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The Principles for Family-Centered Neonatal Care

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As the author of *The Premature Baby Book* (St Martin's Press, 1983), I have received hundreds of letters and telephone calls over the past decade from parents of babies treated in neonatal intensive care units (NICUs). Many of these parents express unqualified gratitude for the skilled staff and new technologies that saved the lives of their children. Others, however, voice concern, even anguish, over the way they and their babies were treated in the NICU. These parents tell of difficulties obtaining accurate information about their babies' conditions, treatments, and prognoses; of parental exclusion from medical and ethical decision-making; of the overtreatment of marginally viable babies and the undertreatment of babies' pain; of concerns about the relentless nursery environment and the use of poorly validated therapies; of unnecessary impediments to the nursing and nurturing of babies in the NICU; and of frustration over inadequate discharge planning, follow-up, and services for NICU survivors.⁴⁻¹⁶

In 1991 I sent some letters and articles that I had received from these parents to Dr Jerold Lucey, Editor of *Pediatrics*. Dr Lucey immediately proposed that the two of us convene a conference in which a small group of parents and physicians could discuss the problems described by parents and explore possible solutions.

At Dr Lucey's request, I assembled a group of articulate parents who were knowledgeable about the NICU from personal experience and from their work in support organizations, disability rights groups, and hospital ethics committees. Because I wanted a group that would be sympathetic to the concerns of medical professionals, I made an effort to choose parents with a background in health care or with a spouse or close family member in the medical profession.

The 10 parents who agreed to serve as conference participants had a total of 32 children, 20 of whom were born prematurely. Four of the babies died in the NICU. One died of a prematurity-related condition in mid-childhood. Of the surviving prematurely born children, 9 are normal or have only mild problems such as learning disabilities. Seven have moderate to severe handicaps. Most of the parent participants had at least 1 child who was "marginally viable" at birth and for whom ethical decision-making was (or should have been) an issue. Some of the parents had extremely difficult relationships with nursery staff. Others, including myself, left the NICU on good terms with our babies' caregivers. All of us, however, share the belief that parents should be able to participate more fully in caring for and making decisions for their hospitalized newborns. We also believe that consumers, working in collaboration with professionals, can exert a powerful positive influence on the provision of medical care.

To prepare for the conference, which was held June 27 through 29, 1992, in Burlington, VT, the parents composed a draft of "The Principles for Family-Centered Neonatal Care," a document that addressed our personal concerns and those we heard frequently from other parents. "The Principles" formed the basis for our discussions with the physicians Dr Lucey had assembled.

During the course of the conference, the physicians suggested a number of changes in our document, many of which we incorporated into the current draft of "The Principles."

Since the conference, we have circulated "The Principles" among parent groups, attorneys, ethicists, physicians, nurses, and others with an interest in neonatal care and follow-up. Most of their suggestions have also been included in the draft that appears below. We urge further input from the readers of *Pediatrics* in what we hope will be a constructive, ongoing dialogue between parents and professionals on how best to provide family-centered neonatal care.

THE PRINCIPLES FOR FAMILY-CENTERED NEONATAL CARE

Preamble

The importance of family-centered care for children with special medical and developmental needs has been recognized by support organizations and disability law. - 1-3

As parents of critically ill newborns and as professionals involved with high-risk infants and their families, we advocate a family-centered approach to treatment in neonatal intensive care units (NICUs). Obstacles to meaningful family involvement in the NICU have been identified by parents, 4-16 medical professionals, 17-44 ethicists, 44-53 academics, 54-61 and journalists. 62-75 The following "Principles For Family-Centered Neonatal Care" have been drafted by parents to address these issues.

We believe the implementation of these principles will encourage families to participate as fully as possible in caring for and making decisions for their hospitalized newborns, will help caregivers respect the diversity of family values and beliefs, and will help parents and professionals form mutually beneficial and supportive partnerships in the NICU and beyond.

Principles

1. *Family-centered neonatal care should be based on open and honest communication between parents and professionals on medical and ethical issues.* Communication in the NICU is a source of frustration to parents and caregivers alike.

Parents report that they are not always accurately informed about the consequences of medical conditions and intensive care treatments or about medical and ethical controversies surrounding the care of their babies. Researchers in the NICU confirm that

the information professionals give parents is often communicated in euphemisms, vague statements, and half-truths and that parents may be shielded from information about uncertainties or controversies surrounding their babies' NICU treatments. 54-57,60,61

Researchers have identified **attitudes** common among NICU professionals that interfere with their ability to communicate openly with parents. For example, caregivers may assume that parents of critically ill newborns are too overwhelmed to assimilate information or make rational decisions. 54,56,57,76 Professionals may be reluctant to inform parents about possible treatment complications or poor developmental outcomes because they believe such information can disrupt the "bonding" process and lead to parenting disorders." ;' Caregivers often strive to present families with a united front to avoid the confusion that might result from parental knowledge of medical or ethical differences of opinion among the staff. 54,57,60,61 Despite evidence that parents are not adversely affected by participation in decision-making,78 some professionals believe that fully involving parents in medical and ethical decision-making will produce parental guilt and other psychological difficulties. 54,61

We feel there is no excuse, however well-intentioned, for withholding important clinical information about a child's condition or prognosis from his or her parents. Parents should have available to them the same facts and interpretation of those facts as the staff. Information must be complete, specific, detailed, and meaningful.

Parents also have a right to know about relevant differences of medical or ethical opinion among the hospital professionals or within the medical community in general. Because neonatal nurses often identify more personally with babies and parents than do other NICU professionals,` their perspectives can be especially valuable and should be freely available to the parents.

In the care of critically ill newborns, communication about ethical issues and treatment choices is crucial. Parents should be actively encouraged to share their ethical views with staff. Some families may wish to do so through the use of family treatment directives, filled out during the prenatal period, in which parents put in writing their requests regarding resuscitation and treatment for their child should he or she be born extremely prematurely or critically ill.

Policies concerning ethical guidelines and medical practices can vary significantly among tertiary centers. 27,28,49,71

We urge that parents be informed of the philosophies and treatment policies of the NICU before the transfer or admission of their baby and that they be made aware of the practices and philosophies of other centers in their area as well.

Communication with parents can take place indirectly through stories in the media of "miracle babies" and "miracle therapies." Dr Mildred Stahlman has written. 'We [neonatologists] have allowed the media to publicize our successes widely, and have minimized our failures to the public .'42 As a result, parents may come into the nursery with unrealistic expectations, which can lead to parental demands for futile treatment and to lawsuits. The time has come for the medical community and the media to present a more sober and realistic appraisal of what neonatal medicine can and cannot do.

Courses in communication with patients and families should be an important part of the medical school curriculum, and all perinatal and neonatal professionals should be trained in the skill of sharing complete, honest, unbiased information with families in a humane and respectful manner.

2. To work with professionals in making informed treatment choices, parents must have available to them the same facts and interpretation of those facts as the professionals, including medical information presented in meaningful formats, information about uncertainties surrounding treatments, information from parents whose children have been in similar medical situations, and access to the chart and rounds discussions. Under the doctrine of informed consent, physicians are obliged to discuss with parents the risks and benefits of performing a given procedure as well as the risks and benefits of alternative procedures.' In neonatal intensive care, where many therapies have not been adequately studied for safety and efficacy 80 and where significantly different approaches to treatment exist,27,28,80 physicians should also acknowledge uncertainties surrounding the short- and long-term effects of inadequately tested treatment. Physicians should disclose whether or not the proposed treatment has been clinically evaluated in controlled trials. Physicians should discuss whether or not the treatment is part of a national standard of care or whether reasonable practitioners elsewhere do things differently. In cases in which the burdens of the treatment may outweigh the benefits, the physician should also be obliged to discuss the option of forgoing the treatment.

Parents must have full and free access to the lay and medical literature pertaining to their child's condition, proposed treatment, and probable outcome. Ideally, this literature would be available in a parents' library in the hospital or in the community. Parents should also have access to the experiences and opinions of other parents whose children have (or had) the same problems as their child. This access could come through parent support groups and networks and through video or audio tapes in which experienced parents discuss treatment choices and their children's outcomes. Such tapes should be balanced, candid, and reflect the spectrum of viewpoints and experiences. These tapes could be modeled on those produced by the Foundation for Informed Medical Decision Making in Hanover, NH, for facilitating informed consent in other areas of medical uncertainty. 81

We urge an expanded role in the NICU for the family's personal pediatrician as an advocate for the parents who can help them in their search for information and additional medical opinions. The pediatrician also can help put parents in touch with support organizations, ethics committees, and community resources.

Although evidence indicates that physicians frequently underestimate the amount of knowledge patients or their families wish to have, 82,83 it must be acknowledged that individuals vary in their desire to be informed and involved in decision-making. Families may also vary in the manner in which they assimilate information. We support systematic investigation into the issue of how parents with differing needs can best be served by various formats of information.

In other countries, pregnant women and new parents are routinely given copies of the obstetric and pediatric charts. 4 We propose that parents in the United States also be given copies or access to *complete* copies of obstetric, neonatal, and pediatric charts on an ongoing basis. Help in interpreting the chart should be offered to parents who wish it. Parents who wish to do so should be encouraged to add their own observations to the chart.

We also encourage staff to allow parents to take part in rounds discussions concerning their baby.

3. *In medical situations involving very high mortality and morbidity, great suffering, and/or significant medical controversy, fully informed parents should have the right to make decisions regarding aggressive treatment for their infants.* There has always been a strong societal and legal presumption that parents are the appropriate decision makers for their children.^{85,86} We affirm this principle, acknowledging the obligation of parents to provide their children with beneficial medical care. When there are differences of medical opinion about the relative benefits and burdens of proposed treatment, parents should be informed of this fact and allowed to choose among accepted treatment options.

For example, there is currently controversy over the benefits of routine aggressive treatment for infants with grade IV intraventricular hemorrhage^{49,71} and for infants born weighing less than 750 to 800 g.^{44,87-90} The value of surgery for infants with hypoplastic left heart syndrome⁴ and the advisability of extracorporeal membrane oxygenation,⁴ especially for premature infants,⁴ are also topics of medical debate. In these and similar situations involving high mortality and morbidity, significant therapeutic uncertainty, and/or prolonged or intense patient suffering, fully informed parents should have the option to accept or decline aggressive treatment. To help determine areas of significant therapeutic uncertainty, professionals may wish to consider guidelines developed by the Infant Bioethics Review Committee of Montefiore Hospital in New York which allow parental involvement in treatment decisions when "the chances of benefit [from treatment] are between 10 and 60 percent, with similar chances of long-term serious disability."⁹⁵

In such cases the physician should make his or her recommendation to the family, but it should be framed as an opinion with which other physicians and the family may disagree. The family should be informed of treatment options and the right to seek other opinions. While many families want to be decision makers for their infants,^{4-16,39-41,49,62,65-75} some may not. Parents who do not wish to participate in decision making should have the option of delegating decisions to a physician of their choice.

We want to emphasize that declining certain procedures is in no way synonymous with the withdrawal of care. Supportive care provided by family and staff should be recognized as a valid and humane alternative to aggressive treatment when the benefit of aggressive treatment is in doubt.

4. *Expectant parents should be offered information about adverse pregnancy outcomes and be given the opportunity to state in advance their treatment preferences if their baby is born extremely prematurely and/or critically ill.* We support the use of directives in which expectant parents advise physicians of their treatment preferences if the appropriateness of resuscitation or aggressive treatment for their infant should ever be in doubt. These directives would serve as an acknowledgment of the principle of shared decision-making and could stimulate dialogue on ethical issues between expectant parents and physicians.

We strongly urge that physicians and childbirth educators offer to discuss medical and ethical issues related to adverse pregnancy outcomes as a standard part of all prenatal care.

5. *Parents and professionals must work together to acknowledge and alleviate the pain of infants in intensive care.* Until recently, many physicians have not recognized the existence of, or the importance of, infant pain.^{7-19,22,36-38,46,47,72-74} Premature infants in particular have had to endure severe acute and chronic pain, including that of major surgery, without the benefit of pain relief.^{17,22} Parent protests^{7,11,12,72-74} and new evidence on the serious, **potentially lethal**, consequences of unrelieved pain¹⁷ have led some practitioners to reevaluate old practices.⁹⁶ Others, however, continue to withhold analgesia and anesthesia from premature infants during surgery and other procedures in which pain relief is commonly given to older patients.^{22,37}

We see our children's unrelieved pain as a moral as well as a medical issue. We know of no religion or philosophy that mandates the use of extremely painful, arguably inhumane, medical treatment to sustain life. For example, the Roman Catholic Church with its strong right-to-life ethic maintains that "burdensome" treatment can be justifiably declined by the patient or the patient's surrogates even when the alternative is death.¹⁷ Examples of burdensome treatment cited by Roman Catholic ethicists and scholars include unanesthetized surgery.⁹⁸ Parents must have the right to refuse such treatment on behalf of their children.

If a physician feels that medication may not be safely given to an infant for the effective relief of serious acute or chronic pain, the physician should share that information with the parents, who should then have the option of seeking another medical opinion or of refusing the burdensome course of therapy altogether.

Discussions of pain management with parents should be ongoing and routine and should include attention not only to acute pain from procedures but also to chronic pain from diseases and treatment side effects, eg, kidney stones from diuretic administration, fractures due to rickets, postoperative pain, and hypoxemia from chronic lung disease.⁹⁹

We believe continued research into infant pain and investigations into the safety and efficacy of analgesics and anesthetics should be given very high priority.

6. *Parents and professionals must work together to ensure an appropriate environment for babies in the NICU.* The NICU environment has been described as "bright, loud, intrusive, frequently painful, . . . unrelenting" and inappropriate for a **premature** baby's developing nervous system.¹⁰⁰ Ambient lighting and treatment lights in the NICU are suspected of playing a role in the development of vision loss from retinopathy of prematurity.¹⁰¹ High noise levels contribute to hypoxemia¹⁰² and may be a factor in subsequent hearing loss.¹⁰³ Infants are handled or disturbed an average of 82 to 132 times every 24

hours.^{104,105} These disturbances may cause hypoxemia and other short- and long-term complications.^{106,101} Supine positioning to facilitate treatment is another source of physiological instability.¹⁰⁸ Reducing the exposure of infants to light, noise, handling, supine positioning, and other aversive stimulation has been shown to improve babies' medical conditions in the NICU and their later developmental outcomes.¹⁰⁷

Avoiding the routine use of invasive procedures may also improve outcomes. For example, a recent survey of neonatal units revealed a high survival rate coupled with an unusually low incidence of bronchopulmonary dysplasia at a unit where very low birth weight (VLBW) babies *were not* routinely intubated.¹⁰⁹

As with the related issue of pain, the impact of the NICU environment and the effects of routine procedures must be thoroughly investigated. Until more is known, we believe the prudent and humane course is to protect babies as fully as possible from unnecessary light, noise, handling, uncomfortable positioning, and sleep disruptions. We strongly urge that our babies be treated in the least invasive manner possible.

To provide our babies with individualized protective care, we support the use of primary care nurses trained in the developmental needs of premature infants.

7. Parents and professionals should work together to ensure the safety and efficacy of neonatal treatments. It is common for new treatments to be introduced into practice in the NICU without controlled evaluation to assess their harmful or beneficial effects.^{27,28,40,42,80} We urge that new treatments be introduced only in the context of properly controlled trials, so that the results of such trials can be used as a basis for adoption or rejection of the treatment for routine use in neonatal care. We also support the use of controlled trials to investigate old therapies currently in use in the nursery that have never been adequately studied for safety and efficacy. Whenever treatments are introduced for use in a new population (eg, extracorporeal membrane oxygenation for premature infants), we urge that this be done only through formal, multicenter, comparative trials.

Experienced parents should have a voice in determining the research agenda, in establishing outcomes of interest, and in educating other parents about the need for ethically and scientifically sound research in neonatology.

8. Parents and professionals should work together to develop nursery policies and programs that promote parenting skills and encourage maximum involvement of families with their hospitalized infant. NICUs should help establish hospital- or community-based support groups and networks for parents who wish contact with "veteran" parents or with parents whose babies are currently in the nursery.

NICUs should allow liberal visitation for relatives, siblings, and family friends.

NICU staff should encourage parents to assume nonmedical aspects of their baby's care and should encourage parents to "room-in" with their child before discharge until they are comfortable with all important aspects of their child's care.

Staff should provide strong encouragement and support for breast-feeding and should make available a private room for milk expression and nursing, provide privacy for mothers who need to nurse their babies at the bedside, refer mothers to a lactation counselor for help with nursing problems, and allow adequate "rooming-in" time for the mother and baby to establish breast-feeding before discharge.

NICUs should include "veteran" families on committees that determine nursery policies.

9. Parents and professionals must work together to promote meaningful long-term follow-up for all high-risk NICU survivors. Extremely few VLBW infants or other similarly high-risk NICU survivors receive comprehensive long-term follow-up, and many receive no follow-up at all.^{25,26} Most children are dismissed from follow-up before the age of three.²⁵

However, from the literature^{25,110} and from our own experience with our children, we know that morbidity and mortality from perinatal conditions and treatments may occur at later ages. A recent meta-analysis of English-language VLBW infant follow-up studies²⁵ has found inconsistencies in the reporting and defining of handicaps. Rates of such problems as cerebral palsy and hearing or vision impairments are not always given.²⁵ In some studies such disabilities are classified as "minor."²⁵ The absence of control groups in many follow-up studies may result in overly optimistic evaluations.²⁵ "Many children are lost to follow-up" with medically and socially vulnerable children being especially likely to escape evaluation."^{2,113} All of these factors may lead to an overly optimistic evaluation of the outcomes of NICU survivors.^{25,26}

Because decisions about individual treatment and resource allocation may be made on the basis of follow-up statistics, and because parents and pediatricians deserve realistic information about the development of high-risk infants, it is important that these statistics be accurate and meaningful.

We endorse the following recommendations, which were adapted from Escobar et al²⁵:

1. Evaluation of the outcome of VLBW infants and other high-risk NICU survivors should be given priority in pediatric research.
2. National pediatric and medical associations, as well as the editorial boards of medical journals, should establish minimum standards for the design, conduct, and reporting of studies of the outcome of high-risk NICU survivors.
3. National pediatric and medical associations should encourage the development of geographically based birth-weight and gestational age-specific morbidity databases so that monitoring of the overall outcome of VLBW infants will be possible.
4. Outcome studies should be prospective, use impartial observers, include full-term infants as controls, and include the views and experiences of the families of NICU survivors.
5. Agreement on defining outcome measures must be reached so that studies can be compared. The experience of population-based cerebral palsy registries should be used as models. 6. Institutional incentives and funding must be offered so that the follow-up of high-risk NICU survivors, particularly multicenter and geographical studies, is financially and professionally feasible. 7. The period of follow-up should extend into adolescence, and, ideally, into adulthood.

10. Parents and professionals must acknowledge that critically ill newborns can be harmed by overtreatment as well as by undertreatment, and we must insist that our laws and treatment policies be based on compassion. We must work together to promote awareness of the needs of NICU survivors with disabilities to ensure adequate support for them and their families. We must work together to decrease disability through universal prenatal care. As parents of children with handicaps or life-threatening illness and as advocates for people with disabilities, we reject the notion that our children are well-served by laws mandating life-sustaining treatment without regard to pain and quality of life. Such laws leave critically ill newborns at the mercy of an ever-accelerating life-support technology with the capacity to inflict intense and prolonged suffering. According to a poll in *The New England Journal of Medicine*,^{20,23,29,30,32,36,48,50-54,56,57,59,65} one third of responding physicians felt that the "Baby Doe" law compelled treatment that was not in the best interest of the child. Two thirds said that the law failed to take into account the suffering of babies. It is a cruel paradox that this law, intended to protect infants from neglectful undertreatment, now promotes abusive overtreatment.

The argument is sometimes made that if society allows quality of life to be considered in life and death decision-making, it will fail to respect its citizens with disabilities. However, the reverse appears to be true. In England and in Sweden, where physicians and parents have greater latitude in quality-of-life-based decision-making, the ongoing care of survivors with disabilities is superior to that available in the United States.⁵³

Adults have the right to refuse burdensome lifesupport for themselves. Critically ill newborns, however, cannot say "no" to life-sustaining procedures, no matter how extreme. Parents must once again have the right to refuse excessively painful, burdensome, or unproven therapies on behalf of their infants. Otherwise, these infants can become the unprotected targets of an unthinking medical activism. We urge professionals to work with parents to change laws and policies that promote overtreatment and rob parents of their rights and responsibilities. Medical treatment of critically ill newborns should be driven by compassion and dedication to the welfare of these children and their families, not fear of politically motivated and poorly drafted laws.

Neonatologists, pediatric surgeons, and, others who care for imperiled newborns must recognize the life-long impact of their treatment decisions on their patients and their patients' families. They must have a realistic understanding of the resources that are (and are not) available to infants with disabilities and their families. The presence or absence of such resources should not be irrelevant to treatment decisions in the NICU.

Part of physician training should include a rotation in a facility or school that cares for children or adults with disabilities. In addition, medical students should have some experience in family settings caring for children or adults with mental and physical handicaps.

We urge perinatal and neonatal professionals to work with parents in advocating for increased public support for children with disabilities and their families and for the prevention of disabilities through universal prenatal care.

We, the undersigned parents, drafted "The Principles For Family-Centered Neonatal Care" and served as participants in the Special Ross Conference Intensive Concern: Parents and Physicians Discuss Neonatology," Burlington, VT, June 27-29,1992. We are signing "The Principles" as individuals and not on behalf of our organizations.

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PARENTS AS DECISION-MAKERS

Parents do have the authority to give or withhold their consent to medical treatment of their child and have rather broad discretion in exercising this authority, though it is subject to imperfectly defined and understood ethical and legal limits. As a report of the President's Commission for the Study of Ethical Problems in Medicine stated: "There is a presumption, strong but rebuttable, that parents are the appropriate decision-makers for their infants. Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents." The U.S. Supreme Court has also referred with approval to a summary of the law in this regard prepared by the federal secretary of health and human services: "The decision to

provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian" (*Bowen v. American Hospital Assn.*, 106 S. Ct. 2101, 1986).

Nelson Q. And the truth shall set you free. the case of Baby Boy Cory. In. Culver CM. *Ethics at the Bedside*. Hanover.. University Press of New England; 1990.

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