

Introduction

The Dilemmas and Their Dimensions

The visitor who enters an intensive-care unit for newborn infants for the first time may have what seems to be a surrealistic encounter with the twenty-first century. The diffuse din of the monitors, the many incubators and intravenous lines, the eerie glow of the ultraviolet lights used to combat jaundice—all the elaborate machinery of the nursery provides a stark contrast to its tiny patients. Next to each incubator stands a nurse who, from time to time, may reach into the porthole to administer medications or take vital signs. At least twice a day, an entourage of physicians stops by each incubator as they make their daily rounds. A group of doctors and nurses may enter the nursery, moving rapidly to bring in a new patient who may have been transported by plane from the hinterland.

The newborn intensive-care unit stands as a monument to science and technology, a living testament to the vast resources that our society has committed to saving life at its beginning. There are, however, times in the social life of the intensive-care nursery when neonatal intensive care may seem less a symbol of progress than a confrontation with the problematic. These moments occur when parents and health professionals, faced with an infant who is terminally ill or who may survive with serious disabilities, must decide whether the infant will live or die. These life-and-death decisions are the subject of this book.

NEONATAL INTENSIVE CARE

Until very recently, this subject would not have been studied at all, for newborn intensive-care units did not always exist. Neonatal intensive

care is a nascent specialization in medicine and nursing that has developed rapidly over the past three decades. The ever-widening knowledge base of perinatal research, coupled with a sophisticated technology, has dramatically advanced the care of seriously ill newborn infants. In 1976, it was estimated that there were twenty newborn intensive-care units in California alone. In 1980, the number of hospitals in the United States having neonatal intensive-care units was estimated to be about six hundred. Each year, approximately two hundred thousand infants, or about 6 percent of all live births, are sufficiently ill to require intensive care.¹

Neonatal intensive care has been directed toward infants with an array of problems. Conditions associated with prematurity, such as respiratory distress syndrome (also called hyaline membrane disease), are the most common reason for hospitalization in an intensive-care nursery. The second largest group of patients is those with congenital anomalies (e.g., congenital heart disease) that require immediate treatment.² However, infants having a number of other serious problems find their way into the newborn intensive-care unit—including, for example, infants born to diabetic or drug-addicted mothers, those born to Rh-negative mothers with increasing quantities of Rh antibodies in their blood, and those suffering from gastrointestinal disorders or generalized infections.³

Since their inception, the technologies of neonatal intensive care have increased in both scope and sophistication. Some of the innovations that have been introduced include devices for monitoring blood gases and blood chemistry as well as techniques for continuously monitoring heart rate and rhythm, breathing rate, and blood pressure. Some diagnostic techniques used for adults, such as CAT scans (brain scans) and cardiac catheterization, are now used for newborn infants as well. Therapeutic technologies include respirators and positive pressure ventilators to treat respiratory problems, phototherapy and exchange blood transfusions to treat jaundice, and intravenous hyperalimentation, a technique for providing nutrition to very sick infants.⁴ Although it is difficult to evaluate the precise contribution of advances in neonatal intensive care to changes in mortality and morbidity,⁵ available data suggest they have played a major role in reducing mortality among critically ill newborn infants.⁶ The long-term outlook for very small, very premature infants, however, is still being evaluated and is the subject of considerable debate.⁷

Although neonatal intensive care is a recent phenomenon, some

technologies for the treatment of sick newborn infants have been in existence for some time. A historical perspective illustrates the radical reorientation that has occurred in the treatment of sick newborns. At the turn of the century, most premature infants died during the first hours of life.⁸ The first incubator, or “warming chamber,” was developed by Dr. E. S. Tarnier in 1878. Dr. Pierre-Constant Budin, who was later to write the first textbook on neonatology, displayed his “child hatchery,” consisting of six premature babies in incubators, at the 1896 Berlin Exposition, in order to attract attention to the techniques that he and Tarnier had developed. This type of equipment was publicized in the United States by Dr. Martin Couney, who exhibited premature “incubator babies” at international fairs and ultimately reared five thousand infants on Coney Island. Eventually, the incubator became a standard feature in the care of critically ill premature infants.⁹

By 1923, when the first American hospital for sick newborns was established, childbirth had already been transformed from a natural, family event to a medical and hospital-centered event.¹⁰ Care of the sick newborn infant became the province of the obstetrician or the family doctor. The approach to newborn infants remained largely noninterventionist. Throughout the first half of the twentieth century, those infants who were considered too young or too sick to benefit from existing therapies were not seen as viable and were simply not treated. In the early and middle 1960s, as intensive-care techniques were developed and as a number of pediatricians began to specialize in the care of high-risk infants, the number of infants who could be treated increased significantly, and the horizons of viability expanded. The development of neonatal intensive care, then, signaled a dramatic transformation to a treatment philosophy of active, aggressive intervention.

LIFE-AND-DEATH DECISIONS

Neonatal intensive care represents a triumph of sophisticated medical technology. At the same time, however, a number of difficult ethical dilemmas have appeared in its wake. Improved medical management and surgical techniques have made it possible to save the lives of many infants who previously would not have survived. Among them are infants who may survive with serious physical or mental disabilities and who may require numerous medical and surgical treatments.

Consequently, many physicians, bioethicists, and parents have asked whether it is always appropriate to try to sustain the lives of these infants.

Consider, for example, three of the better-known dilemmas. Among the most controversial life-and-death decisions are those concerning infants with Down syndrome, a genetic defect accompanied by mild to moderate mental retardation. Thirty years ago, infants with Down syndrome who also had intestinal defects died in infancy, but pediatric surgery to correct these defects has now become routine. Is it right to withhold life-saving surgery from an infant who will be mentally retarded?

Spina bifida (incomplete development of the spinal column) is among the more serious of birth defects. It is often accompanied by hydrocephalus, or an abnormal accumulation of fluid in the brain. The development of the shunt in 1958 made it possible to control hydrocephalus, and refined surgical techniques made it possible to close the spinal lesion. While some children with spina bifida may have normal intelligence, those who are most severely affected are likely to be paralyzed and incontinent and to require numerous surgeries. Is it right to withhold surgery from these infants?

A third example concerns infants who are on the frontiers of viability. Neonatology has made it possible to resuscitate infants who weigh as little as one pound and who are born three months prematurely. Many of these infants die, and those who live risk damage to major organ systems, including brain damage. While these smallest of infants constitute only a tiny fraction of babies in the neonatal intensive-care unit, their costly care consumes a disproportionate share of the nursery's economic resources.¹¹ Is it right to resuscitate infants who may have only a slight chance for normal survival? Is it right to decide, as has been done in other countries, that treatment of some infants is too costly?¹²

Each of these dilemmas poses the hard question of whether what *can* be done *should* be done and calls into question the basic principle on which neonatal intensive care is premised: that of active, aggressive intervention. Each case raises serious questions about the price of medical progress and illustrates how medical decision making has been expanded to embrace judgments about the kind of life that is desirable. Among other issues, the first case raises the question of whether a decision to withhold therapy should be made on the basis of mental retardation. The second dilemma is sometimes character-

ized as a conflict between the principles of preserving life and preventing suffering. The third case raises an additional question that typifies neonatal intensive care: what to do in the absence of sound information concerning the future of an infant whose life is in question.

Life-and-death decisions may arise at any point during an infant's stay in an intensive-care nursery. They include decisions to resuscitate an infant at the moment of birth, decisions to undertake medical or surgical procedures, decisions to terminate life support (e.g., to "disconnect" respirators), and decisions to resuscitate an infant whose heart has stopped beating or who has stopped breathing ("code/no-code" decisions). These decisions are not merely objects of theoretical concern but are actual dilemmas frequently faced by parents and health professionals. The accounts of physicians, journalists, ethicists, and social scientists suggest that these life-and-death decisions are being made in intensive-care nurseries throughout the country.¹³

The question of which infants should receive aggressive treatment raises an array of difficult issues of policy and morality. What criteria should be used to determine when to resuscitate or provide life support for infants who may be terminally ill or severely damaged? Who should be the final arbitrator of such decisions? Can these infants be said to possess a "right to life" or a "right to die"? How can one impute rights to or determine what is in the best interests of those unable to speak for themselves? These decisions involve what Guido Calabresi and Philip Bobbitt call "tragic choices," or decisions made in the face of conflicting values.¹⁴ Inevitably, life-and-death decisions involve judgments about the kinds of lives that are worth saving—and, by implication, the kinds of lives that are not worth saving.

WHY STUDY THIS SUBJECT?

A very rough measure of the importance that our society attaches to life-and-death decisions in the nursery is the sheer number of publications about this subject. Yet a quick glance at the vast literature that has appeared in the past two decades reveals a glaring paradox. It is hard to imagine a topic about which so much has been written, yet so little is actually known. In the past decade, at least seven books by legal scholars, journalists, and social scientists have been published. At least two books and more than a hundred articles have been written about the ethics of newborn intensive care. Because the law has failed to provide clear guidelines for life-and-death decisions, legal

scholars have debated whether these decisions are permissible, and their opinions differ dramatically.¹⁵ If, on the one hand, we are to believe legal scholar John Robertson, those who make some life-and-death decisions face potential charges of homicide by omission. If, on the other hand, we are to believe Elizabeth MacMillan, decisions not to treat infants with the severest mental disabilities, who are unable to survive infancy, can be made with impunity.¹⁶

Ethical and legal discussions of neonatal intensive care are often prescriptive—that is, they tell us how decisions should or should not be made. Yet we know surprisingly little about how life-and-death decisions actually *are* made. Joel Frader, a physician who has written about decisions in the nursery, commented that after more than two decades of research on this subject, we still do not know the dimensions of the problem, or, as physicians say, its incidence or prevalence.¹⁷ Much of the information we do have about life-and-death decisions is indirect and comes from three sources: surveys of physician attitudes, reports of individual nurseries, and well-publicized legal cases.

One source of information about how physicians *think* about life-and-death decisions comes from attitude surveys, in which pediatricians are asked how actively they would treat infants with a number of physical or mental disabilities. Although these surveys ask different questions, a common pattern can be discerned. The vast majority of physicians say they would not treat infants with the severest defects, who could not survive infancy and would be seriously retarded. Responses in the 1970s were divided on the question of treating infants who would survive with physical and mental disabilities—that is, babies with Down syndrome or spina bifida. Most pediatricians surveyed in the 1980s, however, seem reluctant to let these babies die.¹⁸ While highly informative about the beliefs and values of physicians, these attitude surveys do not tell us what physicians *do* in actual practice.

Another piece of evidence comes from a few published reports of the practices of individual nurseries. During the early 1970s, several physicians began to report their policies for making life-and-death decisions in professional journals. One of the first published reports appeared in 1973 in the *New England Journal of Medicine*. In this article, pediatricians Raymond Duff and A. G. M. Campbell reported that they had withheld life-saving treatment from 14 percent of the 299 infants who had died in the Yale–New Haven Nursery. In a

companion article in the same issue, pediatric surgeon Anthony Shaw described actual cases in which he and the parents had decided not to treat several infants with physical or mental disabilities. Dramatically different from the practices of the Yale–New Haven Nursery is the reported policy of Children’s Hospital in Philadelphia, under the leadership of former Surgeon General C. Everett Koop, in which all infants—including those with very serious mental and physical disabilities—are treated very actively.¹⁹ These isolated reports, however, can hardly be taken as representative of decisions made in nurseries throughout the country.

A third source of information is the body of legal cases that have been publicized in the media. The inconsistent rulings in these cases suggest that our society is deeply divided about decisions in the nursery. For example, a 1974 decision, *Maine Medical Center v. Houle*, involved an infant who was born blind and had some brain damage and multiple physical malformations, including one defect that could be repaired surgically, a tracheoesophageal fistula. Unless the defect was repaired, the infant would not survive. Although both the parents and the physicians argued against performing the surgery, the court held that the surgery should be performed because it was medically feasible. The Mueller case in Danville, Illinois, involved Siamese twins who were joined with a single trunk and had three legs. Nurses were told not to feed the twins. An investigation began when an anonymous caller informed the Illinois Department of Children and Family Services that the twins were being neglected. The district attorney filed criminal charges against the parents and the physician, which were ultimately dropped for lack of evidence when the nurses refused to testify against the parents and physician.²⁰

Nowhere are the deep divisions and ambivalence in our society more apparent than in the well-known Baby Doe cases, which have been discussed extensively by ethicists and legal scholars.²¹ In 1983, in Bloomington, Indiana, an infant was born with Down syndrome and an obstruction of the throat. Although the parents decided against performing surgery—that is, to let the baby die—some hospital physicians took the case to court. The Indiana Supreme Court ruled in favor of the parents, but the case came to the attention of the Reagan administration. Baby John Doe died before action could be taken. On October 11, 1982, the infant known as Baby Jane Doe was born with spina bifida, hydrocephalus, and microcephaly (an abnormally small head). Although the parents decided against surgery, a pro-life attor-

ney mounted a challenge to this decision in the courts. New York's Court of Appeals upheld a lower court's ruling that the parents had a right to make the decision.

In the Baby Doe cases, for the first time, decisions in the nursery became a public issue. Pro-life activists, disability rights groups, the medical profession, and the Reagan administration became embroiled in a national debate. The cases also signify a growing trend toward state involvement in medical decisions.²² President Reagan directed Secretary of Health and Human Services Richard Schweiker to draft a series of regulations forbidding nurseries from withholding food, water, or medical treatment from disabled infants. Outraged by these regulations, the American Hospital Association, the American Medical Association, and the American Academy of Pediatrics mounted legal challenges to the policies of the Reagan administration. The Baby Doe rules were finally struck down in the U.S. Supreme Court.

In 1985, three years after the death of Baby John Doe, Congress passed Public Law 98-457, which requires state child-welfare agencies to investigate cases of "medical neglect," defined as withholding medically indicated treatment from critically ill infants. Carefully crafted in response to the competing demands of disability rights organizations, the American Academy of Pediatrics, and pro-life groups, the Child Abuse Amendments and the Department of Health and Human Services rules to implement them were viewed by some as a compromise. Nevertheless, the amendments and the rules continued to mandate aggressive intervention for almost all infants.²³

However dramatic these cases may be and however great their impact on public policy, it is difficult to view them as typical of life-and-death decisions in nurseries throughout the country. In fact, there is reason to believe that these cases are *atypical*. Despite the widespread attention given these cases, most life-and-death decisions do not concern infants with Down syndrome or spina bifida. Rather, they concern low-birthweight infants who pose dilemmas that are not well publicized. Moreover, despite the Reagan administration's concern about the medical neglect of disabled infants, one study of actual life-and-death decisions suggests that many infants are in fact over-treated rather than undertreated.²⁴

In short, pediatricians have openly acknowledged that life-and-death decisions *are* being made; bioethicists have discussed the ways they *should* be made; jurists have discussed the ways they should *not* be made; physicians and sociologists have surveyed the array of physi-

cian attitudes toward them; and social scientists have discussed how life-and-death decisions are made in some settings.²⁵ Yet there remains a curious imbalance in the literature: we still know far more about how people think life-and-death decisions *should* be made than how they actually are made. We also know more about the decisions of physicians than those of nurses, and we know still less about the role of parents in life-and-death decisions.

THE STUDY AND RESEARCH DESIGN: AN OVERVIEW

Much remains to be learned about how physicians, nurses, and parents actually make life-and-death decisions in the nursery. For this reason, this research had three major objectives: first, to identify the major *criteria* parents and professionals use in making life-and-death decisions; second, to examine the decision-making *process*, or how participants communicate to arrive at life-and-death decisions; and third, to explore the influence of the hospital setting and the wider social and historical *context* on life-and-death decisions. Communication and context can best be studied by observing decisions directly, spending time in the nursery, and discovering the concerns of those who work in it. Because they allow the researcher to observe decisions as they are made, field research methods (participant-observation and interviewing) are ideally suited to studying the decision-making process and its social context.

This book is based on data collected in the course of sixteen months of field research in the intensive-care nurseries of two hospitals. I spent twelve months in the setting I call Randolph Hospital. Located in a demographically heterogeneous section of a large urban area, the Henry Maynard Randolph Hospital is part of a major medical school, is closely affiliated with a major university, and is commonly recognized as an elite institution.

The reputation of Randolph Hospital seems to permeate the entire institution. If neonatology may be characterized as medicine on the frontier, the Randolph Intensive-Care Nursery may be said to be on the frontier of that frontier. Several of its attending physicians are pioneers in the field, and discoveries made at the Randolph Nursery have become standard features in the armamentarium of contemporary neonatology.

The prestige of the nursery is apparent throughout its organizational hierarchy. At the top of this hierarchy are the nursery's five

attending physicians, all of whom hold full-time university faculty appointments. Scientists as well as clinicians, the attending physicians alternate their clinical responsibilities in the nursery with research and teaching. During the months they are in charge of the nursery, the attendings (as they are called for short) are formally and legally responsible for all decisions concerning medical management, including life-and-death decisions.

Next in line are the five neonatology fellows, who have completed pediatric residencies and are training to become subspecialists in neonatology. During their rotations in the nursery, fellows perform a teaching and administrative role and are responsible for the nursery in the attendings' absence.

Routine clinical decisions and most diagnostic and therapeutic procedures are the responsibility of the pediatric residents and interns who rotate through the nursery. Admission to the pediatric residency program at Randolph is highly competitive, and most residents have trained at prestigious medical schools. Rotations in the intensive-care nursery are considered an important part of the clinical training of pediatric residents, who are required to complete at least four nursery rotations. The nursery rotations at Randolph are also considered to be among the most demanding, with the heaviest night-call schedules. Although staffing patterns vary considerably, the usual complement of physicians includes the attending physician, three residents, three interns, and, on occasion, one or two medical students.

The Randolph Nursery also employs one full-time and one part-time social worker, who help parents apply for insurance coverage and are formally charged with meeting the various "socio-emotional needs" of the families. The social workers conduct support groups with the parents, arrange for conferences with parents whose babies have died, and lead weekly social service rounds in which the nursery staff exchange information about the families.

Among the most important staff members are the forty-five to fifty intensive-care nurses (including two head nurses and a senior staff nurse). The nurses perform the critical functions of monitoring changes in infants' medical conditions and assisting in resuscitations. Randolph nurses actually perform some procedures usually done by interns, such as changing respirator settings. Like social workers, nurses maintain close contact with the families. Intensive-care nursing demands a high level of knowledge and technical skill and, for this reason, is often viewed as the vanguard of nursing specializations.

Even by the standards of intensive-care nurseries, the Randolph nurses are a highly educated group: all but one are registered nurses (R.N.s), and more than two-thirds hold baccalaureate (B.S.N.) nursing degrees.

The Randolph Nursery occupies one wing of a floor shared with the obstetrical delivery service. The domain of the nursery actually reaches to the "set-up room," located adjacent to the delivery room, which is equipped with sophisticated machinery designed to facilitate the immediate resuscitation of infants distressed at birth. The nursery itself, which has a bed capacity of twenty-two, is divided into three areas, each corresponding to a different intensity of care. The "high-intensive" room accommodates up to six of the most critically ill infants. Most of the babies are on respirators, in incubators, and require frequent biochemical tests to monitor changes in their precarious respiratory function. In the "low-intensive" room, some of the infants require some form of respiratory assistance but need less intensive monitoring. In the "intermediate-care" room, one can already begin to witness some perceptible signs of recovery: many of the infants are able to breathe with minimal or no assistance, and many have begun to feed on their own. Those patients who are no longer critically ill are sent to the "admit-recovery" area of the well baby nursery, where the nursery's physicians continue to follow them.

As one proceeds from room to room, the level of monitoring decreases, and the nurse-patient ratio decreases accordingly. For example, the nurse-patient ratio decreases from 1:1 in the high-intensive room to 1:6 in the intermediate-care room. In addition, the nursery includes a small isolation area for babies with infectious diseases, an office used by the head nurse, a tiny breast-feeding room, and a conference room. Ironically, the prestige of the Randolph Nursery is not reflected in its physical plant, for the nursery is plagued by the problems that attend a chronic lack of space. Physicians frequently find it difficult to locate an area in which they can confer privately with parents.

In 1968, following statewide regionalization of services for the newborn, the Randolph Nursery became a major referral center for a geographic area that spans half the state. Thus, the approximately 480 infants admitted annually to Randolph enter the nursery via two paths. About half are "inborn admissions," delivered in the hospital's obstetrical service, whose medical conditions range from the most routine to the most complex. The others are "outborn admissions,"

some born in nearby hospitals, others transported by ambulance or plane from outlying areas.

The patients who are outborn admissions fall into three major categories. First are those referred to the Randolph Nursery for critical care by secondary-care facilities that lack the requisite support technologies to treat these infants. The conditions of these infants range from “simple” respiratory distress syndrome to birth asphyxia or congenital anomalies. Second are infants referred for diagnostic procedures (e.g., cardiac catheterization) or evaluation by pediatric subspecialists. Third are those referred for pediatric surgical procedures that cannot be performed elsewhere. Many of these infants have congenital anomalies (e.g., intestinal malformations and heart defects) that require surgical repair.

In the past few years, with the proliferation of nurseries that are able to provide critical care (tertiary-care facilities), the Randolph Nursery no longer enjoys undisputed hegemony over referrals, and competition for patients among tertiary-care nurseries in the region has become rather intense. Consequently, the nursery’s attending neonatologists have developed a complex web of delicate diplomatic ties with the hospital’s pediatric surgeons (who perform procedures that can be done in few other hospitals) and pediatricians in the nurseries located in outlying areas (on whom the Randolph Nursery depends for referrals). It is also significant that there are considerable fluctuations in the Randolph Nursery census. In the winter months, the nursery depends largely on referrals from other hospitals, whereas in the summer months, the rate of inborn admissions rises, and some infants from other hospitals must be turned away.

Because the Randolph Nursery serves a wide-ranging geographic area, parents of sick newborns are an ethnically, economically, and occupationally diverse group: migrant farmworkers from rural areas, farmers and carpenters from the mountainous woodlands, physicians, psychologists, and other professionals, and parents from the urban ghettos. This diverse distribution creates a checkered pattern of financing. In the Randolph Nursery, services are financed through a combination of private insurance, Crippled Children’s Services, and Medicaid. Owing to the state’s rather ample financing of neonatal care through Crippled Children’s Services at the time this study was conducted, most parents found that their babies’ care in the nursery was financed by one or more of these third parties, although occasional—and very unfortunate—lapses did occur.

To provide a comparison, I conducted four months of fieldwork in the Special Care Nursery of General Hospital, a setting that contrasts sharply with Randolph in terms of its size and the social class composition of its patients. Located in another region of the same state, General Hospital is a large (over a thousand beds) acute-care hospital for the indigent, financed by a combination of federal, state, and local funds. Like Randolph, General Hospital is closely affiliated with a large medical school and serves as a teaching institution for medical students, residents, and nurses. It is situated in a poor area (although by no means the poorest) of a large metropolis. Like other public hospitals for the indigent, General Hospital's adult services suffer from overcrowding and an almost chronic lack of funds caused by the capricious vagaries of government financing. Residents who had completed their medical training at General related bleak anecdotes of adult patients overflowing into the halls of the wards.

The Special Care Nursery at General provides a striking contrast to the conditions that often obtain elsewhere in the hospital. It is located in one of the newer wings, which it shares with the obstetrical and gynecology service. It is equipped with the most up-to-date technology, and its parent conference room is spacious and well furnished. The nursery's attending neonatologists are actively engaged in research, some have national reputations, and all are closely involved in direct supervision and teaching. Perhaps the reputation of the head of the nursery, the sheer size of the nursery's patient population, and the steady influx of third-party payments spare the nursery from many of the pervasive problems that plague the adult services. However, even the Special Care Nursery is not impervious to the problems created by the formidable task of caring for large blocs of patients who are separated from the staff by the barriers of language and social class.

The obstetrical service at General Hospital is one of the nation's largest, having a delivery rate of approximately fifty live births each day (eighteen thousand annually). Presumably because of the association between high-risk pregnancies and poverty, many of these infants find their way into the Special Care Nursery, which is extremely large (forty to fifty beds). In contrast to the Randolph Nursery, virtually all the infants who enter the General Nursery are inborn admissions, delivered in the hospital's own obstetrical service. Faced with a volume of patients that already strains its bed capacity to the limits, the nursery cannot accept infants referred from other hospitals. This leads to one of the more fundamental and recurrent dilemmas that confront

the General Nursery staff. Owing largely to a critical shortage of highly trained nurses in the area, the General Nursery can accommodate only five infants who require intensive care (i.e., who must be placed on respirators). So while the total bed capacity of the General Nursery is nearly twice that of the Randolph Nursery, the General Nursery has fewer than half the number of intensive-care beds. Faced with an unremitting pressure upon a limited number of intensive-care beds, the staff must make frequent triage decisions to transfer critically ill babies to other tertiary-care facilities in the region. Thus, the General Nursery is not a referral center, and the admission patterns and triage dilemmas that confront its staff differ dramatically from those at Randolph Hospital.

Babies are delivered in General's third-floor obstetrical service, and if they are deemed sufficiently ill to require additional care, they are admitted to one of three nurseries. The Newborn Intensive Care Unit (known as the NICU) has a bed capacity of five, maintains a 1:1 nurse-patient ratio, and is designed to accommodate those infants who are most critically ill. In the same large room is the Acute Care Nursery, designed for the care of twelve infants who no longer require ventilatory assistance (respirators). Separated by a hallway and a conference room is the Convalescent Care Nursery, which accommodates twenty-four infants who require the least intensive monitoring and care. As in the Randolph Nursery, the nurse-patient ratio decreases in each of the nurseries with the decreased intensity of the care provided. However, in contrast to the Randolph Nursery, each of the General nurseries constitutes an administratively separate unit. Although all are under the authority of the head of the nursery, each maintains a separate nursing staff with its own head nurse. In any given month, the medical staff of the NICU includes one full-time faculty member, one fellow, and two residents (interns do not rotate through the NICU). The Acute Care and Convalescent Care nurseries are managed by two large medical teams, each of which includes an attending, a fellow, three residents, and four to six interns (usually including two obstetrical interns). Because the nurseries are divided administratively, the continuity of care is sometimes compromised; as the babies recover, their parents are confronted with not only a changing cast of physicians, but an entirely new group of nurses as well.

Although the formal occupational hierarchies are identical in both nurseries, the staffing patterns in the General Nursery are somewhat more complex. In addition to the neonatologist who is the head of the

nursery, the medical staff includes seven neonatologists who are members of the faculty. Five full-time faculty members head the NICU. However, because of the sheer volume of the patient population, the Acute Care and Convalescent Care nurseries are sometimes staffed by “outside attendings,” neonatologists in the community who serve the nursery on a part-time basis. In addition to the residents who rotate through the nursery, there are five neonatology fellows, who tend to be quite closely involved in patient care. The nursery also maintains a program for training respiratory therapists, who are considered members of the “health care team.” They participate actively in rounds and occasionally in life-and-death decisions.

The full-time nursing staff includes seventy-four nurses and three head nurses. All of the nurses who work in the NICU and all but one of the nurses in the Acute Care Nursery are registered nurses, many of whom have completed their training in the hospital’s three-year diplomate nursing program. The NICU nurses have also completed a special program for critical-care nursing. However, of the thirty-two nurses who work in the Convalescent Care Nursery, more than half are licensed vocational nurses, and three are nursing assistants.

The staff of the nursery also includes one full-time social worker, a part-time social worker, and a full-time discharge planning nurse, who communicate and work with the families. Like the Randolph Nursery, the General Nursery has developed a set of procedures to mitigate some of the potentially disruptive consequences of neonatal intensive care for the families of critically ill infants. While the Randolph Nursery conducts parent support groups and conferences for parents whose babies have died, the General Nursery has developed the concept of discharge planning. A discharge planning team, consisting of a neonatologist, the social workers, the head nurses, and the discharge planning nurse holds weekly meetings and helps families plan for the future care of their babies.

Perhaps the most significant distinction between the two nurseries is to be found in the social class and ethnic composition of their patient populations. All the parents in the General Nursery are poor, and approximately 90 percent are Hispanic. Consequently, care in the General Nursery is financed almost exclusively through Medicaid and Crippled Children’s Services. However, some of the parents are undocumented workers, who are occasionally reluctant to apply for funds that may in their view jeopardize their chances for attaining permanent residency and lead to detection by immigration authori-

ties. One of the major dilemmas of the General Nursery is the communication barrier between the many parents who do not speak English and the many attendings, residents, and nurses who are conversant only with the rudiments of “hospital Spanish.” Thus, members of the nursery staff rely heavily on the social worker, who also serves as an interpreter and participates in most of the conferences between staff and parents, including those in which life-and-death decisions are made.

I intentionally selected the Randolph and General nurseries to provide maximum contrast along the dimensions of size, referral patterns, and clientele. Each of these characteristics has a discernible effect on the life-and-death decisions made in both nurseries. I selected more than one setting to approximate a natural experiment that could illuminate the influence of specific features of each organization upon life-and-death decisions. Undertaking fieldwork in more than one setting enabled me to distinguish aspects of decision making that are unique in each nursery from those that are common to both and, in so doing, enhanced the generality of my conclusions.

The reader may ask—and with considerable justification—whether the nurseries that were studied are typical or representative of other newborn intensive-care units. Both the Randolph and General nurseries are variants of one type of newborn intensive-care unit: tertiary-care centers in teaching hospitals located in urban areas. It is reasonable to assume that the life-and-death decisions made in these nurseries would differ from, for example, those made in certain religious hospitals or in small secondary-care facilities located in rural areas. For example, secondary-care facilities characteristically do not face the dilemma of whether to remove infants from respirators (since their patients usually are not receiving ventilatory assistance). Instead, they confront the dilemmas of whether infants should be resuscitated, certain forms of care should be initiated, or patients should be transported to larger referral centers.

The professionals who work in the nurseries I studied probably exhibit more “permissive” attitudes toward nontreatment decisions than those in hospitals subject to close scrutiny or tight controls by religious groups or local communities. By the same token, smaller community hospitals might allow more latitude for negotiation between parents and family physicians than might obtain in teaching hospitals, in which the relationship between parents and physicians is apt to be more impersonal. However, it is significant that most new-