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HARM AND UNCERTAINTY IN NEWBORN INTENSIVE CARE

ABSTRACT: There is a broadly held view that neonatologists are ethically obligated to act to override parental nontreatment decisions for imperiled premature newborns when there is a reasonable chance of a good outcome. It is argued here that three types of uncertainty undercut any such general obligation: (1) the vagueness of the boundary at which an infant's deficits become so intolerable that death could be reasonably preferred; (2) the uncertainty about whether aggressive treatment will result in the survival of a reasonably healthy child or, alternatively, the survival of a child with intolerable deficits; and (3) the inability to determine an acceptable ratio between the likelihoods of those two outcomes. It is argued that the broadly held view accords insufficient weight to the fact that newborn intensive care increases the likelihood of harm to the child by effecting survival with intolerable deficits. Though treatment may offer a reasonable chance of a good outcome, it is argued that there are situations in which neonatologists should nonetheless defer to parental nontreatment decisions.

KEY WORDS: neonatology, NICU, ethics, newborns, ELBW, death, parental authority, pediatrics

FIVE MINUTES¹

The ethical issue in the case below is a familiar one in neonatology.

Baby B, a girl, has just been born in a tertiary level NICU: 525 grams and 24–25 weeks gestational age. Having experienced two earlier miscarriages, the parents had anticipated the possibility of extreme prematurity and had earlier looked at the NICU's outcome data. Despite intensive care, roughly half of the infants under 750 grams had died before discharge. Of those surviving to discharge, about half had serious deficits (neurological, respiratory, renal, visual, auditory, cognitive, developmental, etc.) and the rest had either moderate or no deficits. With the advice of their obstetrician, the parents had already decided to forego intensive care in the event of a very early delivery. They were apprehensive that aggressive treatment would do more harm than good.

In accordance with hospital policy, a neonatologist is present in the delivery room. At first the infant is depressed: faint heartbeat, no breathing. At 3 1/2 minutes, she is beginning to gasp for breath. As the clock approaches five minutes, breathing

becomes stronger and it appears that death is not imminent. Further delay in intubating the infant could compromise an achievable good outcome.

One option is intubating immediately and transferring the infant to the NICU. This would be done against parental objection. Despite the good response at five minutes, it cannot be said that the baby's chances are any better than what the unit's track record suggests. The infant could die despite treatment or, alternatively, either a normal or a severely handicapped baby could survive.

The second option is to forego aggressive care, make the baby as comfortable as possible and allow her to die. Without a ventilator, death would be expected within 24 hours. Some staff are uncomfortable withholding treatment that brings about pretty good outcomes 25 percent of the time.

PARENTAL REFUSALS OF TREATMENT: THE BACKGROUND

As a matter of professional ethics, when should neonatologists ignore or seek to override a parental decision for nontreatment of an imperiled premature newborn?² In familiar cases a physician recommends aggressive intervention—e.g., intubation, surgery, intensive care—with the goal of saving the child's life. The problem arises when parents reject intensive care, often out of a fear of a poor outcome for the surviving infant.³

Though the babies can be similar, the issues here differ from those that arise when parents demand treatment that physicians judge to be excessively burdensome and ineffective in securing a subjective benefit for the child.⁴ In the Baby L case,⁵ for example, parents demanded and obtained life support that physicians had opposed. The infant survived, blind, deaf, quadriplegic, on a gastrostomy tube, having an average of one seizure per day, and at the mental age of a three-month old. Notwithstanding the importance of this issue, the focus in this paper is not on parents who demand treatment but, rather, on parents who withhold or withdraw consent to it. The case of Sidney Miller⁶ illustrates the type of situation that is the focus of this essay. This 614 gram infant, born at 23 weeks gestational age, was treated over parental objection. Now in her teens, the former patient is partially blind, incontinent and paralyzed in all four limbs. Like Baby L, she also suffers from seizures and has the mental capacity of a six-month old child.⁷ Despite the parallels, physicians objected to treatment in the first case but supported it in the second, even while opposing parental authority in both. Outcomes like

these—Morreim has used the phrase “profoundly diminished life”⁸—raise questions about the meanings of “harm” and “benefit.” Despite the infants’ survival, it is arguable that medical treatment, on balance, did not further the patients’ interests.

Note also that the issues considered below are ethical rather than legal. Despite the controversies surrounding the “Baby Doe” regulations and later judicial opinions, the objective here is to frame and resolve one narrow question: under what conditions are physicians ethically required to seek to override a parental objection to intensive care for extremely low birthweight (ELBW: under 1000 g.) newborns? If there can be clarity about what professional ethics requires in cases like “Five Minutes,” efforts can then be made to conform legal, regulatory and policy mandates to responsible professional practice. That task is unlikely to be undertaken if legal obligations are mistakenly conceived, not as potentially in conflict with ethical obligations but, instead, as paramount ethical obligations. Here, ethical questions are conceived as epistemically prior to legal ones.

The problems arising from parental refusals of treatment have been persistent in professional debates and popular media. Gustafson⁹ famously described the issue in 1973 as it arose in what became known as the Johns Hopkins Hospital Case. The baby had Down syndrome and duodenal atresia. Publicizing that case, a widely-viewed film *Who Shall Survive?* described how physicians had deferred to a parental nontreatment decision. Shortly afterwards, Duff and Campbell¹⁰ and Fost¹¹ debated the issue in the medical journals, the former favoring parental decision-making and the latter favoring stricter limits to parental authority. The dilemma erupted into national consciousness in 1982 with the first Baby Doe case and its complicated institutional, regulatory and judicial sequelae. Robert and Peggy Stinson’s 1984 book, *The Long Dying of Baby Andrew*,¹² again thrust the issue into prominence, as did the notorious Linares Case in Chicago when, in 1989, a frustrated father entered an NICU and, wielding a handgun, disconnected his son from a ventilator.¹³ A 1991 *New York Times* series described a wide range of NICU practices: “cowboys” competing for impressive “saves,” and “angels of death” sweeping through NICUs disconnecting ventilators.¹⁴

Despite a diversity of positions over the decades, a recent book recounts the emergence of what may be “a fairly consistent set of decision-making criteria.” In their, *Neonatal Bioethics: The Moral Challenges of Medical Innovation*,¹⁵ John Lantos and William Meadow describe the current practice of distinguishing between situations

in which the “outcomes are predictably good enough that treatment is considered mandatory” and situations “in which outcomes are uncertain enough or bleak enough that treatment is considered optional.”¹⁶ The two key factors are, first, the chances for survival and second, the anticipated quality of life. Summarizing, they write that if “the prognosis is good enough, then parents are not permitted to refuse intervention.” But when “the outcomes are probabilistically bad ... parents are given the facts ... and allowed to make a decision.”

On this view, the initial clinical imperative is typically to ensure the survival of the infant. The second is to ensure an acceptable quality of life. According to Lantos and Meadow, since the outcome for any particular imperiled newborn is typically unknown, it is best to initiate a trial of therapy: treating all babies that are, for example, less than 750 grams, even though only half can be expected to survive. Under this approach—a variation on what has been called “wait until certainty”—treatment is continued until the babies “declare themselves.”¹⁷ If the infant deteriorates, aggressive treatment can be withdrawn on the grounds that the baby will likely die or survive with severe deficits. But if the infant improves, the increased likelihood of a good outcome warrants continuing treatment over parental objection. Metaphorically, the baby decides.

If Lantos and Meadow are correct, there may be a professional consensus that, unless survival is very unlikely, or possible only with severe medical or neurodevelopmental sequelae, treatment should be continued against parental objection: confidence in a large enough probability of a good enough outcome grounds an overriding ethical obligation to treat. Following this standard, the doctor in “Five Minutes” should continue to treat against parental objection, at least until the baby girl “declares herself.” Of course there may be professional disagreement about criteria. What is the minimum probability of survival? (20%? 40%?) How should we understand the baseline “good enough” quality of life (“severe medical or neurodevelopment sequelae”) below which parental refusals of aggressive care must be honored? Given these unanswered questions, it would still be a challenge to apply the Lantos-Meadow standard in practice. But even if there were complete agreement on these and related questions, one ought still to ask whether the consensus represents a mere practical compromise—one not grounded in principle—or whether there are sound reasons for drawing the line somewhere other than precisely there. For even if neonatologists unanimously endorsed some more specific version of the Lantos-Meadow

standard, the mere presence of such support would not in itself be a compelling reason for accepting the consensus as sound. One would want to know the justification.

It is the purpose of this article to offer reasons for rejecting the current standard. The background strategy will be to distinguish three types of uncertainty in newborn intensive care. This trinity of doubt undercuts much—but not all—of the basis for an overriding medical obligation to treat against the wishes of parents. The goal is to clarify certain problematic features of newborn intensive care and to set out recommendations for dealing with them. In the end, this essay draws a quite different and more precise line between the authority of doctors to treat a neonate in the face of parental objection and the authority of parents to abate treatment against medical recommendations.

ASSESSING THE EFFECTIVENESS OF NEWBORN INTENSIVE CARE

In 1987, the Office of Technology Assessment (OTA) published a landmark evaluation of NICUs.¹⁸ A bar chart in that report, adapted in Figure 1,¹⁹ represents the outcomes for extremely low birthweight infants (less than or equal to 1000 grams) born in level III hospitals in 1960 and from 1980 to 1985.

One sees in Figure 1 the evolving effectiveness of NICUs in altering the natural history of these newborns. The 1960 data were gathered at a time when physicians hesitated to treat premature newborns aggressively: in effect, before the advent of the NICU. They are, in this respect, control data: a baseline of expectations in the absence of newborn intensive care. While 8% of these infants survived in 1960, 52% survived in 1980–85. While 5.7% survived with moderate or no handicaps in 1960, that percentage had risen to 42% in 1985. The report maintains an upbeat tone even in discussing seriously handicapped survivors: babies with severe mental retardation (IQ or developmental quotient below 70); cerebral palsy of significant degree; major seizure disorders; blindness; and severe hearing defects. While the new technologies had increased the proportion of survivors, and therefore, the number of survivors with deficits, it seemed heartening to the authors that *the percentages of survivors with deficits had not changed dramatically*:

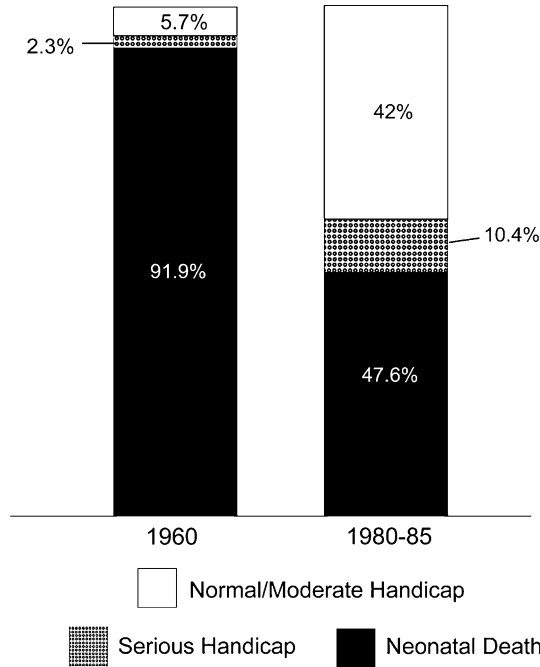


Figure 1. Outcomes for Extremely Low Birthweight Infants (< 1000 grams) Born in Level III Hospitals, 1960–85.

The conclusion that, within birthweight group, the rate of serious handicap among survivors has not changed significantly over time masks the contribution that neonatal intensive care probably has made to improved morbidity, as well as improved mortality outcomes. Since many very sick babies who previously would have died are now surviving, increasing handicap levels among survivors should be expected.²⁰

More recent studies show further development of these trends. Hack, for example, tracked 333 ELBW newborns born in Cleveland from 1992 to 1995.²¹ Of these, 241 (72%) survived to 20 months (corrected age) when 92% (221) of the survivors were assessed. If one extrapolates from the data drawn from the 92% studied, then it may be possible to supplement the two OTA bar charts with a third that roughly reflects the Hack study a decade later (Figure 2). Adapting her data, the “Normal” and “Moderate handicap” babies are merged. At least in principle, babies in both these categories (unlike, possibly, Sidney Miller and Baby L) are likely to have benefited from treatment. More will be said below about the infants in the “Serious handicap” category.

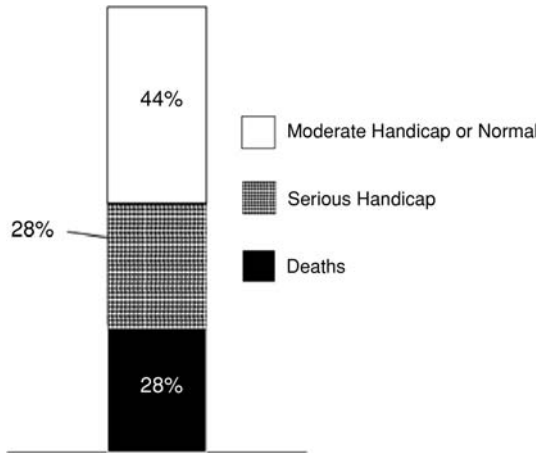


Figure 2. Outcomes for Extremely Low Birthweight Infants (1000 grams) at 20 months 1992–1995 (Adapted from Hack, 2000).

This adaptation of Hack’s data requires some explanation. First, Hack does not in her 2000 paper develop or use a conception of “serious handicap.” However she does record “major neurological abnormalities” and subnormal Mental Development Indices, albeit separately. The former covers cerebral palsy, blindness and deafness: 54 infants were found to have one or more of these deficits at 20 months. And while 95 infants had a subnormal Mental Development Index (< 70), 46 of these also had at least one major neurological abnormality: the remaining 39 did not. Accordingly, one can say that 93 infants examined at 20 months had at least one of these serious deficits: roughly 28% of the 333 infants born into the study. While not perfect, this conceptualization parallels that of the OTA.

It would be wrong to place much weight on the data sketched above. For one thing, their relevance to decision-making has yet to be established. (This will follow shortly.) For another, the pertinent data for any decision involving a newborn would have to emerge from the outcome history of the NICU in question. And finally, a closer look at the data could reveal disanalogies. Even so, the OTA and Hack data are useful for illustrating a general approach to ethical decision-making in the newborn nursery. What is argued for in what follows is a strategy for using comparable data in drawing a brighter line between cases in which parental refusals of intensive care should be respected and cases in which it may, as a matter of medical ethics, be overridden. My use of the OTA and Hack data is intended to

illustrate how comparable outcome data might be queried to secure such guidance.

HARMING AND BENEFITING ELBW PATIENTS

Neonatologists commonly tell parents that their goal is to save the life of the baby, hopefully with few or no deficits. The OTA bar charts reflect that vector—from death to survival with no deficits. In Figure 1, progress in NICU technology is evident in the “movement” of babies upwards from the blacked-out “Neonatal death” box at the bottom of each bar into the two lighter-colored boxes above. Once one collapses the “Normal” and “Moderate handicap” boxes, the vector of technical progress can be represented as in Figure 3.

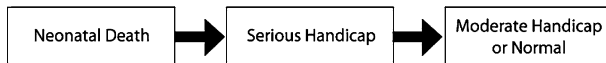


Figure 3. Vector of Technical Progress.

Though iatrogenic deaths and deficits can cause unintended movement toward the left, much of the research in neonatology identifies the effectiveness of intensive care with its evident power to move outcomes away from death and towards the right.²²

However, that death can be preferable to severe and enduring morbidity is a venerable and persistent theme in the literature. There may be an understandable relief at the death of a baby whose capacities for indignity and severe discomfort persist even as its abilities to enjoy any of the enrichments of a distinctly human life are irretrievably lacking. It is not uncommon for the death of a long-suffering loved one to be experienced with welcome relief: they are at last “going to a better place.” Rhoden has observed that almost all physicians questioned in her study of NICU practices in Great Britain, Sweden and the United States believe that certain impairments “can be so severe that death could be considered preferable.”²³ Weir has argued that the “extension of a seriously defective newborn’s life can represent a greater harm than does nontreatment resulting in death.”²⁴ McCormick opined that “life is a value to be preserved only insofar as it contains some potentiality for human relationships.”²⁵ In his writings on newborn intensive care, Engelhardt famously spoke of “the injury of continued existence.”²⁶ Paul Ramsey found in the ravages of Lesch-Nyhan syndrome a challenge

to the proposition that all life should be preserved regardless of its quality.²⁷ But despite wide—but not unanimous—agreement that infants can be so devastated that death would be preferable, there is no consensus about what the level of the deficit is. The point being made here is not that there are such infants, as so many have supposed. It is only that *it is not unreasonable to judge* that there are such infants. Given responsible disagreement in the field, it cannot be said that there is certainty. ***This is the first of the three types of uncertainty: an apparently ineliminable contestedness in the definition of what may be called “intolerable deficits.”*** Although contested standards make it impossible for outcome studies to enumerate infants surviving with such deficits, the ethical significance of these very bad results must not be neglected.

Despite the blurred boundaries of the category, it is possible to say something about what it does not contain. It should not include infants who are expected to develop into people who can confirm unequivocally their attachment to life. This will include most of those commonly described as handicapped: specifically those reasonably capable of communication. If one wants to know whether some condition is tolerable or intolerable, one should begin by asking those who have it. When “tolerable” is the broadly endorsed reply from those in a position to know, that is weighty evidence. However the deficits that are at issue here are more likely to be ones where the survivors, like Sidney Miller and Baby L, will be unable to state an opinion. To be sure, the permanent inability to communicate does not settle the issue of whether a survivor has intolerable deficits. But it is a factor that, along with others, can lend support to responsible judgment.

Accordingly, it is not unreasonable to use the following as a value-ordering of neonatal outcomes (Figure 4):



Figure 4. Value-Ordering of Neonatal Outcomes.

The category on the left is a subset of the “Serious handicap” box in Figure 2. The category on the right includes the remaining babies from the “Serious handicap” box, plus the babies in the “Moderate handicap or Normal” box in Figure 2.

For many premature newborns, intensive care does not effect a change in outcome. The bar chart on the left of Figure 1 shows many

babies dying and a few thriving even before there were NICUs. But apart from iatrogenic deficits and deaths, intensive care can alter the natural history of prematurity in three ethically significant ways.

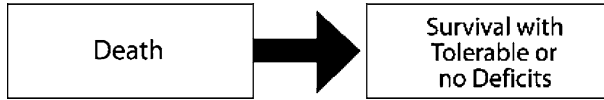


Figure 5. Benefit 1.

Figure 5 represents the achievement of medicine at its best: a baby who would have died will have a life it can be expected to value. Figures 1 and 2 provide evidence that such effects are common occurrences in the NICU.

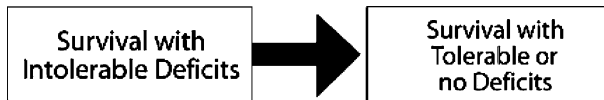


Figure 6. Benefit 2.

Figure 6 represents another significant benefit. Instead of surviving with intolerable deficits, the child survives with no deficits or with tolerable ones. But because newly surviving babies with tolerable or no deficits must be drawn either from those who would have survived with intolerable deficits (however that small category is defined) or from the much larger number of those who would have died, Figures 1 and 2 provide no clear evidence that this effect occurs.

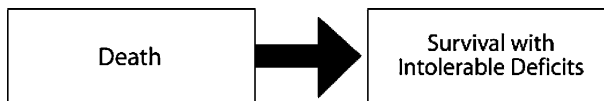


Figure 7. Harm.

Figure 7 is troubling. Infants survive who would arguably have been better off dead. While Figures 5 and 6 describe what are likely benefits to the infant and family, Figure 7 depicts a harm.²⁸ And, as Figure 3 illustrates (The Vector of Technical Progress), the effect is implicit in neonatology's effort to move outcomes away from death and toward survival with moderate or no deficits. Current methods of representing these infants—as in Figures 1 and 2—seem to treat them

as partial successes: survivors who owe their lives to the NICU, as if serious longterm morbidity were *always* an acceptable price to pay for life. Despite the distortion, one can scrutinize the OTA and Hack data to uncover something about the probable incidence of the effect depicted in Figure 7.

THE RISK OF SURVIVAL WITH INTOLERABLE DEFICITS

Since the class of infants with serious disabilities (which we can measure) is a superset of the infants with intolerable deficits (the blurry category), it is not unreasonable to assume that if the superset increases, so does the subset. Consider that, although “tall” is a vague concept, we can reasonably suppose that, other things being equal, if we quadrupled the proportion of people taller than six feet, two inches, we have probably increased the proportion of tall people irrespective of how reasonable people define it. One can likewise use changes in the percentage of infants with serious handicaps *as a marker* for changes in the percentage of infants with intolerable deficits. Focusing on the OTA’s serious handicap category in Figure 1, the incidence of those surviving with serious handicaps increases from 2.3% of all ELBW births in 1960 to 10.4% in 1980–85 (a percentage that is larger than the 8% for all survivors in 1960). Since the percentage with severe disabilities more than quadruples between 1960 and 1980–85, it is reasonable to infer that the subset of survivors with intolerable deficits increased as well. The Hack data suggest that the incidence of severe disabilities has since increased to perhaps 28% of all ELBW births: an order of magnitude larger than the 1960 percentage.

To be sure, the blurred boundaries of the “intolerable deficits” category preclude exactitude. Nonetheless, for babies at certain birthweights, the data lend substantial support to the view that the technology of newborn intensive care can simultaneously increase both the likelihood of the best outcomes (survival as a normal infant or as one with tolerable deficits) and the likelihood of the worst outcome (survival with intolerable deficits). *This is the second type of uncertainty for neonatology: For many babies, it is not known at the time of intervention if, at the end of the day, the baby will have been benefited by intensive care or harmed by it.*²⁹

It is true that survival with intolerable deficits can sometimes be averted by withdrawing life support, but only if the infant is still on it.

Doctors waiting for an infant to “declare herself” will continue to treat aggressively until it is clear that a good outcome cannot be expected. But by then the infant may no longer be dependent on removable technologies. There can be a “point of no return” beyond which the withdrawal of life support will not effect the death of the infant. Weir has recommended active euthanasia for infants in this situation.³⁰ Freeman has suggested that euthanasia can save lives: “[P]erhaps more vigorous initial therapy could be used without the fear by physician, family, and patients that the patient might be forced to survive in an unsatisfactory, limbo-like state.”³¹ Having brought about horrendous and persisting outcomes, parents and physicians may be understandably driven to euthanasia. The Dutch have developed a protocol for infant euthanasia where there is hopeless and unbearable suffering, very poor quality of life, and parental consent.³² But while such measures would mitigate the problems discussed above, it is not the purpose of this paper to recommend them.

There is a moral terror in situations where the same measures that increase the likelihood of the best outcome also increase the likelihood of the worst. Consider a harpooner on a whaling ship. A crewmate has fallen overboard and, though he might be able to swim back to the ship, the cold churning seas will probably kill him before he does. The harpoon has a line attached that is, for now, just long enough to reach him. If the harpoon lands nearby, Crewmate can grasp the line and be rescued. But given the gun’s inaccuracy, firing the harpoon close to Crewmate is indistinguishable from firing it at him. While a lucky miss can ensure survival, an unlucky hit will kill him. Even if Harpooner has a general duty to rescue and even if firing the gun can effect a reasonable chance of a good outcome, *there is no obligation to fire* and risk killing Crewmate.

If Crewmate’s wife and family were present and it were not known what he would have chosen, Harpooner could say to them: “I will do my best if you let me try, but I cannot rule out that I might kill him in the attempt to save his life.” Arguably, those who must live with the consequences ought to own the elective decision.

Parents who are loath to treat out of a fear of a bad outcome have a point. Physicians are fond of quoting the maxim, *Primum non nocere*: Above all, do no harm. The prohibition against harming patients takes precedence over the effort to benefit. And as with Harpooner, *there can be no obligation to treat when doing so increases the likelihood of the worst outcome.*

This conclusion, along with the preceding argument for it, undercuts the Lantos-Meadow representation of neonatology's consensus. For even though aggressive medical interventions increase the likelihood of the best outcome, physicians are not obligated to implement them if, at the same time, those same interventions also increase the likelihood of the worst outcome. (This argument is strengthened to the extent that the interventions in question are burdensome to the infant.) Most of the time, medical interventions increase the likelihood of good outcomes even as they decrease the likelihood of bad ones. Newborn intensive care can be importantly different and—ethically—that difference makes a difference. The Lantos-Meadow standard does not take the difference into account.

There is a rejoinder to this: While there are some very poor outcomes that are generated by newborn intensive care, there are many more good outcomes. The move is a common one and there is a version of it in the OTA report:

... [I]f today's neonatal intensive care was provided for all very low birthweight infants, about 2200 seriously handicapped children would survive who would have died in 1975. This figure must be balanced against the 15,200 net increase in normal infants who would also survive under current conditions. The overwhelming majority of survivors in both the under 1500-gram and the under 1000-gram birthweight groups are normal.³³

The point seems to be that a ratio of 15,200 to 2200 (roughly 7 normal babies to 1 seriously handicapped baby) is respectable enough. The ratio would be even better if we could take into account the ratio of babies with no or tolerable deficits to those with intolerable deficits. *But*—and this is neonatology's third uncertainty—*it is not clear how one can judge the rational acceptability of any ratio between the likelihood of effecting good outcomes and the likelihood of effecting extremely bad ones.* This point is not eugenic. The broad clinical issue must be approached from the patient's perspective rather than from the OTA's societal point of view. Suppose, for example, someone was imminently dying, but a certain drug could provide a single additional year of life. But some of those who take the drug survive indefinitely with what they would regard as intolerable deficits. Given some ratio between the probabilities of having an added year of normal life and having an unknown number of years of devastating morbidity, it is not clear how one would go about demonstrating the clear rationality of a preference for or against taking or administering the drug, let alone any obligation.

When the probabilities are murky and some outcome is plainly unacceptable, it is arguably wiser to minimize the severity and likelihood of the worst possible outcome: wiser even than maximizing expected utility.³⁴ Intensivists should take care not to assume that a reduction in mortality is always worth the increased risk of a profoundly diminished life. And parents should not be judged uncaring or neglectful if they refuse to consent to the imposition of such a risk upon a son or daughter, allowing a child to die in comfort in order to diminish the likelihood of an even worse outcome.

INFORMED PARENTAL CONSENT IN NEWBORN INTENSIVE CARE

In setting out the options for parents, neonatologists should consider the use of visual aids like those below in Figure 8. The pie charts used illustratively here are based on the OTA's 1960 data in Figure 1 ("Comfort Care Only") and on my adaptation of Hack's 2000 data in Figure 2 ("Intensive Care"). In practice and as I have suggested, the chart should be based on outcome data from the unit's own experience.

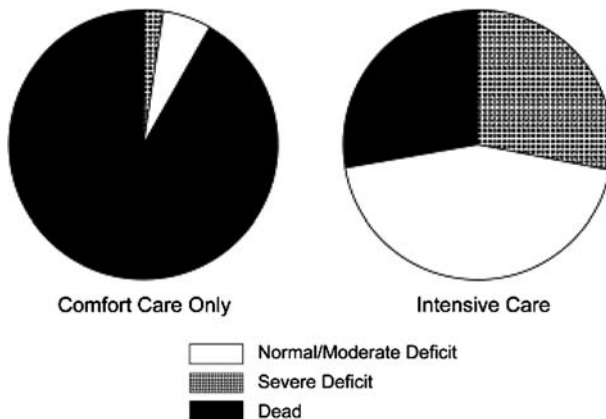


Figure 8. Expected Outcomes: Comfort Care Only vs Intensive Care (Illustrative).

Ethically, scrupulous candor about probabilities is always required, but especially when infants fall into birthweight/gestational age/clinical status categories where the percentage of infants treated aggressively in the NICU who survive with severe deficits is greater than the percentage of comparable infants treated with comfort

measures only who survive with severe deficits. While it can help to put parents in touch with other NICU parents with experience following different choices, clinicians facing the issue in “Five Minutes” might consider using language like the following.

You are aware that what we can do in the NICU can increase the likelihood that your child will survive as a normal baby or as a baby with moderate handicaps. But you may be worrying that intensive care might make it more likely that your child will survive with severe handicaps.

When we treat babies like yours in the NICU, the results we get look roughly like those on the right hand side of Figure 8: “Intensive Care.” But when aggressive treatment is withheld and only comfort care is provided (as, for example, when intensive care was not available years ago), the results we get look roughly like those on the left hand side of Figure 8: “Comfort Care Only.” Either way, we cannot tell what would happen with your baby.

Now some believe there are disabilities so severe that death would be a benefit. While there is no agreement on what these abnormalities are, you need to know that if we treat your child aggressively, to increase the likelihood that your baby will survive in good shape, that same treatment will also increase the likelihood that your child will survive with very serious disabilities. Cerebral palsy, seizures, blindness, deafness, mental retardation: all of these, and some others, are possibilities. If, on the other hand, we hold back on aggressive treatment, that will increase the probability that your baby will die. But she will be less likely to have to live with severe deficits and more likely to remain comfortable before she dies.

In deciding on a course of action, reasonable parents would want to take into account the possibility of an extremely bad outcome for the child and to know of the clinical options that reduce its likelihood.

In the same OTA document, a second bar chart characterized the outcomes for very low birthweight infants (< 1500 grams). A part of that diagram is adapted below as Figure 9.

There is an anomalous reduction in the percentage of seriously handicapped infants from 1960, when the figure is 6.7%, to 1971–75, when it drops to 4.5%. Though the percentage later rises to 11.1% in 1980–85, the 1971–75 numbers suggest that for some infants there may be clinical strategies that can lower the percentage of seriously handicapped infants below comfort care baselines (and, ergo, the percentage of infants with intolerable deficits), even while improving the likelihood of the best outcomes. If aggressive care in the early 1970s was indeed successful in this way, there would have been an ethical obligation to treat against parental objection. Although national standards might emerge, the policies for overriding parental

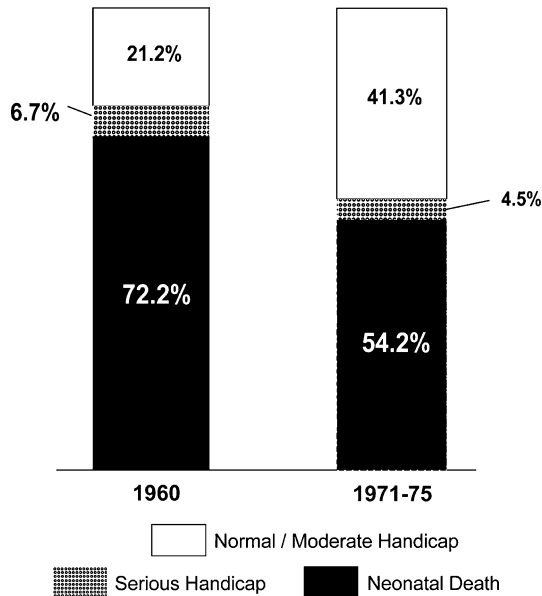


Figure 9. Outcomes for Extremely Low Birthweight Infants (< 1500 grams) Born in Level III Hospitals, 1960–75.

nontreatment decisions would vary with the effectiveness of units in reducing the incidence of severe disabilities in babies.

Hack's study and others like it are encouraging. Neonatology may be shifting its focus from mortality to longterm morbidity. The field would do well to identify treatment and nontreatment strategies that reduce morbidity to something closer to what it was fifty years ago. In this effort neonatologists must reassess their mission and, with humility, work with parents who are struggling to find their way amidst the uncertainties of birth, death, and profound suffering that are such prominent parts of their moral landscape.

ACKNOWLEDGEMENTS

Earlier versions of this work have been presented at the Hastings Center, the Medical University of South Carolina, the Department of Philosophy at the University of Hawaii at Manoa, the annual meeting of the Society for Bioethics Consultation, and Kapiolani Medical Center in Honolulu. Many have participated in its evolution. Appreciation is especially owed to Lainie Friedman Ross, M.D.,

Ph.D.; David Easa, M.D.; Bruce Jennings, Alan R. Fleischman, M.D., Lisa Newton, Ph.D., Larry B. McCullough, Ph.D., Daniel Murai, M.D., Susan R. Martyn, J.D., Ruth Guffee, Ellen Moskowitz, J.D., Harvey Kipnis, Tracy Garvie, Helen Smalley-Bower, Doug Diekema, M.D., Amber Orr, J.D., Julia Morgan, J.D., Leanne Logan, John Constancio Licato and Carson Strong. The author is deeply grateful to the Hawaii Council for the Humanities for its early support, and to the Hastings Center for making available resources that facilitated much of the research that went into this paper.

NOTES

- ¹ “Five Minutes” is loosely based on an actual case.
- ² While the concerns of this paper pertain to extremely low-birthweight infants only, the strategies described might possibly be extended to other categories of patient. The work needed to ground any such further claim will not be attempted here.
- ³ In personal communications, Doug Diekema has emphasized that NICU care itself imposes burdens on the infant: e.g., pain and discomfort. Since many of these infants will die or have very bad outcomes despite treatment, physicians will, on balance, unintentionally harm all infants who fail to benefit from burdensome therapy. Though not the central focus of this paper, these burdens also count against any medical obligation to treat over parental objection. The iatrogenic burden accompanying a not-very-effective treatment—as with some types of chemotherapy for cancer—is a reason some adults refuse aggressive care for themselves. It is not obvious why a comparable parental justification should be rejected for infants.
- ⁴ S.H. Miles, “Informed Demand for ‘Non-Beneficial’ Medical Treatment,” *New England Journal of Medicine* 325 (1991): 512–15.
- ⁵ JJ. Paris, R.K. Crone, and F. Reardon, “Physicians’ Refusal of Requested Treatment: the Case of Baby L,” *New England Journal of Medicine* 322 (1990): 1012–15.
- ⁶ *Miller ex. rel. Miller v. HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003).
- ⁷ H.O. Rumbaugh, “Miller v. HCA, Inc.: Disempowering Parents from Making Medical Treatment Decisions for Severely Premature Babies,” *Houston Law Review* 141:2 (2004): 696.
- ⁸ E.H. Morreim, “Profoundly Diminished Life: the Casualties of Coercion,” *Hastings Center Report* 24, no. 1 (1994): 33–42.
- ⁹ J.M. Gustafson, “Mongolism, Parental Desires, and the Right to Life,” *Perspectives in Biology and Medicine* 16 (1973): 529–30.
- ¹⁰ R.S. Duff and A.G.M. Campbell, “Moral and Ethical Dilemmas in the Special-Care Nursery,” *New England Journal of Medicine* 289 (1973): 890–94; R.S. Duff and A.G.M. Campbell, “On Deciding the Care of Severely Handicapped or Dying Persons with Particular Reference to Infants,” *Pediatrics* 47 (1976): 487–93.
- ¹¹ N. Fost, “Counseling Families Who Have a Child with a Severe Congenital Anomaly,” *Pediatrics* 67 (1981): 321–4; N. Fost, “Ethical Issues in the Treatment of Critically Ill Newborns,” *Pediatric Annals* 10, no.10 (1981): 16–22.

- ¹² R. Stinson and P. Stinson, *The Long Dying of Baby Andrew*. Atlantic, Little Brown, 1983.
- ¹³ J.H. Lantos, S.H. Miles, C.K. Cassel, "The Linares Affair," *Law, Medicine & Health Care*. 17, no. 4 (1989) pp 308–15; L.J. Nelson and R.L. Cranford, "Legal Advice, Moral Paralysis and the Death of Samuel Linares," *Law, Medicine & Health Care* 17, no. 4 (1989): 316–29.
- ¹⁴ Rosenthal Elisabeth. "As More Tiny Infants Live, Choices and Burden Grow." *The New York Times*, September 29, 1991, <http://query.nytimes.com/gst/fullpage.html?res=9D0CE4DC1339F93AA1575AC0A967958260>. Kolata, Gina. "Parents of Tiny Infants Find Care Choices Are Not Theirs" *New York Times*, September 30, 1991, <http://query.nytimes.com/gst/fullpage.html?res=9D0CE4D71639F933A0575AC0A967958260> Brody, Jane E. "For Babies, an Ounce Can Alter Quality of Life" *The New York Times*, October 1, 1991, <http://query.nytimes.com/gst/fullpage.html?res=9D0CE1DA1539F932A35753C1A967958260>.
- ¹⁵ J.D. Lantos and W.L. Meadow, *Neonatal Bioethics: The Moral Challenges of Medical Innovation*. Baltimore, Johns Hopkins University Press: 2006.
- ¹⁶ Lantos and Meadow, *Neonatal Bioethics*, p. 10.
- ¹⁷ Lantos and Meadow, *Neonatal Bioethics*, p. 92.
- ¹⁸ Office of Technology Assessment, *Neonatal Intensive Care for Low Birthweight Infants: Costs and Effectiveness*, Washington, D.C., U.S. Government Printing Office, December 1987.
- ¹⁹ I have collapsed the normal and moderate handicap categories into a single one and have used percentages rather than incidence per 1000.
- ²⁰ Office of Technology Assessment, *Neonatal Intensive Care*, p. 30.
- ²¹ M.B. Hack et al., "Neurodevelopment and Predictors of Outcomes of Children With Birth Weights of Less than 1000 g," *Archives of Pediatric and Adolescent Medicine* 154 (2000): 725–731,
- ²² Note that the OTA data presentation places all outcomes on a single bar graph. Today, survival data are typically presented separately from medical outcomes, obscuring what the likelihoods are at birth. And instead of tracking devastated infants surviving with multiple deficits (like Baby L and Sidney Miller), discrete deficits are tracked separately. The presentation of the Hack data has been adapted to permit comparison with the OTA data and to make it easy to grasp the probabilities of all outcomes at birth, rather than representing survival and morbidity data separately. This feature is preserved in Figure 8.
- ²³ N.K. Rhoden, "Treating Baby Doe: the Ethics of Uncertainty," *Hastings Center Report* 16 (1986): 34–42.
- ²⁴ R. Weir, *Selective Nontreatment of Handicapped Newborns*, Oxford University Press, New York: 1984.
- ²⁵ R.A. McCormick, "To Save or Let Die: the Dilemma of Modern Medicine," *Journal of the American Medical Association* 229 (1974): 172–6.
- ²⁶ H.T. Engelhardt, Jr., "Letter: Euthanasia and Children: the Injury of Continued Existence," *Journal of Pediatrics* 83, no. 1 (1973): 170–171.
- ²⁷ P. Ramsey, *Ethics at the Edges of Life*. Yale University Press, New Haven: 1978
- ²⁸ Omitted from the analysis here is a fourth effect of NICU technology. Infants who would otherwise die fairly quickly can have their deaths delayed by weeks or months of futile pain and discomfort. This too can be a harm.

- ²⁹ To reiterate a point made earlier in fn. 3, where either death or survival with intolerable deficits is the outcome, infants will also have been harmed by any treatments (except palliative ones) that impose pain or discomfort. In the end, the adverse effects are not offset by compensating benefits.
- ³⁰ Weir, *Selective Nontreatment*, p. 221.
- ³¹ J.M. Freeman, "If Euthanasia Were Licit, Could Lives Be Saved?" in *Euthanasia and the Newborn*, eds. R.C. McMillan, H.T. Engelhardt, and S.F. Spicker (D. Reidel, Dordrecht: 1987).
- ³² E. Verhagen and P.J.J. Sauer, "The Groningen Protocol—Euthanasia in Severely Ill Newborns," *New England Journal of Medicine* 352, no. 10 (2005): 959–63.
- ³³ Office of Technology Assessment, *Neonatal Intensive Care*, p. 30.
- ³⁴ In game theory and, derivatively, in social contract theory, the maximin strategy is commonly favored under comparable conditions of uncertainty. Where some outcome is plainly unacceptable and the probabilities are unknown, the best choice can arguably be the one that, as much as possible, reduces the severity or the probability of the worst possible outcome. Instead of maximizing overall expected utility or the likelihood of the best possible outcome, it can be wiser to minimize the likelihood of unacceptably bad outcomes. In a useful discussion in *A Theory of Justice* (pp. 150–61) John Rawls sets out this approach in arguing for the choice of his two principles of justice under the conditions of uncertainty associated with what he calls "the original position."

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