not a single labeled category recognized by clinicians. Indeed, a number of different terms may be used to refer to this concept including "heroic" versus "conservative" treatment, or "supportive" or "ordinary" care versus "extraordinary" care (See the next section for a more complete discussion of the use of the terms "ordinary" and "extraordinary.").

In addition, the term "aggressiveness" is also used in a number of different ways. It is sometimes used as a synonym for "extraordinary treatment" (as discussed below, defined by both patient and treatment characteristics). Although rare, it is even occasionally used to refer to almost the opposite situation when it is used here to indicate a decisive choice to stop a treatment as in the statement "They were aggressive in their decision to take the baby off the respirator." Although the term is used in a number of ways, when used in context in the sense that it is used in this thesis, it is understood by clinicians both in neonatology and in other specialties.
To illustrate, I present the case of Devon, an infant for whom questions arose about the aggressiveness of treatment:

Devon was born about eleven weeks before his due date. When she was in labor, his sixteen year old mother was crying for her own mother. She hadn't used contraception, she didn't really think she would get pregnant. She had thought about having an abortion, but her mother discouraged her. She, her mother, and her thirteen year old sister lived on welfare. Her boy friend was eighteen. Both black teenagers had dropped out of school. Neither was working.

The birth was difficult, although Devon weighed only two and one half pounds. Stephen, a neonatal fellow had difficulty intubating (putting in a tube for oxygen) and asked Martha, a neonatal nurse, to call upstairs for Tom, the anesthesiologist from the NICU; by the time he arrived Stephen had successfully placed the tube. Apgars were 1/1/5. Tom, Stephen and Martha brought Devon to the transitional nursery and stabilized him. After about two hours, on their way to the NICU, they stopped in the recovery room so that his mother, grandmother and father could see him.

His initial course was rocky but not uncommon. He had a PDA (problem in cardiac circulation) and was scheduled for closed heart surgery. He also had a grade III IVH (bleeding in the brain). Both were not unusual for a baby his size. In fact, there had been a number of very small babies in the unit; compared to them, he was doing quite
well. Anne, the resident most involved in his care, commented that the four babies she was caring for weighed less than some full term babies. His mother and grand mother visited daily, his father often came as well.

When he was about nine days old, he developed meningitis, an infection of the central nervous system. Although low birthweight babies are at risk for developing meningitis, it was much less usual than the other complications and its implications were worse. In a baby that small, it often leads to severe brain damage or death. His heart surgery had to be postponed while he was treated for three weeks with powerful antibiotics. Meanwhile, his respiratory condition couldn't improve much because he badly needed the surgery. His weight fell to less than one and three quarters pounds,

As soon as he finished the three weeks of antibiotics, he was sent immediately for heart surgery. Unfortunately, by then, his tissues were friable and a nick of a vessel led to a massive hemorrhage -- he needed two times the volume of his own blood supply before he could leave the operating room.

He returned to the NICU in critical condition. His mother and her mother, and his father and his parents came in. He was still bleeding, his blood pressure was low, he was on the respirator, with tubes through his chest on each side. He wasn't expected to make it. They left, not knowing if they would see him alive again.
Anne and Martha worked on him constantly, sometimes assisted by other doctors and nurses as well. They were giving him syringes fill with blood to replace the blood lost, as well as bicarb to control the acid/base balance in his blood, in an attempt to stabilize his condition.

Anne was frustrated. She wasn't sure that he should have had aggressive treatment like surgery because of the meningitis. If it had been up to her, she might not have sent him. She said that other doctors has pushed for the surgery and now they were saying "don't be too aggressive." She found it difficult to know what to do for Devon, who was probably dying. She said "Some people mean everything but intercardiac meds [powerful medications injected directly into the heart] while others mean much less when they say don't be too aggressive." She thought she might give him dopamine, a powerful drug to maintain blood pressure. Anne said, "That's a treatment some people wouldn't give if they weren't being too aggressive." "Yet," she said, "here he is with chest tubes on each side on a respirator."

She talked to the fellow, Frank; he decided to call the attending, Lane, who was covering that night. Lane decided not to come in, but he did give specific instructions. He said "don't give dopamine because it could increase the bleeding. Don't give adrenaline [to stimulate his heart if it stopped]." "But," he said, "keep giving the bicarb." "Give one, maybe two more pushes [syringes] of blood if he needs it, but then, stop." The feeling was that nothing more could be done, he was dying.
He only needed blood once more. If he had died that night, no one would have considered it a case of withholding treatment. He would have been seen as a terminally ill baby who died.

For a few days his condition improved, then deteriorated and he was again put back on the respirator. His family arranged for him to be baptized in the NICU. Anne, Frank and Lane's month on service ended and other doctors, Andy, Stephen and Ruth took their places.

Most of the doctors and nurses caring for Devon were disturbed. They felt that the bleeding in his brain and meningitis had caused much damage. They called in a neurological consult. He found that Devon only responded to deep pain; he didn't try to cry. The shape and movements of his eyes, lack of primitive reflexes, and a general lack of muscle tone all indicated significant nervous system injury. The neurologist wrote in the chart: "The prognosis for normal neurological development is very guarded."

The doctors and nurses most involved in his care met to discuss his case. Both Stephen and Ruth said that it would be better if he died. They talked to his family. His mother still wanted him to be treated. His grandmother wasn't sure, but she said it was her daughter's baby so she should decide. Some of the nurses thought that Devon's mother was denying the seriousness of his illness.

Ruth felt the mother had made a poor decision. She felt the baby should be taken off the respirator or at least be "no arrest page" (not
to have the heart started if it stops). I asked about giving bloods or antibiotics. While those choices might have been possible when he was dying, now all three doctors, Ruth, Stephen and Karen, another neonatologist who was nearby, looked uncomfortable at the thought. Ruth said, "I feel alright about disconnecting the respirator, or not doing an arrest, but not giving bloods or antibiotics, that's different." Later Karen said that if he arrested, he probably wouldn't be resuscitated.

After that, his respiratory condition did improve, after about a month he could be moved to the semi-acute unit. He became somewhat more aware and gained weight. About two months after that he went home. He continues to be followed and his neurological condition continues to be poor.

Ordinary/Extraordinary Treatment

Another dimension on which treatments are classified is the ordinary/extraordinary dimension. Unlike the dimension of aggressiveness, which in theory depends only on characteristics of treatments, in making judgments about whether treatments are ordinary or extraordinary, characteristics of both patients and treatments are considered.

The distinction between ordinary and extraordinary means grows out of Catholic moral theology (see Chapter II). The most commonly used
definition was offered by Father G. Kelly (1958) "Ordinary means" were defined as "all medicines, treatments and operations which can offer a reasonable hope of benefit for the patient and which can be obtained and used without excessive pain and other inconvenience." "Extraordinary means," on the other hand, are defined as those treatments that do not meet the above criteria. Since the distinction rests on "benefit for the patient," considerations concerning issues related to the patient's benefit, such as the patient's quality of life, as well as the cost and invasiveness of treatment are considered.

When philosophers and theologians use the terms, (reflected in virtually all of the philosophical literature written before 1983) they usually do so in a manner which indicates that they see ordinary and extraordinary treatments as each forming a discrete category. In discussing the withholding of treatment, philosophers often used the terms with the assumption being that the categorization of treatments as ordinary or extraordinary was not problematic.

The terms have been used in the same manner in some court decisions. For example, the terms were used in a pair of 1981 cases before the New York State Court of Appeals, known as the Father Fox and the Storars cases. The decision, issued to clarify policy after the death of Father Fox, stated that "ordinary care must be given while "extraordinary care" could be withheld. (New York Law Journal 1981:5)

However, in doing field work in the neonatal intensive care unit, I observed that clinicians often did not use the terms as dichotomous.
Rather, clinicians seemed to perceive treatments as falling along a continuum between "ordinary" and "extraordinary." Clinicians would talk about treatments being "more extraordinary" or "less extraordinary" than another. There was often disagreement among clinicians about whether a particular treatment was ordinary or extraordinary in a particular case.

In addition to evaluations based on benefit to the patient, most clinicians seemed to be incorporating other elements beside benefit to the patient in making categorizations of treatments as "ordinary" or "extraordinary." Many clinicians considered how usual or unusual a treatment is, whether the treatments were high tech or low tech, invasive or non-invasive, and other characteristics, here discussed in terms of "aggressiveness" in making distinctions according about whether a treatment was ordinary or extraordinary. For example, a clinician might say, "it used to be extraordinary to put a baby this small on the respirator, but now we do it all the time."

Sometimes clinicians will categorize as ordinary any treatment which they feel would be beneficial to a baby and categorize any treatment which they don't feel would be beneficial as extraordinary. However, clinicians have trouble using the terms without incorporating aspects of aggressiveness. Therefore, clinicians will sometimes classify as ordinary less aggressive treatments even if they feel they will not have benefit for the baby and classify as extraordinary aggressive treatments even if they feel they will be of benefit for a baby. On the survey I distributed in 1983, I asked respondents to rank each treatment option on a scale of 1 (ordinary) to 5 (extraordinary)
(see appendix). Mean scores for each treatment choice are shown on Table VI - 2. The variation in categorization of treatments as ordinary or extraordinary was reflected in the responses. The respondents' rankings for every treatment on the survey ranged from "1" (ordinary) to "5" (extraordinary).

In part the ratings of treatments as "ordinary" or "extraordinary" reflected the respondents' feelings about the potential benefit of treatment for a particular infant. This is reflected in the differences in ranking of treatments from case to case and in the correlations between rating on the ordinary/extraordinary scale and respondents' treatment recommendations (see Tables VI - 2 and VI - 3). The ranking along the ordinary/extraordinary scale, however, also reflect the fact that respondents' categorizations incorporate characteristics of treatments as well as characteristics of patients. This is reflected in the fact that the relative ranking of treatments as more or less ordinary was consistent from case to case (Table V - 1) and the fact that even respondents who would not recommend less aggressive treatments would categorize them as more ordinary than more aggressive ones, and, even respondents who would recommend more aggressive treatments would categorize them as more extraordinary than less aggressive treatments (see Table V - 3).
TABLE VI - 2
COMPARISON OF RATINGS ON THE ORDINARY/EXTRAORDINARY SCALE
BY PATIENT CONDITION AND TREATMENT

<table>
<thead>
<tr>
<th>TREATMENTS AND PATIENT CONDITIONS</th>
<th>ORDINARY</th>
<th>EXTRAORDINARY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1  2  3  4  5</td>
<td></td>
</tr>
</tbody>
</table>

**IV FEEDINGS/NUTRITION AND FLUIDS**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down's syndrome and duodenal atresia</td>
<td>83  8  5  2  2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trisomy 13 with cleft palate</td>
<td>63  16 4  7  10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**ANTIBIOTICS**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down's syndrome and duodenal atresia</td>
<td>71  17  7  2  3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trisomy 13 with cleft palate</td>
<td>28  18  18  17  19</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SURGERY**

<table>
<thead>
<tr>
<th>Operation</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>For duodenal atresia (Down's)</td>
<td>33  33  22  7  5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For cleft palate (trisomy 13)</td>
<td>4  9  18  22  47</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**OPEN HEART SURGERY**

<table>
<thead>
<tr>
<th>Operation</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>For baby with Down's syndrome</td>
<td>4  9  27  27  33</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For baby with trisomy 13</td>
<td>2  0  6  11  81</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3 Numbers represent the percentage of respondents who would assign each treatment a particular rating on the "ordinary/extraordinary" scale. For treatments for the baby with Down's syndrome, n = 249. For treatments for the baby with trisomy 13, n = 119.
TABLE VI - 3
RATINGS ON THE ORDINARY/EXTRAORDINARY SCALE
BY RECOMMENDATIONS CONCERNING TREATMENTS FOR
A BABY WITH DOWN'S SYNDROME

<table>
<thead>
<tr>
<th>TREATMENTS AND TREATMENT RECOMMENDATIONS</th>
<th>ORDINARY</th>
<th>EXTRAORDINARY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>INTESTINAL SURGERY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would recommend</td>
<td>n = 216</td>
<td>37 36 19 6 2</td>
</tr>
<tr>
<td>Would not recommend</td>
<td>n = 31</td>
<td>7 10 45 16 23</td>
</tr>
<tr>
<td>CARDIAC SURGERY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would recommend</td>
<td>n = 142</td>
<td>7 15 39 20 19</td>
</tr>
<tr>
<td>Would not recommend</td>
<td>n = 97</td>
<td>1 1 9 35 54</td>
</tr>
<tr>
<td>KIDNEY DIALYSIS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would recommend</td>
<td>n = 67</td>
<td>10 15 21 22 31</td>
</tr>
<tr>
<td>Would not recommend</td>
<td>n = 173</td>
<td>1 3 6 16 74</td>
</tr>
</tbody>
</table>

4 Numbers represent the percent of respondents within each treatment category (recommending or not recommending treatment) who would assign the treatment a particular rating on the "ordinary/extraordinary scale."
Singer, Kuhse and Singer, in a survey of obstetricians and pediatricians in Australia, also found that while some clinicians classified treatments as ordinary, others categorized the same treatments as ordinary (Singer, Kuhse and Singer 1983).

While I had not seen the variation in use of the terms "ordinary" and "extraordinary" discussed a few years ago, it has recently been discussed in a number of contexts. Critics have suggested that the terms are used in so many ways that the distinction is no longer useful (Pres. Comm. 1983:88-89). The terms, however, are still frequently used by philosophers and in the clinical setting in the context of decision making.

**Withholding/Withdrawing Treatment**

In discussions concerning decision making about the aggressiveness of treatment, a distinction is often made between withholding (or not starting) and withdrawing (stopping) treatments. While many clinicians now feel that the distinction should not have much importance in decision making, it continues to play a role in treatment choice.

At first glance, criteria for deciding how to classify a treatment on this dimension may seem to be clear cut and objective. Indeed, "stopping treatment" or "pulling the plug" are the idioms most often used to refer to the subject of limiting the aggressiveness of treatment. However, as discussed earlier, plugs are almost never pulled
and, as with the other dimension of patient condition and treatment characteristics, categorizations of behaviors as starting and stopping treatment are complex and culturally defined.

In many instances, the categorization of a treatment behavior is clear. For example, in choosing not to perform surgery to repair duodenal atresia, the decision clearly pertains to a choice about starting a new treatment, rather than a decision about withdrawing an ongoing treatment. In other instances, however, when a treatment modality can be seen as made up either one single treatment composed of a number of parts, or a series of individual treatments, the distinction between starting and stopping treatment becomes unclear. The following anecdote will illustrate the issue.

Ray was born with a spina bifida. He had a high level lesion and other anomalies which meant that if he survived he would have multiple impairments. At first the exact extent of the anomalies was unclear and his parents didn't know what decisions to make. Antibiotics were started soon after birth and the child was examined by multiple consults. After meetings with physicians, nurses, social workers, and others, his parents decided that "treatment should be stopped and the baby should be allowed to die."

The following morning at social service rounds, a social worker who was involved in the discussion was surprised to find that the baby was still being given antibiotics. She said to the resident "you're not going to give any more antibiotics then, right?" She felt that adding
more antibiotics to his intravenous solution would constitute a "new treatment." The resident, however, seeing the addition of more antibiotics as only part of a single, continuous, seven day course of treatment, said he would "finish the seven days and then stop." He added "that will give the baby time to declare himself." He felt that not to finish the seven day course would be withdrawing treatment; he didn't feel that it would be right to withdraw treatment. The social worker was disturbed. She would not expect the current IV bottle containing medication to be removed, but she didn't think that antibiotics would be added to any subsequent IVs. She conceptualized that as withholding, not withdrawing treatment.

The preceding example illustrates the fact that treatments which require multiple administrations create an ambiguous situation in which not providing the treatment may be considered either withholding or withdrawing treatment. In addition to administration of continuous medication, there may also be differences in categorization when treatments are interrupted. If a baby was ever given a treatment for a problem, for example a blood transfusion, and the baby again needs a treatment for the same problem, not giving the treatment for the problem the next time it occurs may either be considered withholding or withdrawing treatment. The same is true when something happens to interrupt an ongoing treatment. For example, if a baby has been intubated (had a tube placed to deliver oxygen) and the tube becomes dislodged, in some situations a clinician may consider it withholding treatment if the tube is not replaced. Others may feel that not replacing the tube would constitute withdrawing treatment.
Another area in which questions arise about whether a treatment choice involves withholding or withdrawing treatment concerns respiratory care. Very sick babies are often on respirators. The respirators have settings which vary rate, pressure and concentration of oxygen in the gas the baby receives. In general, when a baby's respiratory status is poorer, higher respirator settings are needed for survival. If clinicians feel that a baby is doing poorly, especially if they feel that no matter what they do the baby will not be able to survive, they may not turn the respirator setting up, even if the baby's respiratory status deteriorates. (Pres. Comm. 1983:73-77) In that situation, as in the example of Sal at the beginning of this chapter, they may feel that they are letting the baby's condition rather than the treatment choice determine survival. (This will be discussed at greater length later in this chapter under active/passive euthanasia and in Chapter VII.)

Clinicians may also adjust respirator settings in a way that helps them feel that they are withholding rather than withdrawing treatment entirely if they decide to decrease the aggressiveness of treatment. For example, if a decision is made that it would be best if a baby dies, rather than "pulling the plug" and discontinuing the respirator entirely, the settings on the respirator may be lowered. In that situation, the respirator may be set in such a way that the clinicians know that the baby will die but some clinicians feel that it enables a baby to die more comfortably than if the respirator was disconnected.
entirely. In addition, the clinicians are spared having to remove the respirator and confront the act of withdrawing treatment as directly.

The distinction between not starting a new treatment and stopping a continuing treatment becomes important in the context of the distinction between active and passive euthanasia, where stopping treatment is sometimes seen as "causing death" and not starting a new treatment is seen as "allowing death to occur." This will be discussed in more detail below.

A number of people have criticized those who make a distinction between withholding and withdrawing treatment from a number of perspectives. Some have written that either it is the outcome or the intention rather than the means that is important. Clinicians, such as Dr. Driscoll, director of the nurseries at Columbia, has talked about the importance of being able to initiate treatment in a situation in which the prognosis is very poor or very uncertain in order to be able to establish a proper diagnosis, knowing that treatment which is not beneficial can be discontinued later. Indeed, fear that a treatment once started, could not be stopped has been reported to have prevented clinicians from initiating treatment in cases where it could have been beneficial (Pres. Comm. 1983:75-76).

Sarcastically Gorovitz suggests an ingenious way to handle the problems:
There is a timing device used in English apartment-house halls which automatically turns off the light after a few minutes. We can get devices made to shut off after twenty-four hours, and install them between all respirators and their plugs. Then all the physician would have to do is -- nothing at all; he could let the patient die. Of course, each day, before the twenty-four hours is up, a decision would have to be made whether the switch should be reactivated, thereby to prolong the life. But if it is decided not to do anything, then the case ends.

It is obvious that this scheme fails. It fails because there is no morally significant distinction between the circumstances with the timing device and the circumstances without it.

(1978:5)

Extending this concept still further, Father John Paris, a Jesuit priest, at a conference for clinicians at Columbia in 1984, suggests that each drip of fluid from an IV or each pulse of air from a respirator can be considered a unique treatment. Therefore each could be stopped at any time. Although, in theory, many of the clinicians appreciated the concept, it is harder to accept in real situations.

Despite problems with the operationalization of the distinction, and intellectual arguments about the lack of moral relevance of the distinction, it is clear that the distinction feels very real and has cultural significance to many clinicians. Frequently, clinicians find it more difficult to stop a treatment than to not start a new treatment. Some feel that by stopping a treatment they would be actively ending a life, which is itself a natural process, while by not starting a new treatment, they are not prolonging death, or allowing a natural process to occur (see discussion under active/passive euthanasia and goals, below).
Beyond the issues of control over the outcome, knowledge of the likely outcome, or intention of the decision maker, the physical act of stopping a treatment has importance. Those lower in the staff hierarchy, for example, are upset if the act of stopping a treatment is "dumped" on them. For example, residents are upset if they have not been part of the decision making process to discontinue treatment, but are asked to extubate a baby (remove the tubes attaching a baby to a respirator). Some senior physicians therefore feel that it is their responsibility to physically carry out the act of stopping treatment, by extubating a baby or turning down the respirator settings, as well as take responsibility in decision making.

Sometimes, clinicians who object to a parents wishes about the discontinuation of treatment, say "if that's what the parents want, they should have to carry it out themselves," feeling that the parents would be less likely to stop treatment if they had to do what is seen as the "dirty work" themselves. Although clinicians often feel that in the long run the decision is in the best interest of a baby, the act of discontinuing a treatment is usually seen as a sad event at best, and is usually emotionally upsetting to carry out. It is sometimes likened to an act of an executioner.

Sometimes efforts may be made to avoid having to stop treatment. This may be done by continuing to treat a terminally ill baby. In other situations, in which a baby's condition is known to be deteriorating, if it is felt that the baby should be allowed to die, ongoing treatments
will be continued, knowing that new treatments will be needed but will not be given.

Passive and Active Euthanasia

Probably the most important distinction in the minds of many clinicians in choosing between treatment options is the distinction between active and passive euthanasia. Although there is growing acceptance both among clinicians and in American society as a whole of "allowing death to occur," or "passive euthanasia" there is remains a strong taboo against "active euthanasia" or deliberately causing death (see Chapter II).

While the considerations of selective treatment may start with considerations of quality of life, they will often end with and be decided on the grounds of whether a particular treatment choice would constitute active or passive euthanasia. In almost all cases, treatment choices which might lead to death will only be made if they can be thought of as constituting passive euthanasia.

The passive/active distinction is defined in part by some of the distinctions discussed above. Passive euthanasia is often thought of as not initiating an extraordinary treatment while active euthanasia is often thought of as withdrawing an ordinary treatment. To the extent that there is lack of agreement about the dimensions of ordinary/extraordinary treatment and withholding/withdrawing treatment,
there is also controversy concerning the operationalization of that
definition. In addition, there is controversy about whether withholding
an ordinary treatment or withdrawing an extraordinary treatment
constitutes active or passive euthanasia.

Part of the philosophical basis and acceptance for a distinction
between active and passive euthanasia evolves from the distinction
between omission and commission. Others feel it is not a useful
distinction because what is important is the responsibility for the
outcome if one has the ability to control it, and the intention to bring
about death.

Despite the philosophical criticisms of a distinction between
active and passive euthanasia, culturally it is a crucially important
distinction to those who work in neonatal units. Although some
practitioners may say that the nature of the treatment may not matter,
and that there is no real difference between not starting or stopping
treatment, every clinician with whom I discussed the question, including
a number who would be categorized as in favor of non-treatment in many
circumstances, felt that certain types of non-treatment choices would
constitute active euthanasia, and would therefore be unacceptable.

While the norm against active euthanasia is very strong and
pervasive among clinicians, there is a lot of variation in the beliefs
about whether or not particular choices would constitute active or
passive euthanasia. Here the differences in definition between ordinary
and extraordinary and between stopping and not starting treatments often become crucially important.

For example, let's consider the case of Baby Doe of Bloomington Indiana. Baby Doe was born with Down's syndrome and a TE fistula (a defect in the formation of the trachea and esophagus). According to his pediatrician, at the time of his birth, it was also thought that the baby might have had an enlarged heart indicating a serious heart defect (Pless 1983). The presence of Down's syndrome indicated that the baby would be mentally retarded, the TE fistula meant that the baby could not take normal feedings. The baby would have needed surgery to correct the defect or long term intravenous feedings and fluids in order to survive. Baby Doe's parents and obstetrician decided not to operate and not to give either intravenous feedings or fluids.

It seems reasonable to suppose that his parents and obstetrician considered surgery and intravenous feedings and fluids to be "treatments." Indeed, 50 years ago, before the development of modern medicine, these treatments which we now think of as routine would not have been available. They probably felt that the Down's syndrome, TE fistula, and enlarged heart created a situation in which the baby could not have a good quality of life. Therefore, any treatments could be considered "extraordinary" for they would be without benefit. They probably felt that they could therefore choose to withhold these treatments, and that such a choice would constitute a decision to allow death to occur, or passive euthanasia.
Other people, including many clinicians, would not consider a decision not to do surgery or provide food and fluid for a child with Down's syndrome as passive euthanasia. They feel that a baby with Down's syndrome can enjoy a good quality of life. Therefore, treatment that prolongs survival would be of benefit. Surgery which is commonly done, and which is not seen as very expensive, invasive, risky, etc. would not be seen as extraordinary. Some people feel that the providing food and fluids does not constitute "treatment," and, for a variety or reasons, is something which can never be withheld.

Some of the nurses involved in the care of Baby Doe evidently shared this view. They felt that withholding surgery and food and fluids constituted active euthanasia in the case of Baby Doe and therefore felt that it should not be allowed to occur.

The different attitudes toward various treatment options reflect differences of opinion about what constitutes active and passive euthanasia. In the 1970s, at the beginning of the debate about the care of newborns, there were clinicians and bioethicists who argued that the choices of treatment made in the case of Baby Doe were acceptable. (Duff and Campbell 1973) As attitudes towards the developmentally disabled, and the political climate about the regulation of medical treatment has changed, it is difficult to find any support for that position among clinicians in the literature. Many clinicians would feel, however, that the withholding more extraordinary treatments from an infant with Down's syndrome, such as complex cardiac surgery or
kidney dialysis, was appropriate (see survey results, Table VI - 1) and that it would constitute passive euthanasia.

In the case of Baby Doe, the definition of treatment choice as active or passive euthanasia rests primarily on the ordinary/extraordinary distinction. In other cases the withholding/withdrawing distinction may be the important distinction. In yet others there may be a combination of factors and both may be important. This was the case in a decision about treatment for a very small premature baby which I will describe.

Sarah had a grade IV IVH and a cyst (indicating severe brain damage). In this case, Christine, a neonatologist who usually advocates very aggressive treatment, stated that she agreed with a parental decision and would not put the baby back on a respirator, if she needed it, after the baby had been weaned to CPAP (less aggressive respiratory support). Christine, however, said she would not "feel comfortable" actively removing a baby from a respirator who had the same condition.

Another neonatologist, Ruth, felt that the first physician was making a meaningless distinction between intubating (putting a baby on the respirator) and extubating (taking the baby off the respirator). This second doctor, however, who has a reputation for advocating the discontinuation of aggressive treatment for infants who she feels could only have a very poor quality of life, said that she, herself was uncertain and uncomfortable about taking the baby off CPAP. She noted that although other clinicians agreed that the baby would not be
reintubated, only the parents really questioned why CPAP was being continued. Although a decision to withhold the aggressive treatment, the use of the respirator, was acceptable, stopping a less aggressive treatment, CPAP, was not acceptable to any of the clinicians, although they all acknowledged that the severe brain damage would preclude the possibility of meaningful life for the baby.

Although the decision may not be understood analytically, and may be operationalized differently in different institutions and among different clinicians, virtually all clinicians internalize the importance of these distinctions during the socialization process; they are strongly felt. One final vignette will illustrate.

Justin, a full term baby, because of a series of complications, had a very short intestine. Although for a while it was thought that the baby had enough intestine to eventually feed, after further damage, it was decided that the baby unfortunately did not have enough intestine to ever be able to digest food. Although some babies have been kept alive for as long as 2 years with hyperalimentation through a central venous line (total IV feedings, also called TPN), no newborn had ever survived longer than 2 years. While he survived, most of the time, the baby would probably be hospitalized, hooked up to machines, with frequent infections, receiving a very expensive treatment. The decision was made to stop intravenous feedings.

I asked Sue, a nurse, who was caring for the baby about why Justin was no longer getting "hyperal" (the intravenous nutritional fluid).
She explained that it constituted heroic care for this baby and would therefore only prolong the baby's suffering. With it the baby might live for weeks, months or maybe years, without it the baby was likely to die within the next few days. Then I asked, "Why don't you stop the fluids?" which she was, at that point, attaching to an IV in his arm. Stopping the fluids would have, in all likelihood, have shortened his life span still further. "We couldn't do that," she explained emphatically, "that would be murder."

Whereas to someone not socialized in the clinical subculture, the difference between the two IV fluids may not seem significant, to clinicians socialized in the clinical subculture, there is a crucial difference. Even Surgeon General Koop, one of the nation's strongest advocates of treatment for handicapped infants, approves the withholding of hyperalimentation from infants with no hope of recovering adequate intestinal function for feedings by mouth. On the other hand, even the strongest clinician advocates of withholding treatment from severely impaired newborns, would probably not sanction the withholding of fluids from such a baby. To virtually all clinicians, the first treatment choice, withholding hyperalimentation, constitutes passive euthanasia, while withholding fluids constitutes active euthanasia.
Summary

In the preceding chapter, a number of ways that clinicians conceptualize treatment characteristics when making decisions about the aggressiveness of treatment was discussed. One of the most central to the clinicians' conceptual system, referred to here as the aggressiveness of treatment, was identified. The distinctions between ordinary and extraordinary treatment, withholding and withdrawing treatment, and passive and active euthanasia were also examined. While each is often presented as a clear dichotomous dimension, they were found to encompass complex, cultural defined evaluations. Together with conceptualization of patient condition characteristics, conceptualization of treatment characteristics provide the data used by clinicians in making treatment decisions.

In the following chapter, the goals and principles of decision making, used in making treatment choices for catastrophically ill newborns, will be discussed in order to explicate the way that the categorizations of characteristics of patient conditions and treatments are translated into behavioral treatment choices.
CHAPTER SEVEN

UP TO GOD OR MOTHER NATURE:
DECISION MAKING GOALS, NORMS AND BEHAVIOR

Goals and norms are crucial parts of the decision making process leading to behavior. As discussed in Chapter IV, goals provide the purposes which orient the decision making process. Norms are prescriptive statements about how to relate categories to goals which are used to guide behavior. In the following chapter, the goals and norms of decision making about the care of catastrophically ill newborns will be presented and treatment choice will be discussed.

Goals

The goals of medical treatment, in general, and neonatal decision making, in particular, are:

To Cure
To Care
To Preserve Life
To Do No Harm
While these goals at first may seem unambiguous, their definitions, like
the characteristics of patients' condition and treatment, are culturally
determined. In most cases, the same treatment choices will further all
four goals. In some cases, however, they may be contradictory. There
is variation in how clinicians operationalize each of them, and in how
important clinicians think each may be in a particular case. In this
section, each of these goals will be examined and choosing among goals
will be discussed. The role of conceptualizations about goals will be
considered in more detail and illustrative examples will be provided in
the section on norms and neonatal decision making.

To Cure

For most clinicians, the ideal goal in medical treatment is "to
cure" or to return a patient from an abnormal (pathological) state to a
"normal" one. For example, the majority of infants admitted to ICU are
premature babies, in an abnormal state because they were born before the
end of the normal 40 weeks gestational period. The major goal in their
treatment is to choose treatments which will maintain their vital
functions in such a way that they will be able to be discharged able to
function as any "normal" infant born at full term.

In some cases, clinicians may disagree about whether cure is
possible. Disagreement can take place in two respects. First, there
can be disagreement about the ability to produce a given physiological
outcome. For example, Cindy had a very complex heart condition. There
was disagreement about whether surgery could be successful in correcting
the defect. Second, there was disagreement about whether a particular
outcome would comprise a cure. Peter, one of the neonatologists feared
that the surgery would leave her a "cardiac cripple" with a limited
ability to function and would therefore not provide a cure. He
questioned the benefits of treatment. Christine, another neonatologist,
on the other hand, though recognizing the possibility of the same level
of impairment, believed that this surgery would be a cure for her
(presently more serious) condition and would consider her cured.

To Care

A second goal of medical treatment is to provide care. Providing
care can involve supporting vital functions (by supplying warmth, food,
nutrition, etc.), relieving suffering (by removing unpleasant stimuli,
providing measures to mitigate an unpleasant experience or provide a
pleasant one), and providing means to maintain or increase other
functions (e.g. preserving range of motion through physical therapy).
Karen, another attending, did not feel that the surgery would cure
Cindy, but she did think that doing it would be appropriate care.

Much of the care given to the babies in the NICU entails
monitoring and ministering to their vital functions through feeding,
monitoring and sometimes assisting respiration, monitoring the heart
beat and, if necessary, regulating it with drugs, etc. Other care
involves performing procedures or giving medication (such as antiseizure
medication) to control an abnormal condition which cannot be completely cured.

One aspect of "caring" is to help the individual to function as much as possible given the limits of his or her condition. For example, Sal had bleeding in the brain, leading to cerebral palsy. His caretakers will be unable to completely cure him, the main goal will be to care for the baby by providing exercises and other physical therapies so as to maximize functioning as much as possible.¹

Another aspect of caring is to provide comfort - that is to remove negative stimuli or mitigate an unpleasant experience and provide pleasant ones. For example, Sue, one of the nurses sometimes provides comfort care by carrying a baby in a snugglie (baby carrying pouch). She believes that it both is pleasant for the baby, and, may improve future physiological or psychological functioning. In other circumstances, care is intended only for the current experience for the child. For example, Sue will often hold and rock a dying baby, she says "at least it's something I can do for them."

Sometimes, there may be disagreements about what constitutes good care. For example, if an infant is going to have a painful procedure, such as the insertion of chest tubes through the baby's chest wall and into the lungs, some clinicians feel providing good care for such a baby may involve giving drugs to reduce the pain. Since such drugs may

¹ Those clinicians who use a more functional definition of cure, may consider such measures as intended for cure, rather than care.
depress the infants respiratory status, however, which may result in a higher risk of death, some clinicians do not feel that such medication is appropriate.

In some cases, it is not clear how to provide the best care. For example, treatments that may be best for maximizing care in one respect may cause problems in another. For example, high levels of oxygen, intended to preserve life and maximize future brain functioning may be associated with unintended problems such as chronic lung damage or eye disease.

To Preserve Life

A third basic goal of medicine is to preserve life. Even in cases where cure is not possible, the minimum goal is usually to enable continuation of life. Much has been written on how physicians see death as the ultimate failure or defeat (see Chapter II). The ability to "defeat death" is the function most recognized as characterizing the power which justifies status and power of physicians, in particular, and the health care professions in general. Mortality statistics are often the measure used to judge success of health care programs. While there has been change regarding ideas about the definition of life, and regarding the assumption of unquestioned benefit from postponing death in all cases (see Chapter II), in general, a primary goal of medicine is still the preservation of life.
One doctor, commenting on why it was so hard not to treat, said: "From the first day of medical school, we are taught how to save life. It is very difficult not to save life." (Levin, Palmer and Ross 1984). The techniques that clinicians learn in their training are aimed at maintaining physiological functioning; there is little training relating to recognizing when efforts to continue life may not be appropriate.

Sometimes there may be conflicts between efforts to maintain life in the short term and long term. A procedure intended to promote long range functioning, such as open heart surgery, may engender unintended side effects such as risks to life from complications of surgery.

To Do No Harm

A final basic goal or tenet of medical practice is "to do no harm." Frequently, the maxim: Primum non nocere," above all, do no harm, is attributed to Hippocrates, however, it does not appear in the Hippocratic corpus. Rather, the following appears in the Hippocratic Oath: "I will use treatment to help the sick according to my ability and judgement, but never with a view to injury and wrong doing" (Reiser, Dyck and Curran 1977:5). While intentionally causing harm by use of the medical arts is clearly prohibited, there is variation among clinicians as to how important they feel it is to avoid unintended harms as a result of treatment.
While some clinicians feel that avoiding harm is a primary goal, others feel that a greater degree of risk can be tolerated in pursuit of the primary goals of saving life. These clinicians are more likely to display an activist stance that dictates that doing something is better than doing nothing. For example, such clinicians are willing to try highly experimental, invasive procedures, such as an infant heart transplant, if they think that there is a chance that it might work. Others feel that inflicting that sort of procedure on a baby now would be doing harm.

What is meant by avoiding harm depends a great deal on how harm is defined. For some, harm is narrowly defined in terms of an assault which lessens physiological functioning or decreases the probability of survival. For others, however, probably more often, a broader definition of harm is used. Such factors as pain and suffering (physical or emotional) and loss of autonomy may be seen as harms to be avoided in the practice of medicine. Christine, one of the attendings, believes it is better to save the life of a severely retarded child while another attending, Ruth, believes that it is doing harm to save such a life.

Iatrogenic harms, caused by the side effects of treatment, are among those of most concern to clinicians. Clinicians often seem to be most upset by those mistakes which they see as their fault because they occur as a result of treatment. When harm is done, either as a result of a mistake (e.g. IV infiltrate), or as a side effect of treatment (e.g. RLF), or because the intentional effect of the treatment (e.g.
prolonging life) is later seen as a harm, clinicians often feel that they are responsible. Often they feel worse than when an equivalent condition occurs but is not felt to be a result of their actions.

For example, Harriet's mother's membranes had been ruptured for a while before she gave birth. In order to prevent infection, Harriet was given an antibiotic immediately after birth but a lumbar puncture (test of the spinal fluid) wasn't done to check for infection and drug sensitivity. A few days later she developed meningitis from a resistant strain of bacteria; the clinicians felt especially bad because failing to do the test had resulted in a serious condition which might have been prevented.

Another related area of concern is that there is seen to be a difference between "natural" events or "God's will" and "unnatural" events, seen as the result of "interference with nature." There is a somewhat fatalistic acceptance of unfortunate events that are not seen as directly caused by human actions. On the other hand, there is a feeling that those things that do occur as the result of human actions, could have been prevented and should not have occurred. There is sometimes a sense that interfering with "what was meant to be," even if it is bad, could be a harm. Individual clinicians, however, differ in their ideas about what was "meant to be."

The sense of it being wrong to try to treat what can't be helped is reflected in the writings of Hippocrates (Reiser, Dyck and Curran 1977) and is also reflected in the modern discussion of the artificial
and futile preservation of life (DHHS 1985). On the other hand, to bring about death, even when the patient would die soon anyway, is also seen as doing harm. Sometimes clinicians talk about "tragic choices" and say they feel stuck "between a rock and a hard place." Many clinicians fear causing death even more than they fear prolonging dying; therefore, in general, a choice is made to preserve life.

Other Goals

There are other types of goals, of a different order that also may inform clinical decision making. For example, other goals are to discover more about the causes of disease and their cures, to educate health care professionals or to gain status or prestige. These may influence clinical decision making in some circumstances. In general, these are satisfied by the same treatment choices as those made to meet the first four goals.

While many decisions are made to try new techniques, procedures or substances, these are virtually always done because of the belief that they will promote cure, improve care, or preserve life. When a particular treatment is not given, because the patient is part of a clinical trial, it is generally believed that the benefits of treatment are uncertain. At times, a procedure thought to have little chance of success for a particular baby may be tried because it is believed that it will help future babies with the same or a similar condition.
In the popular conception, there is concern that a child may be kept alive or given a treatment just for "experimentation" or for "teaching material." This is very rarely the case. I did not observe any decisions which would fall in this category, except to the degree that the aggressive ethos generally guiding intensive care, led clinicians to attempt to cure, care, or promote survival in cases which probably had little chance of success.

One example of a case where clinicians performed an extremely aggressive treatment, which was very experimental, occurred when physicians in Loma Linda, California, transplanted a baboon heart into a baby known as Baby Fae. Although critics felt that far too little previous experimental work had been done with animals to justify the procedure, the clinicians who cared for her evidently thought that there was a chance that she would survive; therefore, the procedure was justified for this baby with a lethal heart defect.

In rare cases, aggressive treatment may be given for teaching purposes, as in the case discussed before concerning a baby who was resuscitated in the emergency room. Although she was thought to be dead, she was treated so that a resident could practice intubation techniques. In that case, the resuscitation was successful. Presumably, in other cases, such acts have been performed and have been of no benefit to the baby or have been judged to be harmful. Such acts are thought to be morally questionable, but many clinicians feel that the gain, in terms of knowledge which can later be used to help other babies, outweighs the possible harm. I have heard of no cases, however,
which resemble the cases of human experimentation at Willowbrook, in which children were intentionally given a disease or risky procedure purely for the purpose of research (Rothman and Rothman 1984). By the time I did my field work, there was consensus that such actions were morally unacceptable.

Another situation in which one baby may be treated aggressively for the benefit of another, is when the baby is a potential organ donor. A recent issue of the Hastings Center Report presented commentaries about using an anencephalic baby as an organ donor (1986). While there has been little demand for newborns organs so far, such a demand could increase significantly if infant heart transplant became an accepted procedure.

Other goals sometimes discussed in relation to clinician decision making are to make money or to avoid malpractice suits and to achieve professional status. Although such practices have been documented in other settings (e.g. P. Katz 1985), I don't know of any examples in neonatology. Such goals may help to form the context of decision making, and may in fact help to inform the general standards of care which guide decision making for all babies. At least when I did my field work in 1982, however, I don't think that it directly entered into decision making about the aggressiveness of treatment for particular babies.²

² Pressures from rising malpractice suit rates, and economic pressures from changes in reimbursement policies may create changes, at
Variation in Goals

In general, in a neonatal unit, clinicians are able to orient their behavior toward all of the primary medical goals at the same time— the best treatment serves to cure, to provide care, to preserve life, and to do no harm. At other times, however, behavior is not possible which would maximize all of the goals at the same time. In that situation, clinicians may maximize one goal at the expense of others, or may try to find a balancing point in an attempt to maximize a set of goals.

In general, when cure is possible, it is seen as the primary goal of treatment. When cure is not possible, providing good care may become the primary goal for many clinicians. For example, articles are written with such titles as "When you can't cure, care" (Thullen, 1977). For least at some centers. So far, none that I know of have been documented.

It has been said that living, severely damaged babies bring higher awards in malpractice suits than do dead babies. Under a DRG type plan, shorter length of stay and less treatment could be less costly for the hospital. Potential pressures from changes could theoretically operate either to promote more aggressive treatment or lead to less aggressive treatment.

While many of the treatments intended to promote cure fall under the province of physicians and surgeons, many of the care oriented treatments are under the province of nursing. The goals identified as the reasons for behavior, may differ more than the actual behavior. In the responses to the survey, there were no statistically significant differences in the treatment recommendations between physicians and nurses when other factors were controlled. There were, however, differences in what nurses and physicians identified as factors which should be considered as the most important in making treatment
other clinicians, the preservation of life may be seen as the primary goal.

Some of the differences observed in decision making between individuals and institutions reflect differences in goals. For example, Tom usually recommends very aggressive treatment, such as maximum use of a respirator, because he feels it is necessary, above all, to preserve life. Another physician, Ruth, may recommend discontinuing aggressive treatments such as the respirator and also more ordinary treatments like blood transfusions because she feels that preserving life is less important than not doing harm. She believes that continuing such treatment for a baby who has almost no chance of leaving the NICU is doing harm. Yet a third clinician, Mike, feels that such a baby should remain at an intermediate level of respiratory support in an effort to do what he sees as neither talking life nor doing harm.

The fact that there are conflicting goals between saving life and doing harm is sometimes presented as a modern problem which results from recent technological advances. However, as discussed in Chapter II, such clinicians have dealt with such potential conflicts in goals for a long time.

Clinicians may also disagree in how they define a particular goal. For example, some clinicians may feel that any prolongation of

decisions. More neonatal nurses thought that prolonged pain and suffering should be an important factor. This may be because comfort has traditionally been more of the professional concern of nursing than of medicine.
physiological life is worth striving for, while others may use a more social definition of life and only feel that life should be prolonged when there is some capacity for social functioning (Crane 1975).

Variation in interpretation and choosing among goals will be illustrated in the following section on norms for decision making.

Norms for Decision Making

In choosing treatments for the care of catastrophically ill infants, clinicians are guided by norms for relating goals to culturally defined characteristics of patient condition and of treatments. As discussed in Chapter II, and as will be discussed further in Chapter VIII, as technology has changed, and as other political, economic and social changes have taken place, the norms guiding the care of the critically ill have been changing. Unlike some other situations, in which human behavior in relation to a particular domain is guided by a relatively clear, consistent set of norms, at the present time there is a great deal of variation in the norms used to guide treatment choice. In this section, I will discuss norms that appeared to be guiding treatment choice. I will illustrate the use of norms, including normative variation both among clinicians, and for different clinical situations.
Proportionality

The overarching norm guiding clinical treatment choice is that treatments should be provided which are proportionate to the patient's condition in order to achieve treatment goals. This is conceptualized in terms of the characteristics of patient condition, treatments and goals as discussed above.

In general, to summarize, if there is a high degree of certainty that an infant will be severely impaired, and/or the infant has an impairment that is seen to diminish quality of life and a very critical condition, and/or there is little social value seen to treatment, it is more likely that treatments will not be given. This is especially true for those treatments which are very aggressive, and those which are seen as extraordinary, especially when treatments can be withheld and that act can be thought of as passive euthanasia.

At one extreme, once diagnosed, an anencephalic baby (who does not have a brain), may not be given even relatively ordinary procedures, such as blood transfusions or food. On the other hand, if a baby is likely to be able to enjoy a good quality of life, even if the baby has a very critical condition, then very aggressive, some might say extraordinary, treatments will be given. For example, Ari, a baby with a diaphragmatic hernia (a serious but usually correctable defect) was put on ECMO (a new, experimental, high technology device, something like a heart-lung pump) for a period of time in order to maximize his chances
for recovery. It required round the clock, one to one attention from a pediatric surgeon and a neonatal nurse.

While the overarching norm of proportionality guides overall treatment behavior, subsidiary norms are used to take care of various combinations of conditions, and to specify more completely the details of behavior. I will outline norms used by clinicians for decision making here, and discuss them further below.

NORMS FOR CLINICAL DECISION MAKING

General Principles:

Start with aggressive treatment in order to stabilize the baby and assess the baby's condition. Determine if the baby might be cured. If not, determine if the baby is terminally ill. If not, determine the chances that the baby could have a decent quality of life.

In making treatment decisions, try to maximize all of the goals of clinical decision making. If that is not possible, emphasize goals as appropriate to the case.

In general, try to cure. If that is not possible, make treatment choices to preserve life unless such treatment would constitute doing harm.

In all cases, provide good care.

Active euthanasia (actions which cause death to occur) are not acceptable, but, in certain situations, passive euthanasia (actions which allow death to occur) may be chosen.
If the Baby Could Have a Good Quality of Life:

If the baby can be cured or if future quality of life is not so poor as to be unacceptable, give aggressive treatments to promote survival.

Even if the quality of life is not likely to be acceptable, if there is a significant chance that the baby may be normal, treat aggressively to maximize the chance that the baby will survive.

If the Baby is Terminally Ill:

Give ordinary treatment to provide good care (keep the baby comfortable), but do not treat aggressively by giving extraordinary treatments.

If a terminally ill baby is expected to die within a fairly short period of time, in general, do not start new treatments but continue treatments already started. If new treatments would provide care, they may be given. If already started treatments would prolong dying, they may be withheld.

If the Baby Will Not be Normal and there is a High Probability that the Infant Will Die or be Severely Impaired:

Withhold more aggressive treatments. Choose the level of aggressiveness of treatments according to the following considerations:

In most such situations, continue treatments which are ordinary and/or those which are already started (in order to continue providing care and to allow death to occur).

If it is likely that the baby would survive for a significant period of time, and the baby's life during that time would be of poor quality, then a level of aggressiveness of treatment may be chosen to make it likely that the baby will die relatively quickly (in order to avoid doing harm by prolonging the dying process).
If the infant is probably terminally ill or the quality of life is likely to be very poor, but there is a fair amount of uncertainty, then a level of treatment may be chosen in which the outcome is uncertain (in order to avoid doing harm by either prolonging dying or causing death; "Allow the baby to declare him/herself," or "Allow God or nature to decide").

When Some Treatments would be Withheld:

Treat up to a certain level of aggressiveness, withhold other, more aggressive, treatments.

If the baby's parents want the baby's life preserved despite little chance of a good quality of life, treat aggressively.

For most cases, these norms provide clear guidelines for the provision of treatment. Frequently, clinicians follow these norms in a

4 Somewhat different rules apply in a situation which is clearly considered experimental. In the early stages of development of a new, possibly risky treatment, if a baby is thought to have no chance without a treatment, but might have a chance with it, the baby may be given the treatment in a effort to cure and to promote survival, realizing that it might be likely to cause harm.

During a randomized or sequential trial, however, treatments that might be thought to promote cure, or even survival might be withheld, at least for a period of time, to test the protocol. (Babies not given the treatment initially may be given the treatment later if the clinicians have an option.)

In choosing subjects for testing a new experimental, very aggressive procedure, with limited availability, only those babies who are seen as the best candidates for successful treatment will be selected. This may mean that infants with other known anomalies will be excluded. Characteristics of the family, their ability to understand the experimental nature of the procedure, and their ability to carry out follow up care, may also be considered.

In 1986, such highly experimental aggressive procedures include ECMO (an external oxygenation system similar to a heart/lung pump), the Norwood procedure for hypoplastic left heart surgery, and infant heart transplants. In making decisions about these modalities, other factors
preattentive manner (see Chapter IV); treatment choices are made without conscious reevaluation of categorizations in each case. In other cases, clinicians consciously evaluate how a particular baby's condition and treatment options should be categorized and which norms should apply. I will illustrate treatment decisions below with a discussion of a number of cases.

While this framework is generally accepted by clinicians providing neonatal intensive care, there are many disagreements about what constitutes appropriate care in particular situations. This is largely due to disagreements about how particular characteristics of patient condition, treatments and goals are to be categorized in particular cases. There is also some disagreement about the appropriateness of some norms to guide treatment choice. For example, some clinicians feel that a distinction between ordinary and extraordinary treatments is not significant and that both can be withdrawn in some circumstances. Norms and variation in decision making for babies when 1) the quality of life is expected to be good, 2) they are terminally ill 3) and when the quality of life is not expected to be acceptable, will be discussed. Issues relating to change over time will be examined in more detail in the following chapter.

may be considered beside those usually weighed in the decision making process.
Decisions When the Quality of Life is Expected to be Acceptable

As discussed earlier, in the vast majority of cases, it is felt that the characteristics of the patient condition justify whatever treatments are thought to be necessary to promote cure and survival; aggressive treatments will be given. For example, consider the case of Wesley, a premature baby admitted to the NICU in respiratory distress. By NICU standards she was not very small (1250 grams, a little under 3 lbs.) not very young (30 weeks, two and a half months premature) and there were no other major problems (e.g. no significant bleeding in the brain), none of the clinicians would consciously consider the issue of non-treatment at all in such a case.

Even if, in another case, for a baby who is critically ill, and it is thought the probability is high that the baby will die, if there is felt to be a significant chance of saving the baby, and the baby is not likely to be severely impaired, the level of treatment will be aggressive. For example, Timmy was admitted to the unit in 1978 with a diaphragmatic hernia, a condition in which a hole in the diaphragm during fetal development led to the growth of the intestine in the chest cavity, which interfered with the formation of the lung. Even though it was thought to be unlikely that the infant would survive, surgery was performed. The baby did very well and has no lasting problems. The most aggressive treatments, like ECMO, will often be used first for babies like these, who, if they survive, are expected to be normal.
Many of the critically ill infants with potentially correctable defects have cardiac conditions. For example, Roxanne was admitted with a complex cardiac lesion. Although, again, the feeling was that it was unlikely that the infant would survive, surgery was successful. In many other cases, however, treatment is not so successful. For example, although plans were made to use ECMO for Paul, another baby with a diaphragmatic hernia, he died before he could be moved from the transitional nursery.

Many babies have conditions such as low level spina bifida lesions, that cannot be completely ameliorated, however, the prospects for an acceptable future quality of life are thought to be high enough that aggressive treatments are given in order to do everything possible to preserve life. Even when clinicians would not recommend treatment themselves, if parents want aggressive treatment such treatment will be given. This can be illustrated by discussion of the case of Gerald and by discussion of the responses about the Baby with Down's syndrome on my survey.

Gerald was born with Down's syndrome and also had a serious heart lesion (AV canal complete and an interrupted aorta). After discussion with the baby's parents, plans were made to do a closed heart procedure soon, to be followed by open heart surgery when the baby was a little older and the risks from surgery would be less.

Although there now appears to be a consensus to treat an infant with Down's syndrome and relatively easily correctable defects, there is
less consensus about more aggressive treatments such as open heart surgery for infants with Down's syndrome. For example, in response to the questions about the baby with Down's syndrome in the survey, almost nine out of ten respondents replied that they would recommend relatively simple intestinal surgery for such an infant, assuming that the parents' views were the same as their own. On the other hand, only about six out of ten respondents would have recommended open heart surgery for an infant with Down's syndrome. (See the appendix for information on the survey, and Chapter IV for some of the results.) The clinicians in the unit supported the decision about surgery for Gerald, especially because the parents were very clear about the fact that they wanted surgery.

Unfortunately, Gerald had a very rocky post operative course involving an episode with a severe lack of oxygen which led to renal shut down, destruction of part of the intestine, and imbalance in the acidity of the blood. He was now in a very critical condition. Many of the clinicians now felt that it would be better to allow him to die because of the likelihood of death and the small chance that he could have a good quality of life. It was probable that both the Down's syndrome and his currently very critical condition which led the clinicians to consider non-treatment.

Although few clinicians would probably have wanted to stop relatively aggressive treatment with either the Down's syndrome alone, or the baby's present condition alone, with the combination of conditions a number of clinicians would have recommended treatment be stopped if the parent's wishes were the same as their own. When asked
about kidney dialysis for a baby with Down's syndrome on the survey, only a little more than a quarter of the respondents said they would recommend kidney dialysis.

Gerald's parents, however, did want everything done to preserve the baby's life. When discussing plans for the baby's treatment, Julian, one of the neonatal fellows, asked "Why dialyze?" indicating that he thought it was a disproportionately aggressive treatment. The resident caring for the baby said "That's not a good question, the mother wants it." Because of the wishes of the parents, preservation of life was the primary goal. Because the baby had high social value for the parents, aggressive treatments were not seen as disproportionately aggressive. The baby was given powerful drugs to maintain blood pressure, antiseizure medications, a tube was surgically implanted in a vein in the baby's chest, respiratory support was increased, drugs to regulate the baby's heart rhythm were given, and the baby was put on kidney dialysis.

Despite the fact that these very aggressive treatments were given, it became clear that Gerald was going to die. Lane, his attending physician, was called; he called Gerald's parents. All the treatments were continued until his parents arrived. Then the IV was stopped and the respirator settings were turned down (leaving the baby still attached to the respirator by a tube to the trachea). The baby's physician said that was continued so that there wasn't any sudden change and it wouldn't be too uncomfortable psychologically for the family and
Clinicians. Gerald died in his parents arms, despite all the aggressive efforts to save him.

Decisions for Terminally Ill Infants

As illustrated by the case of Gerald, even when babies are terminally ill, and it is known that no treatments will enable long term survival, clinicians must still make decisions about care. Although some treatments were withdrawn, other treatments were still given even when he was dying. For terminally ill babies, the goals of cure and of preserving life for a long time are clearly not applicable. Sometimes, however, clinicians may make decisions to prolong life for a period of time or to try to ameliorate some particular condition if the baby will survive for a while. The other goals, of providing good care and doing no harm, are usually the primary goal guiding treatment choice for the terminally ill.

In some situations, clinicians will realize immediately upon examination that a baby has a condition which is so severe and so clearly recognizable as a particular condition, that it is immediately known that the infant is terminally ill. For example, some babies are born anencephalic, sometimes indicated by lack of closure of the skull, protrusion of cerebral tissue and lack of the forebrain. Such a condition is always fatal, usually within a few hours or days. In such an extreme case, clinicians may not do anything which they consider treatment for the baby. In the survey only about one out of eight of
the respondents would have recommended resuscitation in the delivery room and only a few respondents would recommend an arrest page for an anencephalic baby. While about three quarters of the respondents recommended feedings by mouth if the baby could suck, only about half would recommend tube feedings if the baby couldn't suck and only one third would recommend antibiotics.

When I first started doing research in neonatology (1977), if an infant was born so premature that the baby's eyes were fused shut (indicating a gestational age of less than 24 or 25 weeks), it was taken as a sign that the baby was not yet viable and no respiratory support or other treatments were given. When I returned in 1982 to observing care delivered immediately after birth, because of the perceived improvement in the technological capability, that was no longer a sign of lack of viability. Babies with fused eyes were sometimes treated very aggressively.

In most cases, however, when infants are first found to have problems, the nature of their condition is not certain. Aggressive treatment is given while their condition is stabilized and tests are done to establish the diagnosis. For example, Sarah was born in respiratory distress with a number of congenital anomalies. From the initial exam, it seemed likely that she had a lethal condition, known as trisomy 13, caused by having three of chromosome thirteen, instead of the normal two. Aggressive support was continued while tests of the chromosomes were done to confirm the diagnosis. After the diagnosis was confirmed, additional aggressive treatments were not started when
Sarah's condition deteriorated, but treatments which were already started were continued. For example, antibiotics were continued, even though the usual reason for their use (control of infection to promote long term survival), was no longer applicable.

In response to questions about a baby with trisomy 13 in the survey, respondents answered that if a baby was diagnosed as having trisomy 13, about six out of seven would continue nutrition and fluids, and six out of ten would recommend continuing antibiotics. However, only about one fourth would put such a baby on a respirator, and only one out of ten would do an arrest page if the baby's heart stopped.

Similar decisions used to be made for infants with hypoplastic left heart, a condition which was considered uniformly fatal until recently. Now some clinicians believe in treating infants with a hypoplastic left heart with a new surgical procedure or an infant heart transplant. Other clinicians feel that those treatments are not yet advisable.

Gary, a full term baby, first appeared to have respiratory problems and was put on a respirator and transferred to the unit. Upon examination, the neonatologists realized that he had a cardiac condition, they gave him aggressive support and sent him for cardiac catheterization for diagnosis. The tests showed that he had a hypoplastic left heart. He remained on the respirator, but no aggressive means were used when his condition started to deteriorate. Sometimes such a baby may live days, sometimes weeks before dying.
I think that when treatment is continued in such a situation it is
done because of the social value of treatment for the parents and/or
clinicians. Some parents and/or clinicians feel that they are providing
better care by supporting the infant and they are not prolonging dying
because they are not starting new treatments. They are able to feel
more comfortable than they might if they withdrew treatments, for they
feel that they are doing nothing to bring on death and, therefore, they
are "doing no harm."

In other cases, treatments are withdrawn when an infant is
diagnosed as having a lethal condition. For example, in one case I
observed, after a baby was diagnosed as having trisomy 13, the settings
on the respirator were turned down; the baby died soon after.
Treatments can also be discontinued in a way that addresses the social
value of treatment and non-treatment for an infant. Different
perspectives on management for social value are illustrated by the case
below.

Pedro was delivered in another hospital. He seemed to be healthy
and was discharged home. The next day he turned blue and his parents
rushed him to the emergency room. After the doctors there resuscitated
him, they transferred him to the NICU. He was sent for tests and was
diagnosed as having a hypoplastic left heart. Mike, the attending, told
Pedro's parents that he was dying. He talked to them about the baby's
condition and asked if they would want to have the baby taken off the
respirator and hold him while he died. They said that they wanted him
to be baptized first. They were joined by the baby's aunt, uncle, and
grand parents. He was baptized. A nurse set up a screen to allow the family some privacy, and brought over a rocking chair which the mother sat in, holding her baby. Although he was taken off the respirator, his IV was left in. Mike said he did that so Pedro wouldn't be so uncomfortable. Mike believed the parents would feel better if they didn't feel that Pedro had been on a machine when it would be of no benefit and he felt that they would be able to adjust better to his death if they had been able to hold him while he died. Mike had thought that he would die within an hour or two, but he lived for seven hours. The nurses on the day shift, and those who came on in the evening were very supportive.

Mike stayed with the family for a few hours but had to leave in the evening. Another attending, Rita, was covering for Mike and took over the vigil when he left. She didn't agree with the way the case had been managed. She would have continued the respirator for 12 to 18 hours to give the parents more time to adjust to the fact that their baby was dying. She said

I don't think it's a good idea to hand the baby to the parents to die anyway. It's good for some people, but they are the exception, not the rule. For Pedro's family, coming in from home with a well baby, it was too much for the parents. For a baby who was sick for a period of time it would be different.

She thought that Mike might have taken the baby off the respirator right away out of frustration.

Not that he meant to be mean or anything, but he was so frustrated at not being able to do anything and therefore, since he couldn't do anything in a long term sense, he just stopped treating.
Dorothy, one of the nurses who had been with the parents when the baby died, disagreed with Rita. She felt that it probably had been very meaningful for the parents, and that adjusting to the death of their baby, especially because they had brought him home, was going to be difficult anyway.

A final situation in the care of a terminally ill infant occurs when it has been thought that an infant might survive, but after the baby's condition becomes very poor, clinicians feel that survival will be impossible. For example, when caring for a very premature baby, very aggressive efforts may be made to treat the baby. If, however, the clinicians feel that treatment has become futile, aggressive efforts will be stopped.

Sherry was born after only 27 weeks gestation. She was a second twin, born at 1300 grams with barely a heart beat (Apgars of 1 and 4). When the transport team arrived they felt that they had a chance to save her and started aggressive treatment. A few hours after they returned to the NICU, the clinicians realized that the baby's prognosis was very poor. She had bad bleeding in the brain, her kidneys were not functioning, she was seizing and she seemed to have heart, lung, and intestinal problems. They continued treating aggressively, awaiting a meeting with the parents, but they felt that she would probably die. Karen, the attending, said they could maintain blood pressure for a while but not indefinitely. Sue, the resident, was instructed to try to put in another IV line, but Karen said, "if you can't, you can't." (For
another baby, with a good prognosis, a resident would keep trying to put in a line, or would call someone else for assistance.) In that type of case, although no conscious decision is made to allow the baby to die, further very aggressive treatment may be judged to be futile.

Decisions When the Quality of Life is Not Expected to be Acceptable

Most discussions of ethics and values of decision making have been about those cases in which an infant might live, with treatment, but decision makers feel it is quite certain that the infant will have a poor quality of life. In those situations, some suggest that treatment should be withheld. There is a wide range of variation in cases in which the future quality of life is likely to be poor. They vary along all of the characteristics of patient's condition including the severity of and the nature of the impairment, the degree of uncertainty, the nature of the critical condition and the social value criteria. In addition, there is also variation in the characteristics of the treatments which could be given. In this section, I will discuss norms for decision making when the quality of life is not expected to be good.

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5 As was discussed previously in Chapter V, both conceptions about quality of life and uncertainty depend on value considerations. There is variation in how individuals evaluate particular outcomes. For the purposes of this discussion, the assumptions made by the clinicians making the choices in the cases examined, will be assumed for the analysis and discussion of norms.
As discussed above, an overarching norm guiding decision making is that treatments should be given that are proportionate to the patient condition. When the outcome is expected to be bad, the more aggressive, extraordinary treatments may not be given. In general, treatments are provided up to a given level of aggressiveness, while more aggressive treatments are withheld. While clinicians vary in which specific treatments they feel are appropriate, decisions generally cluster around a given level of aggressiveness.\(^6\)

A number of factors may influence the level which is chosen. In many situations, there is no specific decision about whether the baby should live or die. Rather, treatments are given which seem to be at an appropriate level of aggressiveness for the condition. In other situations, a level of aggressiveness may be chosen which it is felt will insure death. Finally, in some situations, a conscious decision may be made to put the level of treatment at a point which will neither insure death nor survival.

The decision making process is very similar to decision making for terminally ill infants. In fact, as was discussed in Chapter V, it is often difficult to know if a baby is terminally ill, and, in many cases the probability of death is high. The difference here, however, is that the assumption is that the baby would be able to live with treatment. Whereas with the treatment of terminally ill babies, like Pedro, there

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\(^6\) In the survey, treatment choices seemed to form a normal curve around the most frequently recommended treatments when the treatments were ranked by degree of aggressiveness.
sometimes is a desire to avoid prolongation of the dying process, here there is fear that treatment will lead to a long lifetime of suffering. While there is fear of causing death to occur sooner for a terminally ill child, here there is fear that treatment choice could lead to death for a non-dying child. In a particular situation, however, it may be difficult to draw the line.

For example, in a single case, one clinician may feel that he is choosing not to treat because the baby is dying anyway, while a second clinician, involved in the care of the same baby, may feel that she is choosing not to treat because even though it might be possible to save the baby, the quality of life would be so poor. The occurred in the case of baby Vivian, a very premature baby.

Vivian's mother, a "DES daughter" (her own mother had taken DES during pregnancy and, as a result, Vivian's mother had a malformed uterus) went into labor after 23 weeks of pregnancy; everyone thought that she was probably having another miscarriage. When the baby was born, however, she had a heart beat and spontaneous movements. The neonatal team had been called in case the baby was viable. An attending, a fellow, a resident and a nurse stabilized her immediately, and rushed her to the transitional nursery. She weighed about one and one third pounds (560 grams).

At first she did all right, but then her respiratory condition deteriorated. I asked Mike, an attending who was caring for her, if he would put her on a respirator if her condition got worse. He said that
he couldn't. She was so premature and so small, and the tubes were so big that it was not really feasible to do it for a baby that size.

Later, I talked to Mark, a fellow who along with Mike was caring for her. He said that she could be intubated (have tubes put in to attached her to a respirator), but that it wouldn't make sense to do it in her case because it was almost certain that if she did survive, she would be severely impaired. Both clinicians agreed that it was not appropriate to use a respirator, but these two clinicians who were working together on the same baby had different ideas about why they weren't doing it in this case. She died after 16 hours.

Decisions Where the Outcome is Known to be Death

In many cases only the most aggressive treatments will be withheld. For example, one baby who had a severe heart lesion had suffered severe brain damage with massive bleeding in the brain. The baby was having uncontrolled seizures and had a severely abnormal EEG (test of brain activity). The physicians decided not to do heart surgery, but they continued other aggressive treatments because the parents wanted the baby to be treated. There was no explicit discussion about the reasons for withholding the heart operation; it was obvious to all the clinicians that it would not make sense to do heart surgery for this baby who would surely die. On the other hand, if parents wanted aggressive treatment, the baby would not be taken off the respirator.
Similarly, after the neonatal team stopped after trying unsuccessfully to resuscitate (start breathing and heart beat) for 20 minutes after a baby's birth, there was no discussion about whether they stopped because there was no chance that the baby could survive, or because the outcome would be so bad even, on the unlikely chance, that the baby could survive.

Although the level of aggressiveness may be set at a point at which it is known that the baby will die with that level of care, it is generally felt important that the level of care be one which can be thought of as passive euthanasia, not active euthanasia. For example, consider the case discussed earlier (in Chapter VI, section on active and passive euthanasia) about Justin, a baby who had intestinal problems which had left him with too little intestine to ever be able to digest food normally. A decision was made to allow him to die. IV hyperal for nutrition was stopped but IV sugar water was continued. One nurse who I spoke to considered the hyperal to be "extraordinary treatment and would only prolong his suffering" and that stopping it would be passive euthanasia. She felt that stopping the IV fluids, however, would be murder or active euthanasia. Even when decisions are made that are known to bring about death, it is thought important that they are felt to allow death to occur rather than cause it.

Two management regimes which were practiced in the past, involving the withholding of food and sometimes fluid, have been much criticized. While the clinicians who practiced them probably felt that they were examples of passive euthanasia, some other clinicians considered them
active euthanasia and therefore not acceptable. One involved infants with Down's syndrome, the second involved babies with spina bifida.

Although such decisions would probably not be made today (see Chapter VIII, section on the Baby Doe Regulations) in a number of instances, in the past, at a number of institutions, decisions have been made to withhold surgery from infants born with Down's Syndrome and a correctable intestinal defect. With such a condition, the infants could not be fed normally by mouth. No IV feedings were given, although, in at least some situations, IV fluids were given. The infants died slowly of starvation over a period of days or weeks. Some clinicians felt that withholding feedings, which would obviously lead to death, constituted active euthanasia. The clinicians who did it, however, probably felt that it was allowing death to occur because of the intestinal defect. I know of no case in which a clinician sanctioned the withholding of bottle feedings or tube feeding from an infant with Down's syndrome who could take feedings by mouth. I think that the presence of a life-threatening defect allowed the withholding of food to be seen as passive euthanasia while without the defect, withholding nutrition might be seen as active euthanasia.

The less aggressive the treatment withheld, the more likely clinicians are to see it as active euthanasia. Some of the strong reaction against the withholding of treatment from Baby Doe (the case of the infant born in Indiana in 1982, see Chapter II) might have been generated by the fact that not only nutrition but also fluids were withheld, so he was not only starving to death, but was also dehydrated.
Most clinically socialized individuals, such as physicians and nurses, seem to hold death by dehydration with the total abhorrence.

Another situation in which a plan for the management of care was chosen to decrease the chances for survival occurred in the care of infants with spina bifida in England. When a decision was made not to do surgery to repair the primary lesion because it was thought that the quality of life would be so poor that it would be better to allow the infants to die, the infants were sedated. Then, they were fed only on demand. Since they were sedated, they didn't demand feedings frequently. Babies cared for under this regime almost always died fairly soon, while babies with unrepaired lesions, who were fed on schedule at other centers, often survived for a long period of time despite non-treatment decisions. While some clinicians, such as Lorber, who felt strongly that that active euthanasia was unacceptable, saw sedation and demand feeding as an example of passive euthanasia, some other clinicians considered such practices to constitute active euthanasia, since a practice which led to withholding food would clearly led to death.

In these cases, in which nutrition, and sometimes fluids were withheld, the quality of life would not have been likely to be as poor as for some other babies who were treated more aggressively. In examining why more ordinary treatments were withheld in these cases, it appears that the answer may depend on the degree of certainty about the babies' conditions. Down's syndrome and spina bifida can be diagnosed with a very high degree of certainty, and in all cases there are
identifiable deviations from the norm. Although the quality of life would not be as poor as was likely in other cases, it appears that clinicians felt that it would be all right to choose a management plan where the outcome - death - was certain because there was equal certainty about the diagnosis, and about the fact that the baby would not be "normal."

Decisions with an Uncertain Outcome

In many cases, the level of aggressiveness of care which is chosen leaves the outcome - survival or death - uncertain. For example, such a choice was made in the case of Sal (Chapter V, section on aggressiveness), the first baby I observed for whom a decision was made to limit the aggressiveness of treatment. In that case, the baby was continued on CPAP, but a decision was made not to put him back on the respirator if his condition deteriorated. Also in the case of Ray, a baby with spina bifida (discussed in IV; the section on withholding/withdrawing treatment), a decision was made not to operate but to continue antibiotics for a full course of treatment.

One reason that treatment is sometimes put at an intermediate level, where it is neither certain that the infant will live or will die, is that it enables the clinicians who are caring for the infant to avoid taking responsibility for determining life and death. Sometimes, it is rationalized that the intermediate level of treatment will "enable the baby to declare himself." In other words, the assumption is that if
the baby would do well in the long run, he will get better but if he
gets worse and he needs more treatment, it indicates a poor long range
prognosis.

Frequently, it is an appropriate assumption. For example, for a
small premature baby like Sal, who has had bleeding in the brain,
further respiratory problems may be associated with more serious brain
damage or with chronic lung problems which will lead to years of
dependence on the respirator and eventual death. In other cases,
however, the development of problems needing additional treatment are
unrelated to the long range prognosis.

For example, in Sal's case, he could have developed problems
needing further respiratory support or cardiac resuscitation, yet had no
severe cognitive or motor impairments which would have compromised his
future quality of life. Therefore, he could have died despite the fact
that he would not have been severely impaired. On the other hand, he
could have had serious brain which damage that left him seriously
impaired, and which could have led to a very poor quality of life. Yet,
if his respiratory or cardiac situation did not deteriorate, and he
didn't need the respirator, he would have survived despite the problems.
As it turned out, Sal's respiratory status did not deteriorate and he
never again needed the respirator or cardiac resuscitation. At the age
of five, he had cerebral palsy which affected his lower limbs, but he
had no other physical or mental impairments.
I think that in situations like this, where there is a high level of uncertainty, clinicians are often uncomfortable with having to carry the weight of responsibility for survival with a poor quality of life or for death. By putting the level of treatment at an intermediate level, they can feel that they are not determining the outcome.

I once had a conversation with Peter, a senior neonatologist, who was caring for a very sick, very premature baby who he felt was terminally ill. In discussing the care of the baby, I mentioned that in my sample of fifty cases (see appendix), there were no babies who represented the "classic neonatal ethics case" of a baby who could survive but who had died because treatments had been withheld. Yet, I said, a number of the cases, particularly those involving the care of terminally ill babies, did present situations in which decisions had to be made for care which involved ethical issues. Peter agreed, and said, beyond that, you could say there were ethical issues involved in the care of every baby.

We continued to talk about the care of the terminally ill baby who he was then caring for. Peter said that he thought that it would be best to take the baby off the respirator. But, he said, the parents wanted the baby kept on the respirator "so a miracle could happen." This very devout Catholic physician said that he felt it was the clinician's job to explain to the parents "that [being on the respirator] is not how miracles happen." He said that if there was going to be a miracle, it would happen whether or not the respirator was there. However, he felt that this baby's situation represented an act.
of nature, and that the baby would die no matter what choice was made about care.

A second neonatologist, Hal, had entered the room, and they continued the conversation about ethics and neonatology. Peter, who had earlier said that all cases involve ethical questions, now said, "we never really determine life or death for any of these babies." He felt that "God" or "Nature" really determined the fate of the babies, and the clinician's role was to help bring about what had already been fated to be.

Variants of both views, I believe, are very common among clinicians in neonatology. On the one hand, they feel that they shoulder a huge responsibility knowing their actions can lead to life or death for the babies. On the other hand, they often feel that ultimately the outcome is beyond their control. Some clinicians subscribe primarily to one view or the other, but it is not uncommon for clinicians to express both views on different occasions.

Although outsiders often talk about "Playing God in the Nursery" (e.g. there is a book by Lyons with that title about Neonatal Care), clinicians who work in the nursery generally don't feel that they are "playing God" a term usually used to indicate determining outcome inappropriately. Although they are proud to be able to save the lives of infants who will have a good quality of life, they do not feel that in doing so they have "played God." The term "playing God" is almost always used to refer to human actions which cause an outcome other than
what the speaker feels was "meant to be." But, clinicians who work in the field of neonatology generally do not feel that they are going against fate. Rather, they have a well-developed world view which provides norms for appropriate treatment behavior. While in some situations it is seen as dictating every possible effort to save life or treatment choices which will surely lead to death, in other situations, it dictates a management plan which leaves the outcome uncertain or in the words of one mother of a child with spina bifida, "Up to God or Mother Nature" (Levin, Palmer and Ross 1984).

Treating Up to a Given Level of Aggressiveness

Even after a decision is made to withhold some treatments above a certain level of aggressiveness, other treatments up to that level of aggressiveness are usually given. For example, in the case of Sal, even though a decision had been made to withhold treatment for a cardiac arrest or the use of a respirator, all other, less aggressive treatments were continued up to that level of aggressiveness. For example, the CPAP, blood transfusions, and anti-seizure medications were continued.

Similar decisions were made in virtually all other cases in which treatments were withheld. Although I never heard it explicitly discussed, there seemed to be a strong clinical norm underlying treatment decision making that dictates: Once a decision is made to withhold a treatment of a given level of aggressiveness, all other less
aggressive treatments are still given while more aggressive treatments are withheld.

Although the relative aggressiveness of treatments were not explicitly discussed, as explicated in Chapter VI (section on aggressiveness), the sense of ranking of treatments on this dimension seems to be widely shared by clinicians. As was discussed in that section, this ranking was reflected in the pattern of responses to the questionnaire conducted on neonatal decision making in the Spring of 1983.

I think that this pattern of treatment choice enables clinicians to feel that they are providing appropriate supportive care to infants, even though they are not doing everything possible to preserve life. Sometimes, however, maximizing the goal of providing supportive care may be seen as having the unintended consequence of doing harm by sustaining a baby with a poor quality of life after a decision has been made that it would be better to allow the baby to die.

For example, when antibiotics and regularly scheduled feedings are provided to infants with Spina Bifida they may die slowly or may survive for a long period of time despite a non-treatment decision. This is apparently what happened in the case of Jane Doe. Although I have no personal knowledge of the details concerning the decision making in her case, from reports in the media (New York Times 1983, 1984; Lyons 1985), it is possible to infer a number of things about the decision making process about the management of her care. I think that this famous case
is a good example of a treatment decision in neonatology where a
decision to treat up to a given level of aggressiveness, left the
outcome uncertain.

Jane Doe was the first child a young, affluent Catholic couple.
She was born in a community hospital on Long Island in the Fall of 1983.
Soon after birth she was transferred to Stony Brook Hospital. She was
born with a spinal defect, L₃ to L₄ which would lead to substantial
paralysis of her legs and incontinence of bowel and bladder. In
addition she had hydrocephalus and microcephaly, indicating a high
probability of severe mental retardation, a condition which prevented
her from completely closing her eyes or from using her tongue properly
to suck, spasticity of her arms, and a thumb abnormality that would
prevent her from having full use of her hand. Shortly after birth she
developed meningitis.

When she was born, her parents, in consultation with her doctors,
decided against neurosurgery to close her spinal lesion or shunt the
excess fluid from her brain. They believed that because of the multiple
anomalies, she could only have a poor quality of life. Because of the
level of the spinal lesion, they knew she would definitely have
paralysis and incontinence. In addition, the brain malformations led to
little uncertainty that there would be some developmental delays with a
high probability of severe retardation. Without surgery her anomalies
would be likely to lead to more bouts with of meningitis, urinary tract
infections and uncontrolled hydrocephalus. It was reported in the press
that without surgery, she would probably live for two years, while with treatment she could live for twenty.\textsuperscript{7}

In addition to considerations about patient characteristics, Jane Doe's parents and clinicians considered treatment characteristics in making decisions about her care. While neurosurgical procedures were withheld to close her back lesion and shunt the excess fluid from her brain, they did give antibiotics to treat her meningitis. They also presumably provided such "treatments" as a sterile environment by putting her in an isolette and covering her lesion with a sterile dressing. It is likely that Jane Doe's caretakers considered neurosurgery to be extraordinary treatment which could be withheld, but felt that antibiotics constituted ordinary treatment and may have believed it was mandatory (especially after the prospect of legal intervention was raised). It is also possible that the antibiotics had been started soon after birth, and that her caretakers believed that once started, the treatment had to be continued (see Chapter VI, section on withholding/withdrawing).

The decision to continue the antibiotics was probably crucial for Jane Doe's survival. Without the antibiotics, she probably would have died quickly from meningitis. She recovered from the meningitis and remained in the hospital for about six months. Her back lesion closed

\textsuperscript{7} Although these figures were repeated numerous times in the press, some knowledgeable clinicians felt that the time estimates had no real physiological basis. They said that without treatment she could certainly die sooner and with treatment she could live longer than predicted.)
spontaneously, reducing the chance of a subsequent infection. When her hydrocephalus progressed and caused discomfort, her parents agreed to neurosurgery to shunt fluid from her brain. After the surgery her parents brought her home. Her neurosurgeon says that he sees no reason to revise his original prognosis; he thinks she will be severely retarded and will remain bedridden for her whole life.8

In some situations, clinicians and parents may feel that they are almost marking time waiting for an event to occur which will lead to death. If death does not occur, given the chosen treatment choices, new choices may be made to change the level of treatment.

For example, in the case of George, a badly asphyxiated baby with a serious heart lesion, clinicians continued all medications and kept the baby on the respirator while waiting for the baby to die. That way, they did not have to stop ongoing treatments nor withhold more ordinary treatments. In that way it is easier to think of the management plan allowing a natural death to occur than if decisions are made to withdraw treatments. After a few days, however, George, was still lying unconscious in his isolette, insensitive to pain. The care plan was reevaluated. Some of the more aggressive medications were now seen as prolonging his death and were decreased, allowing death to occur sooner.

8 The latest report on her condition that I heard, on 60 Minutes in the Spring of 1986, said that Jane Doe (now two and a half) doesn't walk but can sit by herself and say a few words and attends a special nursery program.
Since clinicians may feel that only some treatments may be withheld in a given situation, if a baby doesn't die after a decision is made to limit a particular treatment, clinicians may feel that they have no option to withhold other treatments at a later point in time. For example, Tony, a full term baby was born without a heart beat (Apgars 0/1) because of an abruption (separation of the placenta from the wall of the uterus); some might have considered him stillborn. Resuscitation attempts were started immediately, After a long period of time without oxygen he was resuscitated, but he was badly asphyxiated.

Very aggressive treatments were given in the beginning, when it was hoped that the baby might be able to have an acceptable quality of life. By the time the severity of the condition was appreciated (which left the baby unable to be conscious of his surroundings and having periods of violent uncontrolled seizures) his condition had stabilized. He was no longer on a respirator. Although he had arrested (his heart stopped a number of times) at the beginning, he no longer arrested.

Clinicians at the institution where he was being cared for felt that they had no options to withhold other treatments which would lead to his death. He suffered with five bouts of pneumonia. His attending physician said that before the Baby Doe regulations she would have withheld antibiotics but now she felt she had no choice but to give them whenever he needed them. He lived five months before finally succumbing to pneumonia, even with antibiotics. (See Chapter VIII, section on the Baby Doe regulations).
Translating from Cultural Category to Behavior

When decisions are made about the care of catastrophically ill babies, they are generally made in terms of the culturally defined categories of patient condition, treatments and goals. As discussed above, there is wide variation in how these are interpreted. Not only does this affect how information is categorized about the patients, treatments, and goals to be used in the decision making process, but it also affects how decisions are translated into behavior.

For example, if a baby is born with severe anomalies, the attending physicians may meet with the parents and together they may decide to give "no extraordinary treatments." Those providing direct care for the infant must translate that decision, made in terms of the cultural category - extraordinary care - into choices about behavioral acts. There may be consensus that for such a baby "no extraordinary treatments" means no surgery and no resuscitation. There may be variation, however, in how clinicians interpret less aggressive treatments. For example, some may consider tube feedings or antibiotics as "extraordinary care" in such a situation, while others may not (see Chapter VI, section on extraordinary care). After the act of decision making takes place at the cognitive level, the meaning of the decision still must be translated in order for behavior, or the actual treatment choice, to take place.
The implications for treatment behavior may not even be clear when decision making addresses a choice to give or withhold a particular treatment option. For example, in the case of George, the badly asphyxiated baby with a cardiac lesion discussed above, a decision was clearly made not to do open heart surgery. A note about the decision not to perform surgery was written in the chart.

The implications of the decision for other treatments however, was not absolutely clear. Although the attending physician, Hal, assumed that the baby would arrest (his heart would stop) and he would not be resuscitated, he had not written a DNR (do not resuscitate) order in the chart. One of the neonatal fellows said that if the baby had a cardiac arrest, he would try to resuscitate. Later, the attending wrote a note on the chart, and clarified the choice in regard to arrest status.9

Caring for a catastrophically ill infant often involves management choices about scores of possible medications, procedures, and tests for a single baby each day. While the major decisions, such as whether or not to do surgery or an arrest page, may be discussed explicitly by the parents and senior physicians in a unit, many of the seemingly more minor treatment questions may never be specifically addressed. While many of the decisions are obvious, following the general norm of treating only up to a given level of aggressiveness (e.g. if the baby has been taken off a respirator so that she may be allowed to die, no one would put in chest tubes, a very invasive procedure), other

9 The relative aggressiveness of the two treatments is unclear.
treatment behavior reflects preattentive decisions, sometimes made by more junior clinicians.

In some cases, such decisions may reflect the goals which guided the initial decision to withhold treatment. For example, further treatments may be withheld in an effort not to do harm by prolonging suffering. In other cases, the standard practices which guide treatment for the vast majority of infants in the unit, for whom the goal is to preserve life, are carried out for the infants for whom preserving life has been seen as causing harm. In some cases, such practices may be reexamined, in others they go unquestioned.

One example in which such standard practice was challenged only by a bit of black humor occurred in the case of an infant with a high level myelomeningocele. A decision had been made not to treat the baby with the presumption that he would die of meningitis (an infection from the open lesion). A sign had been placed on his isolette "Wear gloves for diaper changes!" Someone had scribbled graffiti on the bottom of the sign asking "Why?" The usual practice for caring for a baby with an open lesion is to take measure to prevent infection. In this case, everyone was waiting for the baby to die of an infection. Sometimes no one questions the continuation of usual practices when the goals of treatment change.
Summary

This chapter discusses the way that the goals of medical treatment - to cure, to care, to preserve life and to do no harm, are culturally defined. Material is also presented on how clinicians make decisions about how to treat, guided by the norms of decision making which indicate how one is to try to achieve the goals of treatment given the characteristics of patient conditions and treatments. Norms of decision making about giving treatment to infants who could have a good quality of life, who are terminal, and who would be expected to have a poor quality of life are discussed. Finally, the way in which decisions are translated into treatment behavior is examined. Numerous case examples are provided.
CHAPTER EIGHT

RAPIDLY MOVING HISTORY: CHANGE IN CONCEPTUALIZATIONS OF DECISION MAKING FOR CATASTROPHICALLY ILL NEWBORNS

In Chapters V, VI, and VII, I have examined how clinicians conceptualize the question of treatment choice for catastrophically ill newborns, discussing some of the categories, goals and norms which guide treatment behavior. In this chapter, I will discuss change in the context of decision making, and the effects of change on the conceptualization of treatment choice and on treatment behavior. I will begin with a discussion of changes in the conceptualization of treatment for infants with two conditions - spina bifida and extreme prematurity. This will be followed by a discussion of the Baby Doe Directives and clinicians' interpretation of their meaning for treatment choice. Finally, this chapter concludes with a more general discussion of changes in the conceptualization of categorization of patient condition, treatments and goals, changes in norms, and changes in treatment behavior.

Changes in Treatment for Infants with Spina Bifida

Prior to the late 1950s, medicine was unable to provide many treatments which could be of benefit to most infants born with spina bifida. Most babies who had open lesions died from meningitis soon
after birth; others whose spinal lesions closed spontaneously usually
developed hydrocephalus which led to death for some and severe mental
retardation for others. Still others died from renal or other
complications. Although some physicians attempted aggressive treatment
(Ingraham and Hamlin 1943; Bluestone and Deaver 1953), most did not
recommend surgery. Most physicians were guided by the norm that
dicted that useless treatments should not be inflicted on hopelessly
ill infants.

During the 1950s and early 1960s, developments in neurosurgical
techniques, medical technology and antibiotic therapy enabled physicians
to close the open lesion, shunt for hydrocephalus, and better manage
renal complications. This change led to changes in the way clinicians
thought about treatment for babies with spina bifida; they were no
longer considered "unsalvageable" but were now "treatable."

Most of the literature on the treatment of children with spina
bifida entailed debates about how to optimize medical management to
assure survival and to increase functioning. Not all clinicians,
however, felt that infants with Spina Bifida should always be treated
aggressively.

For example, as early as 1960, a surgeon, Dr. Bucy, said of his
ideas about the management of children with spina bifida "The difference
of opinion between [himself and two other surgeons] is not one of
neurosurgical methods but one of philosophy" (1962:65). He went on to
give his view that

Modern methods have brought us new responsibilities. It is not sufficient that we merely sustain life with expert surgery and the use of blood transfusions, intravenous fluids, gastric intubation, tracheotomy, antibiotics, and with expert nursing care. We must sustain life with hope and human decency, not just life under any circumstances. We must whenever possible sustain life with a minimum of physical and mental suffering. The decisions related to such problems are difficult ones to make, but we cannot escape them nor solve them by falling back upon a rule of "life at any cost and under any conditions." In these various situations we must ask ourselves if we would want to live or see our children, relatives, or friends live under those circumstances.

(pp. 69-70)

For the next few years, however, there was little written questioning the benefits of aggressive treatment. In general, there was great optimism about the promise of the newly developed treatments. At many centers, such as Sheffield in England, babies with spina bifida were aggressively treated with the newly developed techniques (Sharrard, Zachary and Lorber, 1967). Although some centers did practice selective non-treatment during this period there was relatively little mention about such practices in the literature.

The first published exchange on withholding treatment from newborns that became part of a debate that developed in the clinical

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1 There were a few articles and letters questioning the benefits of aggressive treatment for all infants with spina bifida (See Chapter III, section on withholding treatment).

2 This article, which does not cite any earlier articles discussing a position of selective non-treatment for "ethical" reasons, is the earliest article revealed by numerous computer searches on the topic.
literature in the late 1960s and the early 1970s was written by R.B. Zachary, a pediatric surgeon at Sheffield England. The article, entitle "Ethical and Social Aspects of Treatment of Spina Bifida" appeared in The Lancet (Aug. 3, 1968, pp. 274-76). It some ways it is a strange first article, for it is an argument for aggressive treatment which presumably was the norm at the time. It reflects the fact, however, that the value of always treating aggressively was contemporaneously being questioned by a number of clinicians. In fact, at Zachary's own center, John Lorber, the first widely recognized advocate of selective non-treatment, was probably already discussing the criteria for decision making which he proposed in print three years later (see Chapter II and below).

In that first article, Zachary wrote that there are three alternative courses of treatment available following the birth of a baby with spina bifida:

(1) he should be killed. (2) he should be encouraged to die; whether by giving no treatment at all (e.g. no feeding) or by not treating complications (e.g. no treatment of infection by antibiotics; or (3) he should be encouraged to live.

(p. 274)

He goes on to state:

The ethical principle that direct and deliberate killing of a human being is wrong is widely accepted on a religious and philosophical basis, and has been the basis of medical practice since the time of Hippocrates, and even earlier. ... The second alternative has no better justification. To leave a child without food is to kill it as deliberately and directly as if one was cutting its throat. Even the prescription of antibiotics for infection, such as pneumonia, must now be considered as ordinary care of patients.
Once the principle has been established that the child should be encouraged to live, we are in a position to consider which method of management gives the child the best chance to live, and secondly, which method of treatment will reduce the handicap to a minimum.  

(p. 274)

In the next few pages, I will use the concepts developed in Chapters IV through VII to discuss the debate that followed Zachary's article.

At the time that Zachary published his article, John Lorber was conducting a follow up study, on the basis of which he was to propose criteria for selective non-treatment of some infants with spina bifida (1971). As in other fields of medicine (see Chapter II) physicians and others challenged the norm that a physician should always try to preserve life and that doing otherwise was to "do harm." This was evidenced in letters following Zachary's article in the Lancet.

R.C. Sanders called Zachary's ethical justification for treatment "shallow and cruel" and wrote:

...It is no longer acceptable that the preservation of life as such is the doctor's most important task. We have now considered the patients well being and happiness to be equally at stake. ... If long term survival entails many operations, much pain and disfigurement, no ability to lead a normal life because of incontinence and paraplegia and mental strain and distress to parents, should we always attempt it?

He was thus asserting that there is now acceptance of a new norm which allows physicians not to attempt to prolong life (Sanders 1968, p. 457).
Zachary responded that Dr. Sanders missed the point of his paper. He reasserted that babies should not be "killed" (in his framework, the only alternative to treatment) and states that "the main purpose of treatment is not to save the child's life but to improve his function" which, he writes, the child with spina bifida "deserves." He also challenges Sanders negative evaluation of the "well being and happiness" of children with spina bifida by inviting him to see the children at the follow-up clinic (Zachary 1968a).

That exchange was followed by a subsequent letter by Ian G. Wickes in *The Lancet* (1968) which stated that there is another alternative beside "killing" and "treating" which he identifies as "to let nature take it's course." In terms of our analysis of cultural categories and norms, Wickes here asserted the existence of another category beside "killing" and "treating" He stated that without active intervention, over 90% of the untreated babies die within the first year. He ends the letter by stating:

One can argue that [surgery] is the baby's fundamental right, but have we forgotten that parents and their living children also have rights? Should they not also be considered and consulted?

Wickes not only proposed a new category, but also addressed another goal beside treatment for the good of the child in suggesting attention to the interests of other family members.

In a letter in the Oct. 12, 1968 issue of *The Lancet*, A.A. Fernandez-Serrats, A.N. Guthkelch and S.A. Parker criticized Wickes for not defining the phrase "letting nature take its course" which they
characterize as highly ambiguous. By doing this they questioned the validity of the category, or, at least its applicability in some cases. They went on to challenge the benefit of Wilkes 90% mortality. They stated that even among the most severely affected, those with open thoracolumbar myelocele, with adequate surgical treatment 35% survive to the age of 16 and 70% of the survivors are of normal intelligence. Here they challenged the evaluation of Wilkes in placing patients in a category of having a poor outcome, and assert that the outcome is better than he suggests.

In the same issue, another letter, by P.F. Ellison Nash, criticized Wilkes for denying the neonates the right to a surgical opinion challenging the ability of individuals like Wilkes to make the evaluation of prognosis. He also stated that with treatment, the survivors would have been spared brain damage and paralysis which they did suffer without surgery. Pointing out that a decision not to treat may cause harm, not only by killing, he wrote that denying surgery causes those who do survive to have avoidable impairments. Finally, he tied this ideological dispute to another debated social issue by writing: "Dr. Wickes is extending the principles of social abortion into the neonatal period. This influence is unhealthy in the nurseries of maternity units."

Already, in this first exchange on the issue of selective non-treatment in the clinical literature, the range of responses in terms of changes in categories and norms have been illustrated. The participants in the exchange have debated about the appropriateness of
classifications, proposed and questioned new categories, and justify their behavior on the basis of different goals and norms.

Since then, an extensive literature has developed in which clinicians, lawyers, philosophers, and others have continued the debate about social and ethical issues in the treatment of infants born with spina bifida (see Chapter III). As discussed on Chapters V, VI, and VII, there continues to be debate about the meaning of categories such as "a good quality of life" and about the importance of distinctions between such categories as "withholding care" and "killing" and whether or not quality of life considerations should be important in decision making about care.

Treatment decisions for infants born with spina bifida have varied widely in their level of aggressiveness. Some babies have received very aggressive treatment while for others, some treatments have been withheld. The ideological foundations of treatment decisions have been diverse as well.

It is difficult to say exactly what changes have taken place in the conceptualization of treatment choice for infants with spina bifida. There are no statistical data on treatment in large numbers of actual cases through time, nor even comparable surveys of attitudes. From talking to clinicians and discussions in the clinical literature, it seems that there have been some changes over the past two decade. This may be due to changes in attitudes about the possibilities for an acceptable quality of life with disabilities, partly as a result of the
disabilities rights movement. It also may be due to changing conceptions of the acceptability of passive euthanasia in some circumstances.

Although similar arguments still take place about the definitions of categories, and the applicable norms, it seems clinicians are less likely to advocate the most extreme positions. Clinicians now seem more likely to think that it is possible for an infant to have a decent quality of life with a low level impairment. It also seems that clinicians are less likely to take a position arguing for everything possible to be done to preserve life in all cases. In the late 1960s, it seemed that many infants with low level lesions were not receiving surgery, while many with high level lesions and hydrocephalus were receiving surgery. It now appears that most infants with low level lesions are treated aggressively, while those with high level lesions and other serious impairments are less likely to receive treatment. Although there isn't consensus about treatment, there seems to be somewhat more agreement about treatment choice than in the years immediately after the new treatments were developed.

Treatment of Very Low Birthweight Premature Infants

Unlike the situation for treatment of infants with spina bifida, there have been very clear changes in the treatment of very low birthweight premature infants. Rapid improvements in the technology for
the treatment of small premature infants have been followed by more aggressive treatment for smaller and smaller babies.

Whereas infants under 1500 or 1000 grams (450 grams = 1 pound) were rarely treated in the past, the lower weight limit thought to indicate the threshold for viability has dropped lower and lower. Now, aggressive treatment is routine even for infants of 700 or 800 grams, and is becoming more common for still smaller infants at many institutions.

A recent article in the New England Journal of Medicine (Hack, and Fanaroff 1986) documented changes in treatment practices during the period, July, 1982 to June, 1984 for infants at one neonatal unit. The study showed that during the first year of the study, no infants under 700 grams were put on a respirator, during the second year, smaller infants, weighing as little as 400 grams were put on respirators. This change in treatment practice reflected a change in the categorizations of the infants' conditions. During the first year, the deaths of infants tended to be attributed to "immature lung development considered to be incompatible with extrauterine survival" (p. 662). Later, after such infants were treated and some survived, the infants were seen as viable; the deaths of infants in the same weight category came to be seen as due to disease related or treatment related causes.

Another change that took place during the past two decades has been changes in the conceptualizations about treatments. Such treatments choices as the use of respirators and heart surgery for
newborns were fairly new and experimental at the beginning of neonatal intensive care. Since they are very invasive and costly, and were new and experimental, they were seen as very aggressive treatments and their use was considered fairly extraordinary when they were first used. As their use proved to be successful in preventing mortality and morbidity, and as they have come to be used routinely, their use has come to be seen as fairly ordinary. For example, while the use of respirators and intravenous feedings at first seemed extraordinary for small premature babies, their use now seems ordinary. While such treatments might have only been used in special circumstances at first, now they are used most of the time unless a conscious decision is made not to use them.

There also appear to have been other changes in the conceptualization of treatment choice for premature infants. While in the 1960s and early 1970s, the salvageability of the infant seemed to be the key factor guiding treatment choice, following the questioning of the aggressiveness of treatment for infants with well defined lesions such as spina bifida, clinicians came to question the benefits of very aggressive treatments for some premature infants. One of the important differences between premature infants, and many other infants for whom the benefits of treatment have been questioned is the degree of uncertainty about patient condition. While the range of impairments is more predictable for infants with conditions such as spina bifida, the range of possible defects are generally much broader for a premature infant. Some of the differences in treatment over time for premature infants, seems to have been associated with changes in beliefs about the predictability of impairment.
One of the major problems for premature infants is that they are at high risk for having bleeds in their brains. Depending on a number of factors, including how extensive the bleeding is, and where in the brain it occurs, such bleeding is associated with mental retardation and/or cerebral palsy and other impairments. In the late 1970s, when I started my field work, such bleeding could only be detected at Columbia through the use of a spinal tap. If blood was detected in the fluid, it was inferred that there had been bleeding in the brain. The amount of bleeding and the location was not known. It was a neither a very reliable nor specific test.

The development of CAT scans and ultrasound equipment enabled the visualization of the bleeds in the brain, and the clinicians then had more knowledge about the extent and location of bleeding in the brain. A system for scoring the severity of the bleeds was devised. Early follow-up studies indicated that infants with grade I or grade II bleeds had little impairment, but that infants with grade IV bleeds invariably had serious impairments if they survived.

With more certainty about the level of impairments, some clinicians now felt that they had more reliable information which could be used to predict future quality of life for some infants. With less uncertainty, they felt more comfortable recommending more aggressive treatment for infants who did not have serious bleeds, and for recommending the withholding of aggressive treatments from those who had grade IV bleeds. Later studies revealed that the association between
the grade of the bleed and the level of impairment was not as strong as had previously been thought. In fact, some of the infants who had grade IV bleeds only had mild impairments. Again, with increased uncertainty, many clinicians have been more reluctant to withhold treatment.

Changes in the ability to treat very low birthweight infants, as well as changes in the ability to diagnose and treat second trimester fetuses before birth, are currently leading to changes in the way that infants/fetuses born before 28 weeks are conceptualized. Before the modern era of neonatal intensive care, babies born before 28 weeks of gestational age used to be classified as miscarriages and were not even thought to have lived. Now technological developments enable survival of many babies born after 25 to 28 weeks gestational age, and of some babies who are born even earlier. Currently, use of sophisticated technology, has brought the ability to sustain the life of prematurely born infants to very close to the 24 week threshold frequently used as an upper limit for legal abortions.

Refinement of the use of respirators will not lower the current threshold, because the use of a respirator depends on a level of lung development which rarely occurs before 24 weeks. There are, however, other types of technology which may enable the survival after even less time in utero. ECMO, an external oxygenation system is currently only used for infants over about 1500 grams. At the present time, technical problems prevent the use of ECMO for smaller infants. It is expected, however, that these technological problems will be overcome within the next decade (Weil, personal communication, 1986). Then, with the use of
this very aggressive treatment, it will probably be possible to sustain the life of infants born before 24 weeks; it would probably be very costly in terms of economic costs and staff time and equipment, and the risk of death and of severe impairment would probably be very high.

This will lead to questions which are ethically difficult and complex concerning the management of both "wanted" and "unwanted" pregnancies/babies. Many will revolve around the conceptions of "viability." Viability is generally seen as occurring when a fetus is able to survive on its own. Viability has been seen as an important category in norms pertaining to abortion and refusal of fetal therapy. Technological developments which would lead to viability for the second trimester fetus would present problems with the use of current norms.

Viability is usually taken to mean the ability to survive outside of the mother. Currently, the type of support necessary to enable survival is not considered. Like old definitions of death, this definition of viability may prove problematic for treatment choice decisions. As there was a change in the conceptualization of death to include social as well as physiological criteria, a change in the conceptualization of viability may be necessary for the development of clinical norms to guide the management of the fetus/infant.
The Baby Doe Regulations and Clinical Decision Making

Although widely discuss by clinicians and bioethicists, decision making for catastrophically ill newborns received little public attention until the early 1980s. It was, however, of concern to two political interest groups: The Right-to-Life movement and Disability Rights groups.

One staunch right-to-life activist, who had a special interest in the care of newborns, and who played a major role in bringing the issues wider public attention, was Surgeon General Koop. Before appointment to public office, Dr. Koop was a well known pediatric surgeon. Speaking against abortion in 1979 he stated:

The first domino to fall was abortion on demand, and it has split this country as no other social issue since the practice of slavery. The second domino to fall was infanticide. It fell silently because unlike abortion, which is a public issue, infanticide is practiced behind the shielding facade of the hospital. The third domino is euthanasia: it has been struck and is falling.

(Brozan 1979)

After publicity about Baby Doe (see Chapter III), a child with Down's syndrome who died in 1982 because relatively routine surgery had been withheld, at the urging of Dr. Koop and others concerned with the care of newborns, the Reagan administration issued a directive stating that "Discriminatory failure to feed and care for handicapped infants ... is prohibited by federal law [in institutions receiving "federal financial assistance"] (Department of Health and Human Services 1982). The regulation was based on Section 504 of the Rehabilitation Act of
1973, civil right legislation designed to protect the right of the handicapped to education and employment.

For this regulation, the administration took a broad view of federal law in order to deal with an issue usually considered to be either under the jurisdiction of state governments or not subject to government interference (see Chapter III), by defining Medicaid and Medicare funds to hospitals as "federal financial assistance" and withholding treatment as "discrimination" (a position which had been advocated by some Disability Rights activists).

During the first year, this regulation received relatively little notice from clinicians, bioethicists, and other who had been concerned with the treatment of newborns. It did however, receive much support from some people involved in the disability rights and the right-to-life movements. In 1983, the President's support from many in the Right Wing, especially those concerned with the abortion issues, had fallen. He had been elected to office with a promise to outlaw abortion. As the tenth anniversary of the Roe v Wade Supreme Court decision approached, he had made little progress on the issue. In March of 1983, at a national meeting of Evangelicals, President announced that he planned to enforce rules to prevent the withholding treatment from handicapped newborns. He announced that a "Baby Doe Hotline" would be set up to facilitate the reporting of cases in which treatment was withheld. All hospitals would be required to post signs informing people about the Baby Doe Hotline (New York Times 3/9/83:A18).
Political alliances surrounding the regulations have cut across traditional political boundaries. Not only were these "Baby Doe Directives" applauded by Right to Life and Disability Rights advocates, but also by some members of Civil Liberties organizations. They felt that this interpretation of the law would oblige hospitals to abide by all other civil rights statutes as well. Most health care professionals, bioethicists, people active in the women's health movement and some civil liberties activists, however, opposed the Directives. They were seen as an infringement on the privacy of the physician/patient relationship, on the right to refuse treatment, and on the ability of parents to make decisions for their children. Opposition to the Directives also came from some conservatives. They feared that the broad interpretation of the law would require the federal government to become involved in investigating other alleged instances of discrimination in other institutions (Russell and Barringer 1983), and also feared further encroachment on the State on the private decision-making of its citizens.

Later in March, the administration issued regulations establishing the Baby Doe hotline, requiring signs, and authorizing the federal investigation of instances of possible non-compliance. The regulations included the following requirement:

Under section 504 it is unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

(DHHS 1983)
Many commentators believed that the regulations required the provision of all possible treatments to sustain life without regard to the baby's condition, including very aggressive treatments for very seriously impaired babies and terminally ill infants (Murray and Caplan 1985). Many clinicians, however, interpreted the directives differently. Because of the conceptual model they used to understand treatment choice, they did not interpret the regulations as meaning that all treatments had to be given without regard to the baby's condition. Rather, many believed that the regulations would require giving more treatments than they would recommend, but that even under the directives, it would be possible to withhold the most extraordinary treatments. They used both characteristics of patient condition and characteristics of treatments in making decisions about which treatments they felt it would be permissible to withhold under the Baby Doe directives.

The influence of the clinicians' conceptual model on their interpretations of Baby Doe Directives was evidenced on the responses to the survey which I distributed in the Spring of 1983, soon after plans to enforce the directives were first announced. For every treatment choice, respondents were more likely to think it would be required by the directives than they were to feel it would be best for the baby.³

³ Paired t-tests between treatments recommended and thought required were significant for every treatment option; p < 0.05, for most treatment options, p < 0.01.
TABLE VIII - 1

TREATMENTS RESPONDENTS WOULD RECOMMEND
AND TRENDENTS RESPONDENTS THOUGHT WERE REQUIRED
BY THE BABY DOE DIRECTIVES - SPRING 1983

n = 2494

<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>WOULD RECOMMEND</th>
<th>THOUGHT REQUIRED</th>
</tr>
</thead>
<tbody>
<tr>
<td>BABY WHO IS ANENCEPHALIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedings by mouth</td>
<td>76</td>
<td>90</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>56</td>
<td>82</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>32</td>
<td>75</td>
</tr>
<tr>
<td>Resuscitation in the delivery room</td>
<td>13</td>
<td>63</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>3</td>
<td>31</td>
</tr>
<tr>
<td>Arrest page</td>
<td>2</td>
<td>47</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>2</td>
<td>26</td>
</tr>
</tbody>
</table>

| BABY WHO HAS MULTIPLE ANOMALIES               |                 |                  |
| (BEFORE CHROMOSOMAL ANALYSIS)                |                 |                  |
| Nutrition and fluids                         | 90              | 97               |
| Antibiotics                                  | 81              | 96               |
| Resuscitation                                | 76              | 95               |
| Respirator                                   | 65              | 91               |

| BABY WHO HAS MULTIPLE ANOMALIES               |                 |                  |
| (AFTER CHROMOSOMAL ANALYSIS INDICATES TRISOMY 13) |                 |                  |
| Nutrition and fluids                         | 85              | 93               |
| Antibiotics                                  | 60              | 83               |
| Respirator                                   | 24              | 68               |
| Surgery for cleft palate                     | 14              | 57               |
| Cardiac catheterization                      | 13              | 49               |
| Arrest page                                  | 10              | 51               |
| Open heart surgery                           | 8               | 46               |

4 For the Baby with trisomy 13, and for questions on resuscitation in the delivery room and an arrest page for the anencephalic baby, n = 119; actual base varies slightly depending on the number of ineligible answers (in all cases, ineligible answers less than 5% of total n).
### TABLE VIII - 2 (continued)

<table>
<thead>
<tr>
<th>CONDITION AND TREATMENT</th>
<th>WOULD RECOMMEND %</th>
<th>THOUGHT REQUIRED %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A SMALL PREMATURE BABY WITH AN IVH</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition and fluids</td>
<td>93</td>
<td>98</td>
</tr>
<tr>
<td>Suctioning</td>
<td>92</td>
<td>96</td>
</tr>
<tr>
<td>resuscitation in delivery room</td>
<td>64</td>
<td>78</td>
</tr>
<tr>
<td>Increased respiratory settings</td>
<td>53</td>
<td>88</td>
</tr>
<tr>
<td>Pressors</td>
<td>39</td>
<td>66</td>
</tr>
<tr>
<td>Arrest page</td>
<td>26</td>
<td>55</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>13</td>
<td>42</td>
</tr>
<tr>
<td><strong>A BABY WITH DOWN'S SYNDROME AND DUODENAL ATRESIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intravenous feedings</td>
<td>91</td>
<td>98</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>88</td>
<td>95</td>
</tr>
<tr>
<td>Surgery for intestinal defect</td>
<td>87</td>
<td>90</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>71</td>
<td>76</td>
</tr>
<tr>
<td>Open heart surgery</td>
<td>59</td>
<td>69</td>
</tr>
<tr>
<td>Kidney dialysis</td>
<td>28</td>
<td>57</td>
</tr>
</tbody>
</table>
This disparity ranged from 3 to 45% (see Chapter VIII, Figure 1). Twenty-one percent of the respondents felt that every treatment would be required in every case. However, most respondents thought that even under the directives, some treatments would not be required. In general, there was consensus (more than 75% agreement) that the treatments rated most ordinary would be required but there was controversy (less than 75% agreement) about the treatments rated more extraordinary. For no treatment was there consensus (more that 75% agreement) that it would not be required by the directives. However, in all cases except that of the baby with Down's syndrome, more than half of the respondents felt that some treatments could be withheld.

Opinions about which treatments would not be required varied from case to case. Almost three quarters of the respondents did not think that cardiac surgery would be required for an anencephalic baby, and only 11% thought that it was definitely required.

Many respondents indicated that they were confused about the proper interpretation of the directives by circling that many treatments were "probably" as opposed to "definitely" required or not required. Not only were they unsure whether the Baby Doe Directives would require treatments that they would not recommend, but, in addition, some respondents were not sure about whether they would be required to give treatments that they would personally recommend. For example, about half of the respondents were not sure that cardiac surgery would be required for a baby with Down's syndrome.\(^5\) This included 24 respondents

\(^5\) Includes respondents who circled "probably" required, "probably not" required and "definitely not" required.
who thought that surgery would not be required, even though they would recommend it as best for the baby.

In general, respondents were likely to think that all treatments that they themselves would recommend would also be required by the directives. In addition, most felt that some of the more aggressive treatments, which they would not personally recommend, would also be required. The pattern of responses reflected the same ranking of treatments according to aggressiveness as discussed above in Chapter VI.6

Later versions of Baby Doe Regulations

The original Doe Regulations were over turned by a Court decision in April of 1983. Since then, there have been a number of revisions of the Baby Doe directives based on antidiscrimination statutes (Section 504 of the Rehabilitation Act). Each revision, in turn, has been rejected by the Courts. Most recently, in June 1986, the Supreme upheld a lower Court decision, rejecting the regulations (Bowen v American Hospital Association 1986).

At the same time as regulations were developed based on Section 504, proponents of federal involvement in neonatal decision making also were attempting to have regulations passed in Congress specifically

6 The Guttman scores for the treatments thought required in each case were all above 0.95. The correlation of the aggressiveness of recommended treatments and aggressiveness of treatments thought required was significant (p < .001).
aimed at regulating the withholding of treatment from newborns. Efforts to tie requirements for treatment directly to health care legislation failed. As part of a compromise, most supporters and opponents of the original Section 504 regulations agreed to support an Amendment to the Child Abuse Prevention and Treatment Act defining the withholding of medically indicated treatment as child abuse. The act stated:

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

(U.S. Congress 1984:4)

The amendment also stated that the Department of Health and Human Services should publish guidelines

to encourage the establishment within health-care facilities of committees which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guideline concerning the withholding of medically indicated treatment ... from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions.

(U.S. Congress 1984:6)
While the language of the new Amendment is fairly strong, the enforcement mechanism is quite weak. The harshest penalty is that states that fail to comply will lose relatively small amount of Federal money targeted for Child Abuse agencies. These already overburdened agencies are unlikely to take a very active role in seeking to expand their responsibilities into an area which many feel ill-equipped to handle.

The compromise was acceptable to almost all parties because it addressed many of the concerns of each faction. One objective of the Reagan administration was to accomplishment something that could be seen as a positive step by the Right-to-Life movement. The Baby Doe regulations enabled him to take a strong ideological stance on a Right to Life issue and to claim victory.

Many of the Right to Life and Disability Rights advocates were pleased. The issue of discriminatory non-treatment of newborns had gained national prominence. Much of their concern had always been non-treatment of newborns with mild to moderate impairments, specifically treatment for infants with Downs' syndrome and surgically correctable intestinal defects. There is evidence to suggest that at least the public positions of many bioethicists and clinicians had shifted; many now state that, of course non-treatment of such newborns would be unacceptable. I think that it would probably be difficult for such treatment decisions to be made today.
The associations of health care professionals and many civil liberties advocates could also accept the revised regulations. Their main concern was that the original Baby Doe Regulation would have made it difficult to withhold aggressive treatments from critically ill infants with complex medical conditions. The ambiguous language of the current regulations which permit the withholding of "virtually futile treatments" are seen by many as allowing the withholding of inappropriate treatments.

Finally, opponents were also pleased that the new regulations situated review and enforcement of decisions at a more local level. While in the past, many clinicians had opposed defining the withholding of treatments as child abuse, many now saw such a vehicle as a better alternative than direct federal intervention. The concept of hospital based review committees, also previously opposed by many clinicians, was now endorsed as a means for keeping review within the institution. Since the committees are established by hospitals, and are usually run by physicians from the neonatal intensive care units who appoint the members, in many ways they reinforce rather than challenge the clinical model of decision making.

The implications of the recent Supreme Court decision for the political struggles around Baby Doe Regulations are unclear. The Court affirmed the right of parents stating, "In broad outline, state law vests decisional responsibility in the parents, in the first instance, subject to review in exceptional cases by the State acting as parens patriae." Although the Court did not specifically review the child abuse
amendments, in reviewing the regulations based on section 504, the Court did use strong language in stating "State child protective services agencies are not field offices of the HHS bureaucracy, and they many not be conscripted against their will as the foot soldiers in a federal crusade" (Bowen v American Hospital Association 1986:30). Following the Supreme Court decision, there will likely be renewed efforts by supporters of federal involvement to develop a clear federal justification for intervention; opponents to government intervention will continue efforts to limit the government role.

Effects of the Baby Doe Regulation on Clinical Decision Making

It is difficult to document the effects of the Baby Doe directives on both the conceptualization of treatment choice and treatment behavior. Some clinicians claim that adhering to the Regulations would involve practicing bad medicine and claim that the regulations have affected neither their thinking nor their behavior. Numerous reports, however, of very aggressive treatment for infants who previously probably would not have received such treatment suggest that the regulations did affect treatment in many cases.

It appears that the both the regulations themselves, and the media coverage surrounding them and some of the non-treatment cases, have led to some changes in the way that some clinicians conceptualize treatment choice for catastrophically ill infants. There appears to have been some shifts, so that at least some clinicians, who might have supported
withholding relatively non-aggressive treatments from infants with mild to moderate impairments a few years ago, no longer will do so. For example, although some had previous thought that parents should be able to withhold intestinal surgery from infants with Down's syndrome, now virtually no clinicians publicly advocate such a position. In addition to the fact that many clinicians now feel that it would not be politic to advocate such a position, it appears that many have truly changed their opinions about the quality of life for infants with Down's syndrome and some other disabilities.

Another change that seems to have occurred during the past few years has been a change in some of language used to discuss treatment decisions. The term "best interest of the baby," which was used in the President's Commission Report (1983), seems to have replaced "quality of life" as the term most often used in discussing the rationale for treatment decisions (Arras, forthcoming). In part, this may be due to the fact that some versions of the directives specifically state that decisions based on "quality of life" criteria are not acceptable. It also seems to reiterate the importance of considering the value of treatment from the perspective of the infant rather than the value of treatment to others.

It appears that some clinicians who always felt uncomfortable withholding treatment are using the directives as an excuse to justify aggressive treatment in some circumstances. Sometimes, clinicians have used the directives as a means to compel parents and other clinicians to accept their definition of the boundaries of acceptable choices.
There has been a definite trend towards more aggressive treatment since the announcement of the Baby Doe directives (NEJM editorial 3/6/86) but it is hard tell to what extent, if any, that represents an acceleration of the trend toward more and more aggressive treatment of infants which has characterized neonatology since it's inception. Commenting on the New England Journal of Medicine editorial, a prominent pediatrician said that the "Neonatology imperative" has always been to "Do more and more of what you don't know how to do until you get better at it." He felt that the fact that almost all centers would now try to rescue a 500 gram. baby had less to do with the regulations than with the generally aggressive attitude. He claimed that directives do not force such treatment; he believed that if people thought they were treating because of the directives, they were over reacting (Bill Weil, comments made a Hastings Center meeting 3/17/86).

It is clear that both because of the directives themselves, and the general increased public awareness of the issue of decision making for catastrophically ill infants, clinicians felt that they were more likely to be prosecuted if they withhold treatment from infants. Although some said that they do not let the possibility of prosecution change the way they practice medicine, there were clinicians who were clearly recommending treatments they would not have recommended a few years before.

Although the Supreme Court decision does not actually change the law, since the Baby Doe regulations had already been overturned, it
seems likely to lead to changes in clinicians conceptualization and
treatment practice. Many clinicians had continued to believe that they
had to provide aggressive treatments as a requirement of federal law.
Now, some clinicians seem to feel that as a result of the Supreme Court
decision, such treatment is not longer required. One might speculate
that many clinicians will be more likely to withhold treatment than
during the previous three years. The increased public awareness and
widespread discussion of decision making in neonatology, however, will
probably make clinicians more somewhat more cautious in their decision
making than in the pre-Baby Doe era. The affects of increased parental
awareness of the issues involved in neonatal decision making, if any,
are not yet known nor are the affects of the presence of ethics
committees.

General Changes in Conceptualization and Treatment Behavior

Since the late 1960s, when the issue of withholding life saving
treatment from catastrophically ill newborns was first discussed, there
seem to have been a number of changes in the way that relevant factors
have been conceptualized and some changes in norms and treatment
behavior.
Changes in Categorization of Patient Condition

There have been some changes in the conceptualization of patient condition characteristics. Many clinicians seem to have changed their view concerning the implications of some impairments on future quality of life. This probably reflects at least two factors. First, there appears to be both a general change in attitudes about the capacity of people with impairments and of knowledge of programs and opportunities for independent living, for employment for people with disabilities. In the early literature, the assumption was often made that people born with spina bifida would not be able to marry or find employment. One rarely hears clinicians making such statements in discussions of decisions for non-treatment today. There also have been changes in views of the capacity of people with Down's syndrome and other conditions causing mild to moderate retardation. With deinstitutionalization and special education, and the resultant increase in capabilities of people with developmental delays, the view of their quality of life has changed as well.

In addition, I think that there has been a shift in what capacities many clinicians see as necessary to permit a acceptable quality of life. In the beginning of the debate, the standard of comparison was often the "normal" individual, and impairments which caused limitations in particular functions were all seen to detract from a good quality of life. It was a type of deficit model, each deficit took away from the capability to have a good quality of life. Now, clinicians seem more likely to focus on what the infant will be able to
do which will enable the infant to have life satisfactions. The focus is now more on the capacities that the baby will have that will enable the infant to derive benefit from continued life. There is greater realization that quality of life is more than a sum total ADLs (measurement of function based on "activities of daily living") or of the ability to perform specific functions.

I don't think that there has been a clear trend in either the amount of uncertainty or how clinicians feel about uncertainty. While increased diagnostic capability and better treatments has increased knowledge about diagnosis and prognosis with some conditions, new treatments for which there has not yet been much follow-up, and greater awareness of the range of outcomes with particular conditions, has increased uncertainty about others. Clinicians are still uncomfortable about making decisions in the face of uncertainty, yet such decisions continue to be unavoidable.

As clinicians have increased experience and better outcomes treating particular conditions, these conditions have come to be categorized as less critical. For example, while the condition of a 800 gram premature baby may have seemed very critical 15 years ago, and giving certain very aggressive treatments may have seemed to be optional, the condition of such a baby no longer seems so critical and many treatment would now be felt to be mandatory. On the other hand, there may now be more willingness to recognize babies with some conditions as terminally ill, such as infant with trisomy 13 and 18, and there is therefore more willingness to withhold some treatments.
Changes in the Categorization of Treatments

There have also been shifts in how clinicians feel about a number of characteristics of treatments. In general, there has been a trend to see many treatments as less aggressive than they would have been considered in the past. When treatments were new and were still somewhat experimental, they were more likely to be seen as aggressive than now when they have become accepted as part of standard practice. For example, such treatments as respirators for small premature babies, TPN (total IV feeding) and some forms of surgery, such as a PDA ligation, are considered to be less aggressive now than they were in the past. Also, treatments have come to be seen as less aggressive relative to newer treatments which are considered more aggressive. For example, now, after the development of ECMO, the respirator seems less aggressive because it is no longer the most aggressive life support device for respiratory functioning. Some of the new treatments, however, such as ECMO and infant heart transplants, are considered to be more aggressive than any previous treatments.

There have also been changes in how clinicians categorize treatments as ordinary or extraordinary. Because some treatments are no longer seen as being as aggressive as they had previously been thought to be, there is a greater tendency to think of those treatment as more ordinary. On the other hand, clinicians appear to be more likely to categorize treatments as ordinary or extraordinary on the basis of the
presumed benefit to a patient rather than because of the aggressiveness of the treatments. Therefore, clinicians may be more likely to characterize even less aggressive treatments as extraordinary in some cases. Although there is still disagreement among clinicians about how to categorize many treatments, there appears to be consensus among clinicians about categorizing the most aggressive treatments as extraordinary for some patients who are terminally ill or severely impaired, and those that are not very aggressive as ordinary, especially for patients with a chance at a good prognosis.

It appears that they has been a shift in the way that many clinicians feel about the distinction between withholding and withdrawing treatment. Clinicians seem more likely to see some changes in management, such as increases in respirator settings, or restoring treatments after diagnostic tests, as "new treatments," than previously. Therefore, not giving such treatments may be more likely to be categorized as withholding rather than withdrawing treatments.

There also appears to have been shifts in clinicians conceptualization of active and passive euthanasia. Most important, clinicians seem to be more aware that many decisions they make affect the nature and timing of death for their critically ill patients. Therefore, they are more likely to see treatment choices as instances of passive or active euthanasia that would have previously been thought of as patient management decisions. Also, many clinicians are now more conscious of the criteria they use to distinguish between active and passive euthanasia.
Clinicians are more often now aware of decisions as affecting the course of life and death for their patients. This occurs for two reasons. First, with more powerful medical technology, clinicians are more able to postpone the moment of death, either by providing treatments that will reverse a physiological process (e.g. performing surgery to close an open lesions and prevent infection), substitute for a physiological process by providing life support (such as a respirator or dialysis), or by resuscitating the patient and restarting a vital function which ceased. In addition, however, clinicians now appear to be aware that the use of biomedical means to prolong life, or the withholding of such means, reflects a decisions. In the past, clinicians frequently omitted providing possible treatments which they felt were inappropriate for patients with a given condition. Such decisions were usually seen as based on physiological criteria alone and death was seen as due to the "natural history" of the disease. Now clinicians are more likely to see such decisions as reflecting value criteria as well as physiological criteria. They are less likely to see the course of many diseases as reflecting the "natural history" of the disease, but rather, as having a course in part determined by treatment decisions.

When clinicians first became more conscious about the fact that their decisions were causally associated with death for their patients, many were disturbed. Although some clinicians felt that any decision which led to death was unacceptable, other clinicians wanted ways to distinguish acceptable from unacceptable decisions associated with
death. Some clinicians came to see decisions which allowed death to occur (passive euthanasia) as acceptable, while decisions which caused death (active euthanasia) as unacceptable. At first many clinicians felt confused about whether particular treatment choices constituted active or passive euthanasia. There was much disagreement between clinicians. There continues to be disagreement between clinicians, and many clinicians still feel conflicted about some particular decisions. It appears that now, however, many clinicians feel more able to categorize treatment choices for themselves as passive or active euthanasia. Within the medical community, consensus seems to be developing that some treatment choices constitute passive euthanasia for patients with some conditions, while other choices would constitute active euthanasia.

Changes in Goals

Clinicians primary goal is still to cure their patients when ever that is a possible outcome. It appears that for some conditions, clinicians may now be more willing to acknowledge that cure is not possible. In other cases, however, clinicians may be more likely to use a wider definition of "normal," using functional rather than physiological criteria.

It appears clinicians are less likely to have solely the preservation of life as a primary goal for infants who are terminally ill and or so severely impaired that they will not have an acceptable
quality of life. Clinicians are more likely to use a social rather than only a physiological definition of life (Crane 1975). Clinicians continue to try to "do no harm." Increasingly, allowing death to occur is less likely to be seen as a harm, and the use of very aggressive medical technology without compensating benefit is more likely to be seen as harmful.

Changes in Norms

Over the past two decades, there have been some shifts in the norms guiding neonatal decision making. Although some clinicians are guided by similar norms, others have made major shifts in the norms used to guide treatment choices.

Almost all clinicians now agree that passive euthanasia is acceptable in some circumstances. In cases in which infants are terminally ill, or will have a very poor quality of life, most clinicians are probably now willing to withhold at least some aggressive treatments. Some clinicians may limit treatment only for patients who are probably unsalvageable. Other clinicians choose to withhold treatment from infants who would be salvageable, but who have extremely limited capacities. It appears that fewer clinicians now feel that life with certain severe conditions or dying should be prolonged in order to uphold a principle of sanctity of life.
At the same time, however, many clinicians seemed to have shifted their attitudes about the role of quality of life considerations. In the past, many clinicians were willing to accept non-treatment decisions if they felt that the infant would have a moderate degree of impairment that would be thought to compromise quality of life. Now few clinicians are willing to consider non-treatment unless they feel that the infant will probably have a very poor quality of life. Rather than comparing the quality of life of the patient to the quality of life of a child without impairments, clinicians now seem more likely to consider what they feel will be the "best interests" of the patient in making treatment decisions.

During the past two decades, there appears to have been a trend away from both giving and withholding treatment for the presumed benefit of others, and more focus on the "best interests of the baby." It seems that clinicians may be less willing to consider the possible problems which the life of the infant might cause for the family or costs for society; at the same time they seem to be less likely to feel that making choices to limit treatment would be harmful for families, health care professionals or to society.

Clinicians now seem more willing to give even more aggressive treatments than they previously did, especially if they feel that it will lead to a good or acceptable outcome. Some clinicians, however, seem more willing to withhold less aggressive treatments if they feel that they would be no benefit. An exception to this may occur in cases where the parents want very aggressive treatment that the clinicians do
Clinicians may now be more willing to agree to aggressive treatment if the parents want it to be given.

Clinicians also now seem more willing to withdraw treatments which are already started as well as withhold new treatments. Although psychologically it still seems very difficult for clinicians to stop ongoing treatments, fewer clinicians seem to feel that there is a morally significant distinction between stopping and not starting a particular treatment.

While the majority of clinicians seem to feel that a distinction between active and passive euthanasia is important, some clinicians now question the distinction. Some feel that when death is the desired outcome, it is all right to make decisions which lead to death and that proscribing actions which lead to more immediate death in critically ill patients is not useful. Although some philosophers have advocated active euthanasia using lethal drug injections, virtually no clinicians have advocated such means for infants. In saying that there should be no distinction between active and passive euthanasia, clinicians usually mean it should be possible to omit any treatment which would not be in an infant's best interest. They do not advocate using more active means to cause death.
Changes in Treatment Behavior

It is clear that many more infants are receiving more aggressive treatments now than twenty years ago. It is, however, very difficult to judge the changes which may have taken place in the treatment of catastrophically ill infants during the past two decades.

A major reason for the more aggressive treatment of infants during the past twenty years have been the rapid development of medical technologies. This has involved the refinement and proliferation of some treatments, such as respirators and open heart surgical procedures for newborns, which were in use on a limited scale at first, as well as the development of new technologies such as ECMO and heart transplants. Improved outcome statistics with existing treatments has supported the spread of those treatments and fostered the development of yet more aggressive ones.

In addition, economic, political and social factors have also lead to more aggressive treatments. Changes in law which required third-party payers to finance the care of newborns, and the availability of government funds for the care of newborns, has fostered more aggressive newborn care. The fact that Neonatal Intensive Care Units have become show cases for the power of American Medicine have also promoted the development of still more aggressive treatments. Aggressive treatment was further encouraged by biomedical equipment and supply companies; with government supported research leading to the development of new products, and a ready market interested and able to buy continually...
updated equipment, companies selling biomedical supplies and equipment have promoted the acquisition of sophisticated biomedical technology by NICUs. Regionalization, involving the upgrading of facilities in both tertiary centers and outlying regional hospitals, and the transfer of infants with serious problems to regional centers, also led to more aggressive treatment.

Other factors which have promoted aggressive treatment include the growing involvement of the Right-to-Life movement, which has been advocating for the aggressive treatment of newborn infants as well as preventing abortion. The disabilities rights movement has had an effect both by helping to change conceptions of people with disabilities, and by advocating for aggressive treatment for the disabled. Together, these groups helped promote the Baby Doe Regulations. Many clinicians have felt compelled to give more aggressive treatment than they formerly would have either because they feel it is required by the regulations, or because they fear that Right to Life advocates will come and bring cases of non-treatment to the Courts or to the Media. Finally, professional and parent organizations that advocate for services for those with mental and physical disabilities have also encouraged treatment for newborns. These groups, with their political clout at the government level, as well as advocacy work in the health and social services sector, have promoted more aggressive treatment.

At the same time, however, there have been factors which have increased the ability for clinicians and caretakers to make decisions to withhold treatment in some circumstances. In addition to the conceptual
changes in the clinical decision making model discussed above, these include other changes in laws and bioethical standards in society and increases in the awareness of parents and non-clinicians about the issue of withholding treatment.

Over the past two decades, there has been much public discussion of the issue of withholding treatments from critically ill patients. As discussed in Chapter II, there has been growing awareness and acceptance of the idea of withholding treatments in some circumstances. In part, this results from changes in attitudes about the use of technology, so that the use of technology is less likely to be seen as necessarily associated with progress, and more likely to be seen as involving serious risks. There also seem to be less adherence to a notion that human decision making to withdraw life saving treatment involves "playing god," and more of a sense that withholding treatment allows a "natural death" to occur.

Bioethicists have written much in support of patient's rights to refuse life saving treatment, and the right of surrogates to refuse such treatment for critically ill incompetent patients in some circumstances. (see President's Commission 1983) There have been a number of Court decisions, including those involving the care of adults such as Quinlan, Conroy, and Fox, as well as the case involving Jane Doe which have ruled that the withholding of life saving treatment is a legal option in some circumstances. There have been countless TV programs and articles in popular media dealing with withholding treatment. There have been changes in ideas about death and dying; a "Right-to-Die" movement has
emerged with such advocacy groups as Concern for Dying. With public discussion of these issues, parents have become more aware of non-treatment options and may be better able to choose or accept a non-treatment decision. Many clinicians feel more able to openly discuss non-treatment decisions.

It is difficult to say exactly what effects these two sets of factors have had on the treatment of catastrophically ill newborns. It appears that open discussion of the issues and advocacy by supporters of various positions may have lead to the reductions of decisions that fall at either extreme. In general, it seems, that aggressive treatment is more likely to be given to infants with moderate impairments; infants with devastating conditions are less likely to be treated very aggressively.

Summary

Social, political, economic, ideological and technological changes in the context of decision making have led to changes in clinicians' conceptualization of treatment choice for catastrophically ill newborns. From the first published debate on selective non-treatment for infants with spina bifida, clinicians have demonstrated variation not only in the categorizations of patient conditions and treatments, but also variation in norms and goals. This chapter examines changes in the treatment of infants with spina bifida and very premature newborns. These are seen to reflect both technological and social changes. The
ability to sustain infants formally though to be non-viable are show to have implications that may effect other social issues, such as laws pertaining to abortion.

The history of federal efforts to regulate the treatment of newborns is examined. Political and ideological factors were shown to have contributed toward to promulgation of the Baby Doe Directives. The clinicians conceptualization of treatment choice were shown to have influenced the way that clinicians interpreted the regulations. Political and social issues relating to the recent amendment to the federal child abuse act and the Supreme Court decision on the Baby Doe regulations are discussed.

Finally, general changes in the categorization of patient conditions and treatments, of goals and of norms are discussed. Some of the major changes appear to be higher expectations of an acceptable quality of life with mild and moderate impairments, and less importance vested in distinctions between ordinary care and extraordinary care and a distinction between withholding and withdrawing treatment. Clinicians may now be more willing to acknowledge that cure or preserving life is not possible in some cases. In those cases, clinicians may be more willing to accept passive euthanasia. In other cases, when clinicians feel that a baby may be able to have an acceptable quality of life, with more advanced technology available, clinicians may be more aggressive in treatment.
CHAPTER NINE

TO TREAT OR NOT TO TREAT? THAT IS NOT THE QUESTION:
CONCLUSIONS OF A STUDY ON DECISION MAKING
FOR CATASTROPHICALLY ILL NEWBORNS

This chapter starts with a summary of the study including research findings. Next, conclusions of the study are presented. This is followed by a discussion of implications of the study for future research on decision making about the care of the critically ill and for questions of public policy.

Summary of the Study

The research question addressed in this dissertation is: How do clinicians conceptualize choices about limiting care in a Neonatal Intensive Care Unit (NICU) and what factors affect these conceptualizations. More specifically, how do clinicians choose which treatments to give and which to withhold from the range of possible treatments? How do material and social factors affect the way that clinicians think about treatment choices? The focus of the dissertation is the development of a model for use in elucidating treatment choice. It was derived from observation of clinicians' behavior, including treatment choices and explanations of why those choices were made.
This dissertation is based on data collected by a variety of methods. The principle source of data has been participant observation, mostly in the NICU at Columbia-Presbyterian Medical Center. In addition, a survey of attitudes about neonatal decision making was conducted and documents were examined from the clinical, bioethics, legal and popular literature.

Chapter II presents a general introduction to the issue of decision making about the withholding of treatment from the critically ill. It demonstrates that questions about the aggressiveness of medical treatment are not new phenomena brought about by mid-twentieth century developments in medical technology. On the contrary, healers in other cultures and in our culture through history have made choices about care, including decisions to withhold some treatments that would have been intended to prolong life.

Scientific advances and changes in practice in the 20th century did lead to an aggressive ethos in medicine. The development of life support technology, with the ability to prolong physiological life of questionable quality in some cases, along with concern about other bioethical issues, led to a questioning of the benefits of some medical treatments and a social concern with "the right to die." Clinicians, bioethicists, lawyers, and policy makers have addressed such issues. As
a result, the definition of death, and norms for the delivery of medical care have been changing.

Decisions in a number of legal cases have begun to delineate conditions under which it may be acceptable to withhold treatments. Research on clinical behavior shows that treatments are sometimes withheld, but that, in general, many aggressive medical treatments are given, even to terminally ill patients. Decision making about the care of the critically ill had been a major concern of bioethics. Distinction between ordinary and extraordinary care, omission and commission, and withholding and withdrawing treatment have been used by ethicists to differentiate acceptable and unacceptable choices. Clinicians have established guidelines for decision making about the limitation of care; prominent have been guidelines concerning DNR (decisions not to resuscitate following a cardiac arrest). Surveys have revealed that most clinicians believe that decisions to withhold treatment are acceptable in some circumstances. While discussion has focused on which patients receive treatment (e.g. Crane 1975), there has been little investigation about which treatments are given and which are withheld.

The history of the care of newborns is discussed in Chapter III. It presents a brief cross cultural and historical survey which suggests that other cultures have devised means to promote the survival of most infants, but that, through direct or indirect means, many cultures practice infanticide for some infants who are not socially acceptable
for a number of different reasons. The presence of impairment has been a reason for infanticide in some cultures, but not others.

The history of modern western care for newborns is traced showing the importance of social, economic, political, and technological factors from the earlier development of incubators and special care nurseries to the recent, very rapid, development of neonatal intensive care. During the first half of the twentieth century, improvements in the standard of living, preventative medicine, and the development of antibiotics led to dramatic reductions in the rate of post neonatal (more than 28 days) infant mortality but did little to improve the survival of newborns. Early post-war efforts to improve infant mortality led to the development of special centers for infant care. Aggressive experimental techniques were used in efforts to treat critically ill newborns; this prevented some mortality and morbidity but also caused iatrogenic problems.

Since the 1960s, efforts at prevention have done little to reduce the rate of infants born at risk. There has, however, been a dramatic reduction in the infant mortality rate. This is a result not only of rapid development of increasingly sophisticated medical technology, but also social changes. These include government and other third party payments for increasingly expensive care, regionalization, and special training for physicians, nurses and other health professionals. During the last few decades, survival rates have increased and impairment rates have decreased for smaller and smaller premature babies and infants with cardiac and other anomalies.
While parents and caretakers have always made private decisions about the aggressiveness of care for some catastrophically ill infants, decision making about the care for newborns has only recently become a social issue. In the late 1960s and early 1970s, when many babies with similar problems were brought together in regional centers, and technological developments had enabled dramatic increases in the ability to prolong the lives of critically ill newborns, decision making for newborns emerged as an issue of concern to clinicians and bioethicists.

Since the early 1970s, ethical issues relating to the treatment of newborns have been examined extensively in relation to such issues as the rights of children, the rights of parents, and the use of technology. While there have been a number of legal cases involving the withholding of treatments from newborns, the legality of many practices remains unclear. Clinicians, lawyers, philosophers and others have debated how decisions should be made; they have focused on such questions as Which babies should be treated? and Who should decide?

There have been a number of studies concerning the withholding of treatments from some newborns. Surveys have investigated attitudes, background characteristics, and recommendations and behavior pertaining to the treatment of newborns. A few studies based on qualitative research also document aspects of decision making practices. These studies show agreement to withhold treatment in some circumstances, but controversy about other treatment practices. As with the studies of the
My research in a neonatal intensive care unit shows that decision making about the treatment of newborns rarely involves a single clear cut decision "to treat" or "not to treat" but rather reflects a complex process in which clinicians, and sometimes parents, make decisions about which treatments are appropriate to give at a particular point in time. The clinician's conceptualization of treatment choice is very important in determining how decisions are made. Such decisions reflect consideration of characteristics of treatments, as well as characteristics of patient condition, goals and norms for treatment behavior. These are discussed in more detail in Chapters IV through VII.

Decision making for newborns was not a salient public issue until the 1980s when there was much media coverage of an alleged decision to withhold feedings and treatment from Siamese Twins in Danville, Illinois in 1981, the death of an infant with Down's syndrome, known as Baby Doe in 1982, after his parents refused consent for corrective surgery, the announcement of the Baby Doe Directives and a decision to withhold surgery from a child with spina bifida, known as Jane Doe in 1983.

In Chapter IV, after a brief review of the literature on medical decision making, a general model for examining decision making was outlined. The importance of culture in determining aspects of perception and categorization was discussed, with an examination of
types of categories and sources of variation. Then the roles of goals, norms, and context in the process of decision making were examined.

Chapter IV includes an introduction to the use of the model for the analysis of decisions about the aggressiveness of treatment for newborns. It outlines steps starting with the perception of data about the infant and possible treatments, the categorization of information into culturally defined categories pertaining to patient condition and treatment characteristics. Decisions are made by considering these characteristics in relation to goals and norms for treatment behavior. Then the decisions about treatment are translated into treatment behavior. The entire process occurs in the context of the technological, ideological, political, economic and social environment of the unit and of the society at large.

Chapters V, VI, and VII present the categories of patient condition, treatments and goals and the norms for decision making and explores their cultural construction. Although all are based, in part, on objective data, all are also determined by culturally defined evaluations. Examples are drawn primarily from participant observation and are supplemented by data from the literature and from the results of a survey. Areas of consensus and of controversy are discussed.

Chapter V discusses characteristics of patient condition. Clinicians consider a number of issues in relation to quality of life (benefits and burdens to the patient) including the degree of physical and mental impairment, the capacity to give and receive love, and the
amount of pain and suffering. Such factors as concepts about the "normal," discrimination against people with disabilities and the social class of parents affect clinicians' categorizations about quality of life. Clinicians also consider the risk (known probabilities) and uncertainty (what is unknowable) about the chances that the baby will be normal, about the severity of impairment, and about the chances that the baby will die. Clinicians also consider the nature of the critical condition - what the infant needs to stay alive, whether the infant's condition meets traditional definitions of death, and whether or not the infant is terminally ill. Finally, social value (the benefits and burdens of treatment for others) for the family, for health care professionals and the health care system, and for society are discussed.

Quality of life was found to be one of the most important factors determining the aggressiveness of treatment. Uncertainty about the future condition of the infant, especially if the baby could be "normal," was also found to be important. While salvageability was also important, decisions are still made about the aggressiveness of treatment even for infants who are not salvageable. While the social value of treatment or non-treatment is frequently discussed, it was found to have a less important role in the decision making process about particular babies, except in those cases in which parents wanted aggressive treatment despite clinicians recommendations for less aggressive treatment. Social value, was seen as having a more important role in setting the parameters for acceptable treatment for all babies, than for decisions in individual cases.
In Chapter VI, I present data on clinicians' conceptualization of characteristics of treatments. Even when clinicians withhold some treatments likely to prolong life, they provide other treatments which would also prolong life. Therefore they are distinguishing between characteristics of treatments as well as characteristics of patients, in making treatment decisions. This fact has received relatively little attention in the literature on clinical decision making.

One of the main ways in which clinicians categorize treatments is in terms of their aggressiveness. Treatments which have such attributes as a large physiological effect, which are experimental, which are not frequently done, which are invasive, involve the use of high technology, and/or which are costly in terms of staff time or monetary costs, and/or which are risky are ranked as more aggressive than other treatments which do not have those attributes to the same degree. Categorizations about the degree of aggressiveness are usually not explicit, and the dimension is not referred to by clinicians by a single consistent term. It does, however, appear to be a core concept shared by clinicians, who show a high degree of consistency in their conceptions about the relative ranking of treatments in making choices about which treatments to give and which to withhold.

Clinicians also categorize treatments as being ordinary or extraordinary. According to the original definitions of the terms, which evolved out of Catholic moral theology, the treatments were to be categorized on the basis of the potential benefit of the treatment for the patient. As the terms are currently used in the clinical setting,
however, their use also encompasses notions dependent on the aggressiveness of the treatment. Clinicians also categorize choices not to give treatments as being instances of withholding or of withdrawing treatment. Although the difference may seem clear cut, this distinction, as the other characteristics of patient condition and treatments, is culturally defined.

The final characteristic found to be important in the conceptualization of treatment choice was a distinction between active and passive euthanasia. In some situations it has become acceptable to practice "passive euthanasia" or allow death to occur, but it is not acceptable to practice "active euthanasia" or cause death to occur. Some clinicians consider withholding new extraordinary treatments as passive euthanasia, and the withdrawing of ordinary treatments as active euthanasia. There is not, however, either agreement about the definitions of these categories, nor about this definition.

In Chapter VII, I examine goals, norms, and treatment behavior. The chapter starts with a discussion of the goals of medical treatment identified as to cure, to care, to preserve life and to do no harm. As with the characteristics of patient condition and treatment, there is disagreement among clinicians about the meaning of these concepts. While for most infants admitted to NICUs, it is possible to choose treatments which will further all of these goals simultaneously, in some cases these goals are seen to as coming into conflict. In such situations, clinicians may try to maximize the attainment of a single goal or may try to choose behaviors which will balance a set of goals.
Behavioral norms, which guide the choice of treatment for catastrophically ill infants, are discussed. In those situations in which the quality of life is expected to be acceptable, whatever treatments are necessary to preserve life are usually given. In those situations in which infants are terminally ill, as well as those in which the quality of life is not expected to be acceptable, choices are made about which treatments to give and which to withhold. Such principles as notions of proportionality, and a desire to neither prolong suffering nor to cause death are discussed. In some situations, decisions are made which are certain to lead to death; in other situations, choices are made which leave the outcome uncertain. In general, decisions about care can be characterized as decisions to treat up to a given level of aggressiveness, and then to withhold more aggressive treatments.

Finally, the translation of decisions about treatment choice in terms of culturally defined categories into treatment behavior is discussed. Since clinicians differ in how they interpret characteristics of patient condition, treatments, and goals, they differ in how they translate decisions into behavior. Therefore, clinicians who claim to share the same norms may differ in treatment behavior, and clinicians who claim to adhere to different norms may, in practice, make similar treatment choices.

In Chapter VIII changes in the conceptualization of decision making are discussed. The first published debate about selective non-
treatment of newborns (Zachary 1968 and letters) are examined in detail. Variation in norms and goals as well as variation in categorization are found from the beginning of the debate.

Next, changes in technology and attitudes are shown to lead to a variety of changes in the conceptualization of treatment choice for infants with spina bifida. Advances in the technical ability to treat very premature infants are shown to lead to a clear trend toward treating very premature infants more aggressively. Further technological changes, which would enable the treatment of still more premature infants/fetuses, would create problems for the use of current norms for abortion and fetal therapy. In part this is due to a definition of "viability" as the ability to survive outside of the uterus. It is suggested that changes in the definition of viability, similar to changes in the definition of death, to incorporate social as well as physiological criteria, would be one way to handle the dilemmas.

Next, the Baby Doe regulations are discussed. Starting in 1983, the Federal Government, with the support of disability, Right-to-Life and some civil liberties groups, issued a series of directives designed to prevent the withholding of treatment on the basis of legislation designed to prevent discrimination against the handicapped. After objections from health care professions and others led to court decisions overturning the regulations, both sides agreed to compromise legislation defining the withholding of treatment from some newborns as child abuse, and recommending the establishment of hospital review
committees. This Spring, the Supreme Court issued decisions supporting the lower Courts decision.

Data from the survey are presented on clinicians interpretation of the directives in 1983, very soon after plans to enforce the directives were first announced. The clinicians conceptualization of the problem of treatment choice was found to influence their interpretation of the directives. Clinicians did not feel that the regulation required the provision of all possible treatments. They did, however, feel that the regulations would require giving more treatments than they felt were in the best interest of some babies.

Finally, general changes in the categorization of patient conditions and treatments, in goals and norms are discussed. Some of the major changes appear to be higher expectations of an acceptable quality of life with mild and moderate impairments, and less importance vested in distinctions between ordinary and extraordinary care and in a distinction between withholding and withdrawing treatments.

There were also changes in the conceptualization of goals. In some cases, clinicians may now be more willing to acknowledge that cure is not possible, and they may be less likely to treat only to preserve life. In general, clinicians may now be more likely to give aggressive treatment when they feel that a baby could have a good quality of life, but, if not, they may be more likely to accept passive euthanasia. Clinicians also appear to be more likely to make their decisions based on the presumed best interests of the baby and less likely to consider
the interests of other family members. Changes in treatment were seen
to be associated with changes in treatment technology, attitude toward
withholding treatment from older patients, attitude toward disability,
and as a result of the public attention brought to the issue as a result
of the Baby Doe Directives.

Major Conclusions of the Study

To summarize, the major conclusions of this study are:

- Decision making to limit the aggressiveness of treatment is not a new
  phenomena of mid-twentieth century medicine, but rather reflects
  clinical practices which pre-date the recent technological
developments.

- The modern debate about the treatment of newborns began to emerge in
  the late 1960s (at least five years before the publication of Duff
  and Campbell 1973), starting with clinician attempts to devise
  standards for appropriate treatment.

- The treatment of catastrophically ill newborns is heavily influenced by
  the way that clinicians conceptualize the issues involved in
  treatment choice. Rather than an all or nothing decision "to
  treat" or "not to treat," the clinical model of decision making
  involves choices about which treatments to give and which to
  withhold from the range of possibilities. This is conceptualized
in terms of making a decision about the "aggressiveness" of treatment.¹

- In making treatment choices, clinicians make categorizations of characteristics of patient condition, treatments, and goals, along a number of culturally defined dimensions:

Patient condition characteristics

- Quality of life
- Uncertainty
- Critical Condition
- Social Value

Treatment characteristics

- Aggressiveness
- Ordinary/Extraordinary
- Withholding/Withdrawing
- Passive/Active Euthanasia

Goals

- To Cure
- To Care
- To Preserve Life
- To Do No Harm

Clinicians are guided by behavioral norms that prescribe the choice of treatments seen as commensurate with the characteristics of the patient's condition in order to achieve clinical goals.

¹ This is an analytic model devised to account for clinicians' treatment decisions. It is not a model consciously used by clinicians, nor the only possible model which could be used to explicate such decisions. Likewise, the dimension of aggressiveness is not always consciously addressed in clinical decision making; the ranking of treatments on this dimension can be used to explicate treatment choice.
Although the categorizations on the dimensions of patient condition, treatments and goals, are often considered dichotomous, the dimensions are, in fact, used as continua. For example, although clinicians often talk about treatments as "ordinary" or "extraordinary," they use the concepts as ranked entities; they rate some treatments as "more extraordinary" than others "extraordinary" treatments.

Most clinicians use all of the dimensions discussed above in making some treatment decisions. There is much variation, however, among clinicians in how particular conditions, treatments and goals are to be characterized, and in how important they believe each dimension should be, for individual cases.

Over the past few decades, treatment for newborns has become more aggressive. This primarily reflects the development of more sophisticated technology and practice which has enabled better outcomes for catastrophically ill newborns. There appears to be growing clinical consensus about norms to guide the limitation of treatment in some cases where treatment would prolong dying or would lead to a very poor quality of life. There is also growing consensus to provide certain treatments to infants with moderate impairments. Controversy remains about other treatment practices.
The clinical model of decision making affected clinicians' interpretations of the Baby Doe Directives. Most clinicians have felt that the directives required more treatments than they would recommend, but believed that the regulations permit the withholding of some treatments that would promote survival. While some clinicians have not changed treatment practice, many clinicians have become more aggressive in treatment as a result of the Baby Doe Directives.

Issues for Future Research

This study raises many questions for future research on decision making about the care of critically ill in general and about the care of catastrophically ill infants in particular. Some of the questions involve ways to gain better understanding of the components of the cognitive model. Others involve questions pertaining to how the cognitive understanding is developed and used in the social context. Finally, questions are raised pertaining to the relevance of the model for understanding decision making in other settings.

Research on Components of the Model

In this research, the components of the conceptual system were derived primarily from observation of ongoing behavior and articles in
the literature. The only categorizations studied directly using quantitative methods were categorizations of treatments as ordinary or extraordinary on the survey. Evidence for other categories, including quality of life and aggressiveness was inferred from the survey responses. Many questions remain about categorizations about patient conditions, treatments and goals which could fruitfully be studied by qualitative methods. For example: What are the components used in making categorizations on each dimension? What happens when a characteristic is categorized as high on one component but low on another? Is there much variation in the importance given to the various components. What happens with change over time? How much consistency is there in categorizations? Is there more consistency about some dimensions than other? I think that it would be particularly interesting to investigate categorizations on the dimensions of "aggressiveness" and "quality of life."

To what extent do such factors as cost, invasiveness, risk, or the fact that a treatment is still experimental affect the categorization of the treatments on the dimension of "aggressiveness". It would be fruitful to have informants rate treatments on each of these components and also on the overall dimension of aggressiveness in order to study the relationship of the various components. What happens when a treatment is experimental and expensive in cost and staff time but not very invasive (for example, a new monitoring device)? To what extent does the context matter? Is a drug which replaces an invasive surgical procedure seen as more aggressive than one which replaces another drug? How do conceptualizations change over time as a treatment is no longer
experimental, as cost go up or down, or as people think of the condition as a medical rather than a surgical problem?

It would also be interesting to systematically investigate categorization about the components of quality of life. How do people rate various components such as particular mental or physical impairments, or functional deficits. To what extent do clinicians change their categorizations for a particular case according to the presence of other conditions or as mediated by the perceived level of support or services available from families or institutions? To what extent is there agreements among clinicians about the categorizations on various components, and overall on the implications of different conditions for future quality of life? Do clinicians feel fairly certain about the quality of life implications of most conditions? Is there a sharp threshold for most clinicians between those conditions that justify very aggressive treatments and a gray area where in which non-treatment would be an option? Between the gray area and those conditions where prolonging life would not be seen as a benefit? Is the gray area small or wide?

It would also be interesting to use formal means to compare categorizations on different dimensions. For example, are those clinicians who perceive less uncertainty about patient condition, also more likely to be more or less aggressive in their treatments than those who perceive more uncertainty? Would there be more agreement among clinicians in their categorizations about "aggressiveness" and "quality of life" than about "ordinary/extraordinary care." Although one might
think that there would be, because aggressiveness and quality of life are components of ordinary/extraordinary, it appears that there may no more variation, in fact, there may be less. Rather than being formed only by a summation of the component parts, categorizations such as those on the ordinary/extraordinary dimension, may serve an important role in providing means for the organization of diversity (discussed more below).

Research on the Development and Use of the Cognitive Model

A major area for research concerns how characteristics from clinicians’ backgrounds and personalities affect their attitudes about factors which contribute toward the use of the model. Another major area for research concerns socialized into the clinical subculture of neonatal intensive care. Finally, one could look at many research questions concerning how clinicians use the conceptual model in social interaction with other clinicians, with parents, and others.

There are many questions about how characteristics of clinicians background affect categorization on the dimensions of patient condition, treatments, and goals. For example, are those clinicians who have had more contact with people with disabilities more likely to see the possibility of a good quality of life even with major impairments? Does education in biomedical ethics result in clinicians feeling that a distinction between withholding and withdrawing treatment is less important. What role do experiential factors play in the degree to
which clinicians are invested in prolonging life or accepting death. How does social background characteristics such as religion, ethnicity and social class, and personality characteristics such as authoritarianism or the capacity for empathy, effect categorizations on each dimension.

Much has been written about the socialization of medical and nursing students but relatively little has addressed socialization about many of the specific issues addressed in this dissertation. One issue that I find of interest concerns the development of the overall clinical model for approaching treatment decisions not as choices to treat or not treat, but as decisions about which treatments to give and which to withhold. From work with second year medical students who had not yet begun clinical work, it appears that their conceptualization of the issues is similar to that of people who are not clinicians. They expected babies to be treated and or not treated. They were surprised by decisions to give some treatments and not others. I distributed an early version of the questionnaire to pediatric residents on their first day of training. The pattern of their answers were very similar to those of more experienced clinicians - they recommended giving some treatments but not others depending on patient condition and treatment characteristics. Medical students must be socialized about the use of the model during their clinical years of training. It would be interesting to study the process of acquisition of this aspect of the subculture. Is the socialization process similar for nurses, and other health science students?
Older clinicians tend to be less aggressive in their treatment recommendations (Levin 1985). What factors affect the conceptual system later in training and in practice? What role does first hand experience actually play? To what extent is there socialization from the institutional subculture where clinicians train or work? What learning is specific to neonatology and what reflects experience with other services (including pediatric follow-up)? What roles do lectures or reading in bioethics play? How does maturation and general life experience affect the conceptualization of treatment choice.

Although physicians and nurses did not differ significantly in their overall recommendations about treatment when other background characteristics were controlled (Levin 1985), they do differ in predictions about prognosis (Anspach forthcoming), and in the factors identified as the most important for making choices about treatment (Levin 1985). What contributions do differences in background, professional socialization, and work role make to inter-professional differences in the conceptualization of treatment choice.

The treatment of newborns in the NICU is not only determined by the cognitive system of the individual clinicians but is also a result of the social processes that take place among the infants' caretakers and the constraints of the larger social system. In addition to other types of research one could conduct, it would be interesting to examine how clinicians use the clinical model of decision making in negotiations about patient care.
Parents usually know little about the conditions of their infants or about the options for treatment prior to the time that their infants are admitted to the NICU. They typically learn about their baby's condition and about the options for treatment from the clinicians caring for their baby. The condition and options are defined by the clinicians in terms of the clinical conceptual system. In presenting information to the parents, the clinicians present most treatments choices as mandatory, but may present some treatment choices as optional.

It would be interesting to study how parents develop an understanding of their baby's condition and of treatment options as these are presented by clinicians. To what extent do they accept the clinicians' presentation of the situation? To what extent do they try to challenge these assumptions? One could examine the interaction between clinicians and parents who do not accept the clinicians' framework according to the components of the model? Do they present alternate categorizations of their characteristics of patient condition, treatments or goals? Do they weight the importance of characteristics differently (for example, weighing more heavily the implications of a treatment choice for themselves or their other children)? Do they introduce new dimensions for consideration? Do they make decisions according to the norms guiding treatment choice for clinicians?

What happens when they use a different cognitive system. What happens when parents want to use different norms for decision making: what happens when they espouse norms which support an absolute sanctity
of life position demanding all life saving treatment? What happens if they feel that the level of aggressiveness of treatment is irrelevant, believing instead that decisions should be made solely on the basis of the future quality of life for the child? One could examine how negotiations between the parents and the clinicians are affected by the nature of the differences in their cognitive models. Are clinicians more willing to accept alternate definitions of some categories, such as quality of life, more easily than others. For example, the nature of the critical condition? Are clinicians (or parents) able to manipulate the system to achieve the choice desired; for example, will clinicians stress uncertainty when parents are unwilling to accept recommendation for treatment choice based on predicted quality of life?

The conceptual system could also be used to study interactions and negotiations between members of the staff. One could examine the variations in the conceptualization of the case among clinicians caring for a baby? Are there differences in categorization of characteristics or goals, or in the norms used to guide treatment choice? What characteristics of clinicians (e.g. profession, status, age, location of training, religion, etc.) are associated with various positions? Are the clinicians aware of the differences? My research suggests that there are often striking differences among clinicians who are caring for a single baby in how they categorize patient condition and treatment options. Yet, despite these differences, they will often agree on treatment choices.
It would be interesting to investigate how and why the diversity in conceptualization exists, along with agreement on treatment choice. It may be that through the experience of working together and observing choices made, clinicians develop expectations about treatment choice in particular situations. Most of the discussion in the unit focuses on the medical management of the infants, rather than on the value considerations underlying treatment choice; There is much more emphasis on learning and agreeing on what treatments are to be given. The "shared culture" of the unit may be primarily in terms of behavior because there could be strong sanctions against individuals who made inappropriate treatment choices. Yet, individuals rarely share the value defined reasoning behind treatment choice. In addition, even when views are shared, there is probably tolerance for divergent views as long as they don't result in behavior that is considered inappropriate. In this situation, in which there is diversity of ethical standards within the medical community and in society at large, variant definitions of a particular case may be tolerated as long as the behavior seems acceptable.

It would be important to gain an understanding of what takes place when divergent definitions of the situation would lead to different treatment choices. In those situations, how do clinicians negotiate with each other to make treatment choices. Do clinicians negotiate with each other to redefine the situation so that they can reach consensus. If so when and how does that take place? Do senior clinicians exert power to force acceptance of choices that they feel are appropriate? If so, when and how? Are less senior clinician's able to appeal to outside
standards or authorities to promote their choices? In particular, how does the possibility of appeal to outside authorities play a role in the decision making process?

It would also be important to investigate how, and to what extent, decision makers are limited by outside constraints, particularly by the threat of enforcement of hospital policies and of state or federal laws? Are parents and clinicians generally able to make the treatment choices that they feel are appropriate for the infants, or do they feel that the law compels them to provide treatments which they would not choose? If so, is this due to their desire to obey the law or does it reflect threat of action by hospital administrators, people who might inform the authorities, actual intervention from child welfare workers, district attorneys or others who might intervene to determine treatment choice? Do clinicians, parents, or others use the threat of hospital sanctions or legal interventions in their negotiation about treatment choice? If so, how?

One could also investigate how the conceptual system of clinicians plays a role in the resolution of potential conflicts in such forums as ethics committees and the Courts. To what extent does the conceptual system, as defined by clinicians, determine the options considered in these forums? It appears that in most case the courts accept the options as defined by the clinicians. It would be interesting to study how the clinicians' conceptual system is communicated to judges, committee members and other non-clinicians, non-family participants in the decision making process. Are members of ethics committees able to
maintain critical perspectives on decision making? How do their backgrounds affect their participation in the decision making process? Are they able to alter the way that clinicians define some situations? If so, how?

Although the general clinician model seems to be used in virtually all intensive care units, there seems to be a lot of variation in how patient conditions and treatments are classified and in how important various characteristics and goals are considered in the decision making process. There also appears to be much variation in the degree to which diversity in the degree of aggressiveness of treatment is tolerated in the units, and the degree to which parents, nurses, the hospital administration, ethics committee members and others are able to participate in the decision making process. It would be interesting to investigate the factors associated with various practices.

Research could also be conducted on the communication process between individuals at different institutions. How and to what extent are clinician conceptualizations influenced by those of clinicians at other institutions? To what extent do changes in conceptualization take place because of direct communication between clinicians working at different institutions, through articles and/or editorials in professional journals, or as a result of positions established by professional organizations (e.g. positions taken by the American Academy of Pediatrics)? How are positions influenced by the movement of clinicians from institution to institution? To what extent do changes in conceptualization and practice at different institutions reflect
independent adaptations to similar changes in technology and political, economic and social conditions as opposed to the diffusions of ideas from institution to institutions? Under what conditions is variation in practice tolerated and when is there pressure toward hegemony?

Perhaps the most interesting issues for future research involve investigation of ongoing effects of changes in the political, economic and social factors in the wider social context on the conceptualization of treatment decisions. For example, will changes in law or organization (e.g. HMOs) and/or financing of care (e.g. DRGs affect treatment decisions? How will changes in the conceptualization of treatment choice for catastrophically ill newborns be affected by other social issues such as those relating the disability, abortion, civil liberties, the use of technology, and the decision making about older children and adults who are critically ill?

Much of the recent debate on decision making for newborns has been a reflection of struggles around the abortion issue and disability rights. What factors lead to the linking of issues and the choice of positions by parties involved in these wider conflicts? What happens when alliances around one issue entail parties adopting positions which violate their usual stance on other issues? For example, what position will civil liberties organizations adopt on the parents role in neonatal decision making? What factors enable individuals or organizations to isolate issues and maintain positions which have implications which seem to conflict? How does debate about broader social issues affect the
definition of characteristics of patient condition, treatments or goals and the norms of neonatal decision making?

Use of the Model for Research in Other Settings

The final topic I will discuss in this section on research implications is the use of the model developed for looking at decision making in neonatology for the study of decision making about other issues. First, I will discuss decision making for the care of other critically ill patients. Then I will discuss the use of the model for examining decision making about the care of other types of patients and for additional questions concerning the use of technology. Finally, I will discuss some general issues relating to the use of a decision making model for social science research.

It appears that the model of decision making developed for elucidating the care of newborns has applicability for the study of decision making for the care of other critically ill patients. Clinicians seem to consider the same characteristics of patient condition and of treatments in making decisions about the care of critically ill older children and adults. They appear to be trying to achieve the same goals and are guided by norms which prescribe treatments which are proportionate to patient condition characteristics.

It would be interesting to investigate whether clinician categorizations on the various dimensions and norms are similar or
different when considering the care of older patients. For example, are the same criteria used for evaluating the future quality of life with similar impairments? Are similar standards used concerning the uncertainty? Are some treatments seen as more aggressive for either infants or older patients?

In some circumstances, it appears that clinicians would be more likely to conceptualize similar aggressive treatments as justified for a child or young adult who had an accident, than for an infant with a similar prognosis. Does this reflect a higher social value placed on the value of continued life for an individual who has formed more social attachments? In other circumstances, however, it appears that clinicians will be more aggressive in the treatment of infants. Do such decisions reflect the fact that even a very impaired newborn can perform the social role of being an infant, while an older person who suffers an accident might be unable to perform their accustomed social role? Clinicians sometimes withhold even very non-aggressive treatments from very elderly patients, especially those with limited mental capacity (Brown and Thompson 1979). To what extent does the length of time of expected survival and/or the certainty of prognosis affect such decisions?

It would also be interesting to examine other factors affecting such decisions. For example, how does specialty training in internal medicine, geriatrics or pediatrics affect the aggressiveness of treatment? How does the setting affect the aggressiveness of care? What, if any, are the systematic differences in care provided in intensive
care units, in other acute care settings, and in chronic care facilities such as residential treatment centers and nursing homes?

It might be useful to try to adapt the model for the study of other types of clinical decision making, beside the care of the critically ill. While the characteristics related to active and passive euthanasia would not be applicable, and the dimension of "critical condition" would have to be modified to something like the "potential for diminishing quality of life," the other dimensions would be considered in making other types of treatment decisions. Other characteristics might be added, or the existing categories might be elaborated. The components of the goal of "care" - functional improvement and relief of suffering - might be considered as separate goals.

For example, the model could be used to study decision making about the extent of rehabilitation services to offer a head trauma patient. One could examine the future quality of life possible with various physical and occupational therapy interventions, the uncertainty surrounding the effectiveness of those interventions, the potential fourth condition leading to diminished quality of life if the interventions are not given, and the social value of treatment for the patient's family, care givers and society. One could also look at the aggressiveness of the interventions, whether the interventions would be ordinary or extraordinary considering the aggressiveness and potential benefits for the patient, and whether the interventions had already been started. These could be considered in terms of the goals of improving
functioning, relieving pain and suffering, and "doing no harm." Even for interventions which would not directly be related to preserving life, one could consider the potential of the intervention for preserving life under certain conditions (such as increased dexterity for a patient which could be advantageous for preventing accidents). One could then try to identify the norms used by clinicians in making decisions about treatment choices. One could examine how clinicians behaved according to the patient condition and treatment characteristics and goals. In addition, one could study the relative importance of various dimensions.

The model could also be used for the study of other issues concerning the use of technology. One would have to identify the relevant characteristics of both the problems being addressed by the use of the technology and characteristics of the technology itself in relation to the goals of the actors. One could then identify the norms which guided the use of the technology.

For example, the model could be used for studying the introduction of computers to assist in performing various tasks in departments of hospitals. One might find it useful to consider such characteristics of the tasks as the nature of the changes in the tasks (e.g. speed or accuracy of task performance), the degree of uncertainty about the expected changes, the complexity of the tasks, the importance of changes in performance of the tasks for the functioning of the department, and the importance of changes in the provision of the tasks for other
specific departments, for the hospital as an institution, or for the community served by the hospital.

The characteristics of the technology's use in the setting would also have to be considered. For example, one would want to look at costs, both financial and others. One would want to examine initial capital outlay and the costs of continued use. One would also want to look at costs in terms of training of personnel and perhaps other types of changes such as transformations in the nature of the work and/or the loss of information that might result from standardization. These could be considered in terms of the goals of the institution - such as patient care, teaching, research, and financial solvency. One could use such an analytic model in analyzing the norms prescribing the importance of various dimensions and the resultant guides for behavior. It could be used to explain, for example, why patient billing has often been the first department to rely heavily on computers.

A focus on decision making, like a focus on other analytic constructs, such as exchange or status and role, can orient research in many aspects of human behavior. It is particularly useful for it enables the researcher to integrate a dynamic aspect in studies of cognition and also allows consideration of cognitive aspects in studies of resource allocation. A major limitation, however, of a decision making approach is that it focus attention on the conceptualizations and behavior of individual and/or groups. A decision making perspective alone doesn't provide information on the factors which account for the larger context in which decision making takes place. The opportunities
and constraints from the larger context are taken as given in studies focused on decision making. Research on decision making needs to be coupled with investigations using other theoretical perspectives to provide information on the larger social context.

Implications of the Study for Improving the Process of Decision Making and Devising Social Policy

The care of catastrophically ill infants presents difficult decisions for parents, clinicians, and others involved directly in the care of newborns and those involved in devising social policy. It is hoped that this dissertation will provide information and an approach for looking at decision making that will be useful both for case by case decision making and for the formation of social policy. In this section, I will discuss how the model developed in this dissertation can be used by decision makers in evaluating elements - categories and norms - used in the decision process. Finally, I will discuss the roles of ethics committees and the government in fostering better decision making.

A proposition underlying this discussion is that parents should, in general, be the primary decision makers about the medical care their children, including treatment for critically ill infants. At the present time, there is a diversity of opinion about the appropriate care of catastrophically ill infants in our society. Decision making about the aggressiveness of treatment for infants necessarily involves
decisions based on value considerations. Parents generally are the people who care most deeply about the well-being of their children. They may also be seen as best able to articulate the values that the infant would be likely to espouse if the infant had been raised and socialized by that family. Therefore, I believe that parents should be able to determine the course of treatment for their infants, except in those situations where their decisions clearly violate widely shared social values. The important issues therefore become devising means to enable parents to make decisions in accord with their own values, and developing criteria to identify poor decisions and develop processes to prevent poor treatment choices from being made.

Use of the Model for Clinical Decision Making

Since parents typically know little about many factors relevant for making decisions about the care of newborns prior to the birth of their child, they are very dependent on communication with clinicians. Clinicians, themselves, sometimes have little awareness of the assumptions and values that underlie decisions. The model of decision making developed in this dissertation can be used in making decisions about the care of individual newborns by facilitating discussions among clinicians, between parents and clinicians, and with other participants in the decision making process such as members of ethics committees. It can be used to critically evaluate the categorizations made on some or all of the dimensions and the norms used in making decisions. More awareness of the values and assumptions underlying decision making on
the part of both clinicians and parents could help improve the quality of decisions.²

Frequently issues are discussed in terms that are too general. This sometimes leads to problems in communication. For example, an indirect evaluation of physician/parent communication (using hypothetical cases) indicated that parents believed prognosis to be poorer than physicians though it would be based on the physicians' statements (Clyman 1979). Discussions of the specifics on each of the dimensions used in making decisions may be useful for ensuring an adequate information base for decision making.

The model may be used in focusing attention on issues involving quality of life considerations. In deciding the care of an individual baby, clinicians and parents should talk specifically about the likelihood of particular impairments and the possibility of specific causes of pain and suffering. Rather than saying that a child will probably be severely retarded, they should endeavor to be as specific as possible. For example, rather than saying an infant will have brain damage, clinicians should tell parents if they think the child will be able to perform simple activities but will not be able to read, or will never be able to recognize his/her caretakers.

² This discussion is not meant to imply that decision makers don't often critically evaluate these categories and norms, nor that they don't frequently communicate well with parents. Rather, it is intended to focus attention on some problems that sometimes impede good decision making.
Parents should be provided with as much good information as possible and be helped to evaluate the implications of various conditions for their infant's potential quality of life. Since so many people, including clinicians, have so little knowledge about the potential for people with impairments and many share general stereotypes and prejudices about life with disabilities, particular attention needs to be paid to providing information about the potentials for satisfactions for individuals with impairments. It is also important, however, to provide information on the negative consequences of particular conditions. Clinicians who are used to feeding tubes, chronic respiratory support, frequent operations, etc. may sometimes underestimate the effects of such interventions for the quality of life of the patient. Parents should be provided with as much information as possible on both negative and positive consequences of specific conditions.

One of the major problems, of course, is the degree of uncertainty about future prognosis. Currently there is much diversity among clinicians in predictions they would make for a given condition. Clinicians should be encouraged to share their uncertainty about prognosis with each other and with parents as fully as possible. Efforts should be made to collect information on the likelihood of various outcomes with various conditions.

While clinicians may want to put the greatest emphasis on the chances for cure, or for a good outcome, other aspects of uncertainty should also be considered. Clinicians should be concerned about the
best outcomes that treatment could offer. In making decisions about care, however, it is also important to consider the most likely, and the worst possible, outcomes. Following their values, some parents may choose to forego treatments in order to avoid a very poor outcome, rather than believing that they should necessarily treat if there is a possibility of a good outcome.

Similarly, parents and/or clinicians can discuss categorizations on other dimensions of the model. These discussions can focus on both the data and the criteria used to make evaluations. In addition to examining patient condition characteristics, they can examine treatment characteristics. For example, they can explore the criteria used to classify a treatment choice as passive or active euthanasia. They can also discuss whether a particular treatment choice will help to achieve a given goal. They can ask if an intervention which temporarily relieves acute suffering, but prolongs life which is characterized by chronic suffering truly furthers the goal of providing "care."

Decision makers may also want to use the framework to help identify the importance that is given to various criteria in making treatment decisions so that priorities about the relative importance of various dimensions can be evaluated. For example, some people feel that the best interests of the child, usually understood to be determined primarily by quality of life, should be the only criteria used in making a treatment decision [see In the matter of Claire Conroy (1985), for an example concerning the choice of treatment for an adult]. In some cases, however, when the potential benefit of treatment for the child
may be very small, and the social costs of treatment are very high, decisions makers may want to consider social value considerations. If an infant is so severely brain damaged that the infant could only have minimal awareness of his or her surroundings, and the continued life of the infant would cause distress for the family and be very expensive, then it might be reasonable to consider withholding some treatments.

Identification of the norms used in clinical decision making may also be useful for challenging the way that decisions are made. For example, this dissertation has demonstrated that clinicians consider not only characteristics of patient condition, but also characteristics of treatments in making treatment decisions. Parents, policy makers, and others may want to question the moral relevance of treatment characteristics for decision making.

While looking at the history of decisions to withhold treatment and the evolution of medical ethics, it is understandable that clinicians make differentiations between treatments. It is not clear, however, that such considerations should be used to justify the provisions of treatment on the basis of any criteria other than those related to patient condition characteristics. It could be argued that the consideration of treatment characteristics is necessary to uphold certain traditional standards of medical ethics, or that certain treatments, such as the provision of warmth, nutrition or fluids must always be provided to show respect for human life. One could also argue, however, that such arguments are inadequate to justify the
provision of treatments that are not warranted on the basis of patient condition characteristics.

The Role of the Ethics Committee for Improving Decision Making

One mechanism which has been suggested for improving decision making in neonatal intensive care has been the ethics committee (Pres. Comm. 1983, Fleischman 1986). It has been suggested that it can be a useful vehicle in four primary ways. First it can provide education about issues relating to neonatal decisions, usually to the staff of a neonatal unit, and sometimes to others such as members of the community. Second, the members of the ethics committee can work toward devising general principles to guide the decision making process and/or the substance of decisions. Third, it can serve as a forum for the discussion of difficult cases where perspectives can be presented by people with varied ideas. Finally, ethics committees can review the appropriateness of decision making in actual cases. (Typically, ethics committees do not themselves play a decision making function). I will say a little here about what my research suggests about the functioning of ethics committees.

One of the most important functions that an ethics committee can play is to be involved in educating the staff. As discussed in this dissertation, decisions about the aggressiveness of treatment are not only comprised of the major life and death decisions commonly identified as "ethical issue" but components play a role in many of the seemingly
more minor decisions about the management of care. In the day to day work of treating infants, clinicians frequently choose treatments without consciously considering the basis of those decisions (see Chapters IV through VIII).

Time set apart for consideration of ethical issues, both in committee meetings, and sometimes in more widely attended ethics rounds or others forums, can increase the opportunity to examine assumptions underlying both the routine and major decisions. Hopefully, this education will increase the awareness of clinicians as to a value base for a wide variety of decisions.

Together, members of the ethics committee and other staff members can begin to develop more general principles which can help guide the decision making process and substance of decisions. These principle should help to clarify the basis of many decisions which can continue to be made without individual reconsideration in each case. They should also help to identify decisions to be individually considered on a case by case basis. The committees could help to develop mechanisms to insure that certain types of decisions are discussed among members of the staff, with parents, and with members of the ethics committees.

The ethics committee can serve as a forum for the discussion of difficult cases. The perspectives brought to bear on these cases, of course, is dependent on the make up of the committees. A potential problem is that committee members are almost invariably chosen by the senior physicians and/or the hospital administration. In order to widen
the breadth of perspectives presented about cases, it is important that members with a range of views serve on the committee and that the committee members are able to function independently rather than primarily as protectors of the physicians or hospital. Mechanisms should be developed to insure representation of individuals with varied views and to insure independence in committee function.

Review of difficult cases depends on identification of these cases, and depends on presentation of the cases for review. Frequently, only those cases which physicians recognize as difficult are brought for review. Mechanisms should be developed to alert parents and other staff members to the existence and role of the committee and to encourage them to present cases.

It may be difficult for the entire ethics committee to review all of the potentially difficult cases. Smaller multidisciplinary subcommittees of the larger ethics committee should be established which could quickly be called to help in the decision making process. Even a subcommittee, however, will not always be able to spend an adequate amount of time learning about the details of each case, discussing them with the parents and clinicians and exploring the complexity of cases. It could be beneficial to identify one or two individuals in each unit who could serve as resource persons on decision making. Such a person could be a neonatal nurse, social worker or ombudsman with knowledge of the clinical and ethical complexities of such cases. Typically, the clinicians, social workers, and others working in a neonatal unit are too busy with their other responsibilities to be able to spend prolonged
periods of time and be available to explore the value issues in all cases. If part of such a person's time was freed from other duties, that person could serve as a valuable resource to the parents and clinicians deciding the care in individual cases.

Another issue to be considered concerns the identification of cases for mandatory review. Frequently, the guidelines for ethics committees mandate that all cases should be reviewed in which life prolonging treatments are withheld. As discussed in this dissertation, life prolonging treatments are frequently withheld, most often from infants who are considered to be terminally ill. The categorization of infants as terminally ill, however, is not always clear cut, and, often depends on treatment choices. In other situations, in which infants are certainly or probably terminally ill but not immediately dying, there can be serious ethical questions about care. In some cases, with aggressive treatment, these infants could live for a substantial period of time, especially if very aggressive treatments are given (see Chapter V, section on the critical condition, and Chapter VII, section on decisions for terminally ill infants). It seems impractical for the ethics committee to try to directly review decision making in all of these cases. Mechanisms should be established, however, to monitor the process of decision making in such cases and identify problems which might arise.

While most of the attention has been paid to cases in which life saving treatments are being inappropriately withheld, situations also arise in which parents wish to provide treatments which are seen as too
aggressive. (A number of cases brought to the attention of at least three ethics committees have been of this type.) Ethics committees can serve an important role in such cases by providing a forum where the problems concerning over-treatment can be presented and discussed. In some situations, the committee may be able to provide education and support to help parents make decisions to withhold overly aggressive treatments. In other cases, the committee may help the clinicians accept the parents' decision to continue treatment.

Finally, ethics committees can serve as forums for review to prevent the occurrence of clearly inappropriate treatment decisions. As I stated before, there is great diversity of opinion about what constitutes appropriate treatment choice. In general, I believe that parents ought to be able to make health care decisions for their children. In rare instances, however, parents make decisions which seem to clearly violate widely accepted standards for treatment. In such cases, if after discussion with the ethics committee no satisfactory resolution can be achieved, cases can be referred to the state authorities.

The Role of Government

There are a number of roles that the government can play in fostering better care for catastrophically ill newborns. Most important, the government should take measures to prevent the birth of so many high-risk infants. The government should play an important role
in improving the quality of life of infants with disabilities and for their families. The government could also take a number of steps to promote good decision making.

Most of the infants admitted to NICUs, and many of the infants for whom decisions are made to withhold treatment are low birthweight infants who are born prematurely. As discussed in Chapter III, there is a strong correlation between the rate of birth of low birthweight babies and socioeconomic factors. The government could do much by establishing programs to eliminate the factors which lead to the birth of low birthweight infants by providing birth control programs for teenagers, better nutrition for low income children and particularly for low income pregnant women, and programs for better prenatal care. In addition, the government should increase funding for programs to identify and eliminate risk factors for the birth of children with congenital impairments.

The government should also increase funding to improve the quality of life for infants with disabilities and their families. One of the reasons that both parents and clinicians give for deciding not to treat some catastrophically ill infants aggressively, is that there are inadequate services to provide a decent quality of life for many children with impairments (Gliedman and Roth 1980). If clinicians and families felt that there would be adequate financial and social supports for these children and their families, they would feel that infants with disabilities would have a better quality of life and more would decide to treat.
The government could also provide better information about treatment and prognosis for infants with impairments. The most recent version of the Baby Doe regulations called for the establishment and operation of national and regional information and resource clearinghouses for the purpose of providing the most current and complete information regarding medical treatment procedures and resources and community resources for the provision of services and treatment for disabled infants with life threatening conditions.

(DHHS 1985)

So far, funds have not been allocated for these centers. The government could provide an important service by providing such information. It would also be valuable if the government sponsored more, and better coordinated, collaborative research studies to follow-up infants who have been cared for in the NICU and provide information on the medical and social outcome of care.

I believe that "Baby Doe" type regulations (see Chapter VII, section on the Baby Doe Regulations) are an inappropriate mechanism for a number of reasons. Here I will discuss two of the most important. First, the definition of cases in which treatment may be withheld is too restrictive. The latest revision of the regulations only allows lifesaving treatments to be withheld when an infant is chronically and irreversibly comatose, treatment is futile, or virtually futile in terms of survival. Many parents, clinicians, ethicists and others believe that there are other situations as well when aggressive medical
treatment is not in the best interests of an infant, and that parents have a legal and a moral right to make decisions to withhold treatment.

Second, federal enforcement is neither an appropriate nor effective mechanism for regulating the care of the critically ill. Health care law has traditionally been under the jurisdiction of localities and the States (see Chapters II and III, sections on the law and withholding treatment). I believe that no compelling argument has been made to support federal involvement. Second, federal involvement has not been effective. While the Baby Doe Regulations were in effect, it was not demonstrated that federal involvement led to even a single case in which an infant who would not otherwise have been treated received life saving treatment (Bowen v. American Hospital Association) as the result of a federal investigation. There is, however, much anecdotal information suggesting that fear of federal intrusion did lead to inappropriate aggressive treatment for some infants (Shapiro and Rosenberg 1984).

Despite the fact that no physicians or parents have been found guilty of a criminal offense as a result of withholding treatment from a catastrophically ill newborns, clinicians and parents sometimes feel compelled to provide more aggressive treatment than they believe is in the best interests of a baby because they fear criminal prosecution. Changes in law which would make "good faith decisions" to withhold treatment, with the approval of an ethics committee, exempt from criminal prosecution could free parents and clinicians to make what they consider to be appropriate decisions. State laws dealing with
child abuse and with the conduct of medical practice should provide adequate enforcement to prevent inappropriate decision making.

Increased Awareness and Critical Examination of the Criteria for Neonatal Decision Making

Decision making about treatment for catastrophically ill newborns is very complex. Ultimately, I believe that better decision making for catastrophically ill infants depends on more awareness and critical evaluation of the factors involved. During the past two decades, clinicians, bioethicists and members of our society at large have become more concerned about both the power and the limits of medicine. There needs to be more awareness and discussion both about the basis for decision making for individual newborns and about the issues involved in the care of the critically ill in general.

In gaining an understanding of the care of the critically ill, members of our culture are grappling with issues involving the role of families, professionals and the state, issues concerning the nature of human life, dependency and autonomy, the power and limits of science and medicine and the role of human action and of fate. All of these crucial areas of concern for members of our culture are part of the debate on treatment for catastrophically ill newborns.
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APPENDIX I

METHODOLOGY

This appendix describes some of methodology of the research in more detail and supplements material in the introductory chapter. It starts with a discussion of preliminary research in the unit, discusses the systematic review of cases, other research activities, and document review.

Preliminary Research in the NICU

During the academic years 1977-78 and 78-79, while I was working for the Task Force on Ethics and Values in Neonatology, I observed in the unit, usually half a day a week; when there was an especially interesting case, I would spend more time. I concentrated on learning as much as I could about the general operations of the unit and about the care of cases identified by the clinicians as raising "ethical issues." After the task force ended, I continued to do informal observations in the unit, following cases of interest. In the Spring of 1981, I presented "Treatment Decisions in Neonatology: Issues for Anthropological Research" at research rounds at the Division of Neonatology, formally announcing my intentions to do my dissertation research in the unit. At that time, I administered a pilot questionnaire to the eleven people present. That year, I also
administrated a questionnaire to the twelve incoming pediatric residents, new fellows and new NICU nurses.

Project on Ethics and Values in Health Care

From 1978-1983, I worked for the Project on Ethics and Values in health care. The project was designed to developed curriculum materials for health science students and develop a short course in Ethics and Values in Health Care, which we taught at the College of Physicians and Surgeons for four years. Along with other projects, including a study in the adult medical ICU, I worked on an interdisciplinary task force on spina bifida. We conducted an in depth case study of a child with spina bifida, interviewed the child (then 6-8 years), her parents, her teachers, her nurses and her doctors. We explored issues about the decision that was made not to treat her when she was born, about subsequent care decisions, and about her life beyond the medical context for a written report and video tape (Aranow, et al. 1981-82; 1984; Levin, Palmer and Ross 1984).

Systematic Case Review

In order to do a more systematic observation of decision making in neonatology, I followed the care of 50 babies admitted consecutively to the acute section of the NICU in the Fall of 1982. That series was somewhat atypical of the 668 babies admitted to the unit that year for
it included almost forty percent of the smallest premature infants. Infants with lethal heart defects were probably also over represented. There was only one baby with a serious neural tube defect. Missing from the sample were any babies who became chronic NICU patients, unable to be discharged from the unit for more than one year. (Babies have been in the NICU at Columbia for more than three years.) The range of conditions represented, however, was fairly typical of infants admitted to the unit.

Thirty four of the fifty babies in the sample were premature (born before 37 weeks of the normal 40 weeks of gestation) and thirty eight were "low birth weight" (under 2500 grams or about five and one half pounds). Twenty seven of the babies were "very low birth weight" (under 1500 grams or about 3 and a third pounds), most born before thirty weeks. All of the premature babies above 1500 grams survived. Of those under 1500 grams, nine died, all born before 30 weeks. The smallest only weighed 540 grams (about one pound, three ounces) and was only 23 weeks. In addition to prematurity, one of the premature babies had a serious heart defect, one had intercerebral bleeding, another had pulmonary and vascular abnormalities, one had hydrocephalus, and another's mother tested positive for syphilis. Some of the babies suffered complications of prematurity including RDS (respiratory distress), IVHs (bleeding in the brain), NEC (destruction of part of the intestine), and BPD (chronic lung disease), infections including meningitis, and some needed closed heart surgery for a PDA (a problem with cardiac circulation).
The other large category was infants with heart conditions. Columbia probably attracts an unusual number of cardiac infants because it is a major center for cardiac surgery. Eight babies, including one who was premature, had serious cardiac conditions. Five died; one was the premature baby, two had hypoplastic left hearts (the then lethal condition later to be made famous by "Baby Fae" and "Baby Jesse"), one had complex heart disease and had also suffered a long period of time without oxygen, one had an AV canal, complete, and one, in addition to the heart defect, also had Down's Syndrome. Two of the babies who survived had transposition of the great vessel, another had complex heart disease associated with a number of other congenital anomalies.

The other babies, who all survived, had a variety of conditions. Five had respiratory problems, one had a fractured skull, one had myelomeningocele, one had an abdominal pseudocyst with perforation and peritonitis, a final baby who had a low fetal heart rate spent a few hours in the acute section, waiting for space on the semi-acute side.

In each of these cases, I followed decision making about major and minor decisions closely. The possibility of non-treatment was raised in a number of these cases, however, none led to the "paradigmatic ethics case" in which treatment was withheld, and an infant died who otherwise would have survived. Nevertheless, the series was crucial to the research for through it I realized the importance of many minor decisions, and the extent of decision making about the care of terminally ill newborns.
I had intended to distribute a questionnaire to the staff of the NICU in the Spring of 1983 in order to use quantitative methods to test some of the hypotheses I had developed about neonatal decision making. When the Baby Doe Regulations were announced (see Chapter VIII), I was concerned about collecting data on withholding treatment from respondents who worked in a single unit. Fortunately, I had the opportunity to distribute the questionnaire at a Conference, "Which Babies Shall Live: Humanistic Dimensions of the Care of Imperiled Newborns" presented by the Hastings Center and Montefiore Medical Center. This conference, held in New York City on April 6, 1983, attracted people who worked at NICUs throughout the Metropolitan area and some from other places. It was also attended by non-clinicians interested in neonatal decision making. Questionnaires were distributed to the 251 people who attended the conference. (For a copy of the questionnaire, see below.)

At the conference, I was invited to distribute the questionnaire at a Columbia Department of Obstetrics Retreat. Having collected data from staff at other centers, as well as Columbia, I agreed to distribute a slightly modified version of the questionnaire to the 52 participants at the retreat, and also obtained permission to distribute it to the 129 physicians, nurses, and other professional staff who worked in the NICU at Columbia.
The first portion of the questionnaire, based on the work of Diana Crane (1975), presented hypothetical vignettes of cases of newborns with four critical conditions -- Down's syndrome with duodenal atresia, anencephaly, trisomy-13, and extreme prematurity (25 weeks gestational age). For each case, respondents were presented with a list of treatment choices, each of which they were asked to assume would increase the baby's chance of survival if given and they were asked to assume that the parents' views were the same as their own.

Next respondents were asked to indicate: if they thought it would be best to give or to withhold a number of treatment options for each baby by circling whether they would either definitely, probably, probably not, or definitely not recommend each treatment, (2) whether they thought the treatments would be required by the Baby Doe Directives, and (3) how they would rate each of the treatments on a scale from one (ordinary) to five (extraordinary).

Another portion of the questionnaire consisted of multiple choice questions concerning how decisions should be made for individual newborns, how policies should be set, and which factors should be important in making such decisions. In addition, there were questions requesting background demographic and other information on respondents. The questionnaires maintained the respondents' anonymity.

In total, 249 of the 432 questionnaires distributed were returned: 130 from the Conference, 97 from the NICU, and 22 from the Obstetrics
and Gynecology Department Retreat. The return rates from the response
groups were 52, 75, and 42% respectively. Although
this is not a sample of a defined population, it does provide a set of
responses from a number of people, most of whom are very knowledgeable
about treatment decisions for catastrophically ill newborns. The NICU
subsample does provide a survey of an entire population. The responses
of the conference and Columbia respondents were similar when responses
of members of each occupational group were compared. Unless otherwise
noted, all responses are combined and reported together.

Of the respondents to the questionnaire, 30% were neonatal nurses,
18% were other nurses, 13% were neonatologists, 14% were other
physicians, 18% worked in other occupations or settings related to the
delivery of health care (medical social work, hospital clergy, hospital
administration and so on) and 6% worked in law or journalism (most with
a special interest in health) and special education. Three percent
worked at other occupations or their occupations were unknown. Seventy-
six percent of the respondents had professional experience working with
catastrophically ill newborns.

Respondents ranged in age from 21 to 73 years, with an average age
of 37. Seventy-four percent of the respondents were female, 26% male.
Only the Columbia respondents were asked about religion and religiosity.
Of these, 28% identified themselves as Protestant, 41% as Catholic, 17%

1 In addition, four respondents returned questionnaires in both the
first and third response groups; their responses were tallied only in
the second subsample.
as Jewish, 7% as other, and 7% as none. Eleven percent characterized themselves as deeply religious, 60% as moderately religious, 26% as indifferent to religion, and 3% as opposed to religion. The response rate per item was generally high. Reported percentages are based on answers from at least 240 responses, unless otherwise noted.

Following Crane (1978), there is said to be "consensus" when there is agreement of at least 75% of the respondents to "'yes' or 'probably yes'" or to "'no' or 'probably no'." Controversy or lack of consensus is said to exist when less than 75% of the respondents were in agreement. Some of the results from the survey are reported in the body of the dissertation. (For a more complete and concise report, see Levin 1985.)

Other participant observation research activities

I also visited four other NICUs in New York, units in three other cities in the Northeastern United States and one unit in Canada. I interviewed clinicians who worked in at least eight other units across the country. In order to maintain anonymity, cases discussed in this thesis are draw from these other locations as well as Columbia.

In this complex process of studying a subculture of my own culture, where the "natives" are themselves interested in analysis, and I am to some extent being socialized into the subculture, the lines between the object of study and the process of study are often hard to
draw. Over the years, I have attended numerous conferences on neonatal
decision making. Typically, these were helpful both because they
presented an academic analysis of decision making (that helped to inform
my own analysis), and were, themselves, occasions to research the
perspectives developing on decision making both by clinicians and
others.

Similarly, I have been very fortunate to have been able to be a
participant in the Hastings Center Research Group on Ethics and the Care
of Newborns. This group, with participation of some of the nation's
leading and most knowledgeable philosophers, lawyers, physicians, nurses
and others concerned with neonatal decision making, has been exploring
the complexities of the issues and working toward developing a social
policy statement. In addition to providing colleagues who are also
studying this issue, it has presented an extraordinary opportunity both
for observation and informal interviews of some of the actors who are
involved in making individual care decisions and in establishing
national policy.

The same type of merging of research and observation has occurred
as I have presented papers on my own work. In the Spring of 1983, at
research rounds in the Division of Neonatology, I presented my "research
subjects" with the preliminary version of my analysis including the
conceptual framework I had developed to understand neonatal decision
making. Their acceptance of the model affirmed its ability to mesh with
their understanding of decision making. I have heard that my
observations have even been referred to in the process of discussing the
management of cases. Numerous times, when I have presented at other forums, clinicians have come up to me afterwards and told me that they had never thought of it in quite the same way, but that what I presented described what happens in their clinical setting and would often provide case illustrations. This, of course, itself, is research material.

Since 1983, I have followed occasional cases in the NICU but have not done systematic field work. In the Winter of 1983-4, I was invited to be one of the founding members of the Neonatal Bioethics Review Committee for the NICU at Columbia. Initially I tried to be both a researcher and a participant on the committee; finding too much role strain, I have opted to be primarily a participant. Nevertheless, the committee meetings have provided some additional data used in this dissertation.

Document Review

In addition to participant review, I tried to learn as much as I could about neonatal decision making from a review of the clinical, legal, bioethics, and popular literature. When I began this research in 1977 there was relatively little written on neonatal decision making and social issues in neonatology. I was able to obtain most of the books and articles I had heard about, not only on ethical issues in neonatal intensive care but on the experience of parents and staff in the NICU. I conducted a number of computer searches of the literature.
In the past few years there has been an explosion in the number of books and articles on the topic, especially in the three years since the announcement of enforcement of the Baby Doe Directives. Since then I have tried to concentrate on articles of particular relevance to my research interests.

I was especially interested in books and articles describing clinical cases, in order to see if I could find any which indicated that other clinicians made treatment choices in ways that were very different than the clinicians I was studying. I was particularly interested in books and articles by clinicians, social scientists and others such as Anspach (forthcoming), Bell (1975), Bogden, Brown and Foster (1982), Colon (1981), Crane (1975), Duff and Campbell (1973), Guillemin and Holmstrom (1983), Gustaitis and Young (1986), Lorber (1973), Lyon (1985), Magnet and Kluge (1985), Marshall, Kasman and Cape (1982), Shaw (1972), Shelp (1986), Stinson and Stinson (1983) and Weir (1984), among others that described clinical practice. Although, clearly some clinicians made decisions which differed dramatically in substance and process from those made by the clinicians I was studying, they all "made sense" in my analytic framework.

I also systematically sought articles on a few particular categories. These included those which discussed differentiations between treatments (see Chapter VI), articles published before Duff and Campbell (1973) (frequently mentioned as the first major article on this topic), and articles written by social scientists (see Chapter III).
I also read the literature with a desire to understand the larger context in which decision making about newborns was taking place. I followed the popular media on decision making in neonatology, particularly the coverage of "The Baby Doe" issue. I read articles on legal issues pertaining to neonatology and closely read the Baby Doe regulations and many of the related legal decisions. I examined follow-up studies on the graduates of neonatal intensive care and on the costs and structure of NICUs.

Although not able to survey other topics as comprehensively, I also examined the literature on withholding treatment from older patients, medical decision making, reproductive decision making (especially prenatal diagnosis), decision making about the care of children, the use of medical technology, and general issues in biomedical ethics.

As with the "other research activities," the literature provided both analytic background and was, itself, research material.
QUESTIONNAIRE DISTRIBUTED IN THE

NEONATAL INTENSIVE CARE UNIT

SPRING 1983

See description of the survey methods, Appendix, pages 434 - 437.
PLEASE CIRCLE THE NUMBER WHICH CORRESPONDS TO YOUR CURRENT POSITION (CIRCLE TWO IF APPLICABLE)

<table>
<thead>
<tr>
<th></th>
<th>Attending Neonatologist</th>
<th>NICU Nurse</th>
<th>Fellow in Neonatology</th>
<th>Perinatal Nursing Student</th>
<th>Pediatric Resident</th>
<th>Midwifery Student</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

PLEASE READ THE FOLLOWING FOUR VIGNETTES. FOR EACH ONE ASSUME THAT:

-- THE PARENTS' VIEWS ARE THE SAME AS YOURS.
-- EACH TREATMENT, IF GIVEN, WOULD INCREASE THE BABY'S CHANCE OF SURVIVAL.
-- YOU ARE ASKED TO RECOMMEND WHAT YOU THINK WOULD BE THE BEST TREATMENT DECISIONS FOR EACH BABY.

PLEASE CIRCLE THE NUMBER WHICH MOST CLOSELY RESPONDS TO YOUR OPINION FOR EACH TREATMENT.
(Please disregard numbers at the far right margin which are for coding purposes only.)

QUESTION ONE—THE CASE OF BABY "A"

Baby "A" is born with Down's syndrome (Mongolism). Soon after birth, the baby is also found to have duodenal atresia, an intestinal defect which can be corrected by routine surgery. Without surgery, the baby cannot drink milk or other fluids by mouth.

A. WOULD YOU RECOMMEND:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intravenous feedings?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Surgery to correct the intestinal defect?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Antibiotics, if it is suspected that the baby also had an infection?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Cardiac catheterization—an invasive diagnostic procedure?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Open heart surgery (for VSD)?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. After heart surgery, suppose the baby developed chronic kidney failure, would you recommend maintenance dialysis?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Suppose the baby was also found to have a heart defect, WOULD YOU RECOMMEND:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Cardiac catheterization—diagnostic procedure?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Open heart surgery (for VSD)?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. After heart surgery, suppose the baby developed chronic kidney failure, would you recommend maintenance dialysis?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The Department of Health and Human Services recently issued a directive stating that hospitals must post signs saying "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by Federal law." No specific guidelines were issued to aid in interpreting the directive. A decision by a Federal district judge struck down the new rule. The Department of Health and Human Services has appealed the decision.

B. IN INTERPRETING THE FEDERAL DIRECTIVE, DO YOU THINK THE FOLLOWING TREATMENTS WOULD BE REQUIRED OR NOT FOR BABY "A"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intravenous feedings</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Surgery to correct the intestinal defect</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Antibiotics</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Cardiac catheterization</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Open heart surgery</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Kidney dialysis</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

C. ON A SCALE FROM 1 (ORDINARY) TO 5 (EXTRAORDINARY), HOW WOULD YOU RATE THE TREATMENTS LISTED ABOVE FOR BABY "A"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>ORDINARY</th>
<th>EXTRAORDINARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intravenous feedings</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>2. Surgery to correct the intestinal defect</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>3. Antibiotics</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>4. Cardiac catheterization</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>5. Open heart surgery</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>6. Kidney dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
QUESTION TWO: THE CASE OF BABY "B"

At birth, Baby "B" is found to be anencephalic (lacking the cerebrum, cerebellum, and the flat bones of the skull), which indicates that the baby could have no upper brain function. Most anencephalic babies die within the first few days of life; all die within the first few weeks.

A. WOULD YOU RECOMMEND:

1. resuscitation—trying to start respiration if the baby isn't breathing—in the delivery room? ................................ 1 2 3 4
2. feeding by mouth if the baby can suck? ................................ 1 2 3 4
3. gavage (tube) feeding if the baby can't suck? ................................ 1 2 3 4
4. antibiotics if it is suspected that the baby also has an infection? ................................ 1 2 3 4

Suppose the baby was also found to have a heart defect, WOULD YOU RECOMMEND:

5. cardiac catheterization—an invasive diagnostic procedure? .......................... 1 2 3 4
6. open heart surgery (for VSD)? ................................ 1 2 3 4
7. an arrest page—restarting the heart if it stops beating ................................ 1 2 3 4

B. IN INTERPRETING THE FEDERAL DIRECTIVE, DO YOU THINK THE FOLLOWING TREATMENTS WOULD BE REQUIRED OR NOT FOR BABY "B"?

1. resuscitation in the delivery room ......................................................... 1 2 3 4
2. feedings by mouth .......................................................... 1 2 3 4
3. tube feedings ............................................. 1 2 3 4
4. antibiotics ............................................. 1 2 3 4
5. cardiac catheterization ............................................. 1 2 3 4
6. open heart surgery ............................................. 1 2 3 4
7. an arrest page ............................................. 1 2 3 4

C. ON A SCALE FROM 1 (ORDINARY) TO 5 (EXTRAORDINARY), HOW WOULD YOU RATE THE TREATMENTS LISTED ABOVE FOR BABY "B"?

1. resuscitation in the delivery room ......................................................... 1 2 3 4 5
2. feedings by mouth .......................................................... 1 2 3 4 5
3. tube feedings ............................................. 1 2 3 4 5
4. antibiotics ............................................. 1 2 3 4 5
5. cardiac catheterization ............................................. 1 2 3 4 5
6. open heart surgery ............................................. 1 2 3 4 5
7. an arrest page ............................................. 1 2 3 4 5

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QUESTION THREE: THE CASE OF BABY "C"

Baby "C" was born with multiple congenital anomalies—low set ears, skin folds around the neck, a cleft palate, and cardiac anomalies—suggestive of trisomy 13, a chromosomal anomaly which is always associated with severe mental retardation and severe physical impairments. Most of these babies die within the first few months, almost all die within the first year. If Baby "C" doesn't have trisomy 13, he may have only correctable physical defects or he may have uncorrectable physical and/or neurological defects.

A. WOULD YOU RECOMMEND:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. resuscitation—trying to start respiration in the delivery room?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. nutrition and fluids?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. putting the baby on a respirator if he can't breathe for himself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. antibiotics, if it is suspected that the baby has an infection?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Now suppose that after resuscitation in the delivery room Baby "C" was breathing on his own and was admitted to the neonatal intensive care unit for evaluation. Two days later, chromosomal analysis indicated that he does indeed have trisomy 13.

B. WOULD YOU RECOMMEND:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. nutrition and fluids?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. surgery to correct the cleft palate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. antibiotics, if it is suspected that the baby has an infection?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. putting the baby on a respirator if he can't breathe for himself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. cardiac catheterization?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. open heart surgery (for VSD)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. an arrest page—restarting the heart if it stops beating?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

B. IN INTERPRETING THE FEDERAL DIRECTIVE, DO YOU THINK THE FOLLOWING TREATMENTS WOULD BE REQUIRED OR NOT FOR BABY "B"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY YES</th>
<th>PROBABLY YES</th>
<th>PROBABLY NO</th>
<th>DEFINITELY NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. resuscitation in the delivery room</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Before chromosomal analysis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. nutrition and fluids</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. respirator</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. antibiotics</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>After chromosomal analysis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. nutrition and fluids</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. surgery to correct the cleft palate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. antibiotics</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. respirator</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. cardiac catheterization</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. open heart surgery</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. an arrest page</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

C. ON A SCALE FROM 1 (ORDINARY) TO 5 (EXTRAORDINARY), HOW WOULD YOU RATE THE TREATMENTS LISTED ABOVE FOR BABY "C"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>ORDINARY</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. resuscitation in the delivery room</td>
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<td>2</td>
</tr>
<tr>
<td>Before chromosomal analysis</td>
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<td>2</td>
</tr>
<tr>
<td>2. nutrition and fluids</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. respirator</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. antibiotics</td>
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<td>2</td>
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<tr>
<td>After chromosomal analysis</td>
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<td>2</td>
</tr>
<tr>
<td>5. nutrition and fluids</td>
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<td>2</td>
</tr>
<tr>
<td>6. surgery to correct the cleft palate</td>
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<td>2</td>
</tr>
<tr>
<td>7. antibiotics</td>
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<td>2</td>
</tr>
<tr>
<td>8. respirator</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. cardiac catheterization</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. open heart surgery</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. an arrest page</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
QUESTION FOUR: THE CASE OF BABY "D"

Baby "D" was born at a gestational age of 25 weeks (15 weeks before the end of a full term pregnancy) weighing 560 gms. (1 lb. 3 oz.). He was born vaginally. His Apgar score at birth was 1—a score which indicated that he had probably suffered from lack of oxygen, his eyes were fused—indicating that he was very premature. He wasn't breathing on his own but did have a slow heart beat.

A. WOULD YOU RECOMMEND:

1. Resuscitation—trying to start respiration—in the delivery room?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

Suppose Baby "D" was resuscitated and put on a respirator? The following day, ultrasound—a diagnostic test—revealed that he had a grade III—IV IVH—a large amount of bleeding in the brain. He therefore has approximately a 50% chance of survival. If he survives, he probably has less than a 50% chance of being normal. Deficits could range from moderate to severe mental retardation and/or neurological impairments (such as cerebral palsy).

WOULD YOU RECOMMEND:

2. increasing respirator settings—giving the baby more oxygen?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

3. nutrition and fluids?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

4. suctioning to remove excess fluid from airways?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

5. pressors—powerful drugs to maintain blood pressure?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

6. an arrest page to restart the heart?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

7. kidney dialysis if the kidneys failed?  
   DEFINITELY PROBABLY PROBABLY DEFINITELY  
   YES YES NO NO

B. IN INTERPRETING THE FEDERAL DIRECTIVE, DO YOU THINK THAT THE FOLLOWING TREATMENTS WOULD BE REQUIRED OR NOT FOR BABY "D"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>DEFINITELY</th>
<th>PROBABLY</th>
<th>PROBABLY</th>
<th>DEFINITELY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. resuscitation in the delivery room</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. increased respirator settings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. nutrition and fluids</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. suctioning</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. pressors</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. an arrest page</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. kidney dialysis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

C. ON A SCALE FROM 1 (ORDINARY) TO 5 (EXTRAORDINARY), HOW WOULD YOU RATE THE TREATMENTS LISTED ABOVE FOR BABY "D"?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>ORDINARY</th>
<th>EXTRAORDINARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. resuscitation in the delivery room</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. increased respirator settings</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. nutrition and fluids</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. pressors</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. an arrest page</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. kidney dialysis</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

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QUESTION FIVE

A. HOW DO YOU THINK THAT DECISIONS ABOUT TREATMENT FOR INDIVIDUAL CATASTROPHICALLY ILL NEWBORNS SHOULD BE MADE? Assume that disagreements could be referred to the Courts. (Please circle the one statement which best describes your view.)

- By the physicians caring for the baby ........................................ 1
- By physicians, nurses, and other professionals caring for the baby ........ 2
- By the baby's parents with the advice of professionals caring for the baby . 3
- By a joint decision by parents and professionals with disagreements referred to a Hospital Ethics Committee .......... 4
- By a Court in all cases .................................................. 5
- No decisions should be made on a case by case basis, all should reflect specific policies ........................................ 6
- Other ___________

(please specify)

B. HOW DO YOU THINK THAT POLICIES SHOULD BE SET REGARDING TREATMENT FOR CATASTROPHICALLY ILL NEWBORNS? (Please circle the one statement which best describes your view.)

- Specific guidelines set by hospital ethics committees ........................................ 1
- Broad guidelines set by hospital Ethics Committee ........................................ 2
- Specific guidelines set by State legislatures ........................................ 3
- Broad guidelines set by State legislatures ........................................ 4
- Specific guidelines set by the Federal Government ........................................ 5
- Broad guidelines set by the Federal Government ........................................ 6
- No policies should be set, all decisions should be made on a case by case basis . 7
- No policies should be set, all newborns should always receive all treatments . 8
- Other ___________

(please specify)

QUESTION SIX

A. WHICH FACTORS DO YOU THINK SHOULD BE IMPORTANT IN MAKING DECISIONS ABOUT WITHHOLDING CARE FROM CATASTROPHICALLY ILL NEWBORNS? (A) Please circle the number corresponding to each factor which you think is important.

- severity of physical impairment ........ 1
- severity of intellectual impairment .... 2
- amount of prolonged pain and suffering .... 3
- capacity to give and receive love .......... 4
- uncertainty about the extent of impairment ........ 5
- impact on parents .................. 6
- impact on siblings ................ 7
- ability of parents to have other healthy children .......... 8
- financial burden to family ........... 9
- parents' wishes ................... 10
- if treatments are heroic ................ 11
- if chance of successful treatment is small ........ 12
- feelings of staff caring for baby ........ 13
- if treatments are already started ........ 14
- if non-treatment would be active euthanasia .......... 15
- cost of neonatal intensive care .......... 16
- long term costs of caring for disabled child and adult ........ 17
- availability of resources for other sick children .......... 18
- availability of resources for other medical care .. 19
- danger of lessening the "value of life" .......... 20
- availability of resources for other, non-medical, social needs .......... 21
- Other (please specify) ................ 22

B. Please list the numbers of the three factors (listed above) which you think are most important.

number: ........................ number: ........................ number: ........................
(most important) (2nd most important) (3rd most important)
QUESTION SEVEN

UNDER CURRENT LAWS, AN ABORTION MAY BE PERFORMED FOR ANY INDICATION UNTIL THE 24TH WEEK OF GESTATION. AFTER THE 24TH WEEK, ABORTION IS ILLEGAL. DO YOU THINK THAT ABORTION SHOULD BE LEGAL FOR THE FOLLOWING INDICATIONS? If so, circle "YES" and indicate up to which week following the last menstrual period an induced termination of pregnancy should be legal. If not, circle "NO." Please give an answer for each indication.

1. contraceptive failure ..................................... YES _____ wks. NO
2. economic hardship ......................................... YES _____ wks. NO
3. unmarried mother ........................................... YES _____ wks. NO
4. rape ........................................................... YES _____ wks. NO
5. incest .......................................................... YES _____ wks. NO
6. risk to mother's psychological health (eg. severe depression) .......................................................... YES _____ wks. NO
7. risk to mother's physical health (eg. uncontrolled diabetes) .......................................................... YES _____ wks. NO
8. risk to mother's life (eg. eclampsia) .......................................................... YES _____ wks. NO
9. prenatal diagnosis of:
   a. baby of the undesired sex .................................. YES _____ wks. NO
   b. Down's syndrome (see quest. 1) .......................... YES _____ wks. NO
   c. encephaly (see quest. 2) .................................. YES _____ wks. NO
   d. trisomy 13 (see quest. 3) .................................. YES _____ wks. NO
   e. bilateral polycystic kidneys—a lethal condition involving non-functioning kidneys .......................... YES _____ wks. NO
   f. thoracic spina bifida—physical defect involving paraplegia and incontinence of urine and stool YES _____ wks. NO

PLEASE CONTINUE ON NEXT PAGE

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FINALLY, A FEW QUESTIONS ABOUT YOUR BACKGROUND: (please be specific)

1. OCCUPATION: ____________________________________________________________

2. TITLE OF POSITION: _____________________________________________________

3. SPECIALTY: _____________________________________________________________

4. SEX: (Please circle) M F

5. AGE: __________

6. DO YOU HAVE CHILDREN? (Please circle) YES NO

7. EDUCATIONAL DEGREE(S) AND SPECIALTY TRAINING (Please specify fields and dates.)

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

8. HOW LONG HAVE YOU WORKED IN A NEONATAL INTENSIVE CARE UNIT? (please count rotations by month)

   never .....................................................  1
   under 3 months ......................  2
   3 months- 1 year ..................  3
   1-3 years ..............................  4
   3-5 years ..............................  5
   5-10 years .........................  6
   10-15 years ......................  7
   over 15 years ....................  8

9. HAVE YOU WORKED IN A RELATED AREA (e.g. obstetrics, pediatrics)?

   never .....................................................  1
   under 3 months ......................  2
   3 months-1 year ..................  3
   1-3 years ..............................  4
   3-5 years ..............................  5
   5-10 years .........................  6
   10-15 years ......................  7
   over 15 years ....................  8

10. IF THE ANSWER TO QUESTION 9 is 2-8, PLEASE SPECIFY AREA

   ____________________________________________________________

11. HAVE YOU HAD ANY PERSONAL EXPERIENCE WITH CATASTROPHICALLY ILL NEWBORNS?

    (Please circle) NO YES (If so, please describe briefly)

PLEASE CONTINUE ON NEXT PAGE
BACKGROUND QUESTIONS (Continued)

12. RELIGION:
   A. Protestant ____________ (denomination) ........................................ 1
   Catholic ........................................ 2
   Jewish: Orthodox, Conservative or Reform ............................................... 3
   None ........................................... 4
   Other Please specify ................................................................................. 5

B. DO YOU CONSIDER YOURSELF (please circle):
   deeply religious .......................................................... 1
   moderately religious ......................................................... 2
   largely indifferent to religion ............................................. 3
   basically opposed to religion ............................................. 4

13. IN YOUR POLITICAL VIEWS, DO YOU CONSIDER YOURSELF (please circle):
   radical left .............................................................. 1
   liberal ................................................................. 2
   middle-of-the road ......................................................... 3
   conservative ............................................................ 4
   radical right ...................................................................... 5

14. HAVE YOU RETURNED ANY OTHER QUESTIONNAIRES WHICH WERE PART OF THIS STUDY?
   (please circle appropriate nos.)
   distributed in the unit, Spring 1981 ............................................. 1
   distributed to 1st year residents, July 1981* ........................................ 2
   distributed in the unit, April 1983 ..................................................... 3
   distributed at the "Which Babies Shall Live" conference, April 1983 ......... 4
   distributed at Arden House, April, 1983 ............................................. 5
   No ......................................................................................... 6

15. ARE THERE ANY COMMENTS THAT YOU WOULD LIKE TO MAKE?
   (If any of the questions were particularly difficult to answer, please indicate which ones
   and why.)

Thank you very much for your cooperation.

*also distributed to new nurses and fellows.