

## Overtreatment of Neonates? A Personal Retrospective

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*Man's power over Nature is really the power of some men over other men, with Nature as their instrument.*

—C. S. Lewis

The question of overtreatment of seriously compromised neonates with life-prolonging hardware is, in the end, a weighing of values—a moral judgment. The most pressing issues of our time, it has been said, are not matters of engineering, but of human values. And, didactic opinion to the contrary notwithstanding, I am prepared to argue that moral judgment is not monolithic. A system of values is not the same everywhere and for everyone. Nor is it an unchanging construct over time—even throughout one's own lifetime.

Piaget,<sup>1</sup> Kohlberg,<sup>2</sup> and Rest<sup>3</sup> have all made a strong case for the view that differences among people, in the way they evaluate moral problems, are determined, largely, by their concepts of fairness. A sense of right grows more discerning with age and is influenced by the amount and the complexity of social experience.

Let me explain what I am getting at, by relating the growth of my own social experience as a rescuer of extremely small neonates. It began 47 years ago, when I was on the housestaff at The Babies Hospital in New York City. On January 27, 1945, a premature neonate was born in a small hospital in the Bronx, at 5½ months of gestation; birth weight was 600 g. The obstetrician was astounded that this extremely small girl breathed spontaneously and he was even more amazed to find her still alive the following day. The neonate was then sent to The Babies Hospital in Manhattan.

In those days, out-born premature infants were cared for in a primitive four-bed premature nursery that was the responsibility of the senior residents. That is how this minute baby, who weighed 620 g on our scale, was thrust into my completely inexperienced hands. I had never seen a live baby this small (Fig. 1). As I learned later, no infant of this size had ever lived for more than a few hours at our institution.

As it turned out, this remarkable child survived for 3½ months, and she more than tripled her birth weight. I was thrilled by my beginner's luck. I looked

up Levine and Gordon's "how to" article published in 1942<sup>5</sup> and kept their instructions next to the incubator. And, with one exception, I followed their instructions as a cook follows a recipe. As advised, I stabilized fluctuations of body temperature and made no effort to warm the infant anywhere near 37°C; I prescribed continuous oxygen; and I gave subcutaneous clyses twice a day, until gavage feedings of a low-fat, high-protein formula were sufficient to sustain weight gain.

My one deviation was a novel treatment for recurrent episodes of apnea and cyanosis. I came across a suggestion that a defect in blood gas transport might be the result of low levels of carbonic anhydrase in the blood of prematurely born infants. The handicap might be overcome, it was theorized, by small transfusions of adult whole blood. This optimistic suggestion for an untried treatment was just the kind of bold action I was looking for. I began to transfuse the infant daily with a few milliliters of my own blood. I quickly became convinced that it was my carbonic-anhydrase-rich blood that was keeping this baby alive—and I was not unmindful of the fact that she was setting a new hospital record for longevity!

Now, was this *overtreatment*, 47 years ago? The question never entered my head! And it never seemed to occur to my teachers. The baby was presented at grand rounds as a triumph of mechanism-guided treatment, and I was made to feel like a hero. My rescue fantasy was fulfilled.

I was very disappointed that the parents did not share these joyous feelings of high adventure. They were both in their late 40s and had two grown children. They were completely overwhelmed by what I was doing to prolong the life of this unplanned and unwanted baby. I tried to focus their attention on the miraculous present, and I was annoyed that their thoughts were fixed on an uncertain future. They kept asking about long-term outlook. I was forced to admit I had no idea about prognosis because few, if any, infants of this size ever survived. The longer the baby lived, the more angry the parents became at the thought that I—a young, childless, house officer, with no personal experience in rearing a normal child (much less one who might be disabled)—now held in my hands an important determinant in the fate of this family. And it was quite clear to them that I was not accountable for the social, to say nothing of the financial, consequences of my actions. Not surprisingly, when the baby died rather suddenly at 3½ months of age, the parents refused to allow an autopsy.

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## IMAGE UNAVAILABLE

As I take a long look back at this experience, I see that the moral judgment of these parents was much more highly developed than mine. I was operating under a fixed assumption that laws provide norms of behavior that must be categorically and impersonally enforced. (Rest<sup>3</sup> refers to this stage in the development of moral judgment as "The morality of law and duty to the social order: Everyone in society is obligated and protected by the law.") According to my tunnel view of the social drama enacted in the nursery, my unshakable obligation to prolong life trumped all other considerations.

The parents, on the other hand, were appealing to a more mature moral judgment: a comprehensive view of the principle of justice in complex situations; an outlook that takes into account the balance of competing interests needed to create a social equilibrium. (Rest refers to this development as "The morality of nonarbitrary social cooperation: How rational and impartial people would organize cooperation, is moral.")

Now I must relate that the treatment I prescribed for my patient was not the community standard of 1945. At that time, all newborns weighing less than 1 kg at birth were classified as "previable." If this 620-g neonate, born at 5½ months of gestation, had been born on our obstetric service, she would never have reached the in-born premature nursery located in another building of the medical center complex. "Previable" and severely malformed newborns were placed in a cold corner of the delivery room and allowed to die. The decision was made by the obstetrician, who knew the family, knew the parents' circumstances, and often knew the parents' wishes. There was little or no discussion of the dark drama by the few other attendants in the delivery room (unlike the delivery room scenes to follow). Everyone tried to ignore the gasping respirations—death never came quickly enough to relieve their acute, but silent, discomfort. The outcome of the delivery was reported as "stillborn."

Religious parents usually accepted the result fatalistically; some asked only that the baby be baptized: this was God's will. Some parents specifically requested that "Nature be allowed to take its course." Those who raised animals recognized a flawed outcome as a manifestation of Nature's trial-and-error strategy for survival—the wide range of biologic variation in offspring seen in the evolution of all life on this planet.

The 1-kg "natural limit of viability" was established by Budin,<sup>6</sup> based on his experience in France at the end of the last century. His approach was farm-like: he provided ideal environmental conditions for survival and nurses expert in the techniques of feeding, and he reasoned that those babies who were *meant* to live would do so. I have no doubt he would have labeled my efforts in 1945 as "overtreatment," and he would point to the end result with the French equivalent of, "I told you that infants under 1 kg are not *meant* to live."

In 1949, Richard Day opened a 20-bed premature infant station at The Babies Hospital with federal funds, and he asked me to assist him. This project was part of a national drive with a clearly stated goal: reduce mortality of low birth weight infants. The small neonates accounted for the largest single cause of infant death—the national statistic was made newly prominent by birth certificates that recorded weight-at-birth for the first time. The program of care was essentially the neutral approach of Budin. Care was very much in the hands of skilled nurses who discouraged any unnecessary handling of "their" babies. House officers complained bitterly that there was no exciting action in this quiet backwater of the hospital. Budin would have approved this passive screening program to find out which babies were destined to live; and, I soon learned, so did many of the mothers and fathers.

I was impressed by the number of parents who made it clear they feared disability much more than death. They feared overtreatment and said so very directly: "Please don't try too hard, doctor. Please give us another chance to have a normal baby!" These pleas came at a very distressing time: slowly and painfully, we were beginning to realize the treachery of received wisdom.<sup>7</sup> The long-accepted treatments we prescribed with such confidence were turning out to be dangerously wrong. For example, the prolonged, high concentrations of oxygen we used for 12 years were found to be responsible for blinding thousands of infants. We were badly shaken when a 25-year-old claim that the very small neonate was poikilothermic was completely overturned by controlled trials demonstrating the fatal consequences of surprisingly small increases in heat loss. Follow-up observations of infants fed the low-fat, high-protein milk indicated that their cognitive development had been adversely affected. And, to make things even more confusing for me, when my wife and I began to have children of our own, I had to admit that we identified completely with the fears of the young parents who pleaded with me every day in the bright new premature infant station. As my social experience grew, so did my moral ambiguity.

In the early years, relatively few "preivable" neonates were admitted to the new facility. But the situation changed when activity in the delivery rooms was revolutionized. The change began when systematic appraisal of the newborn at age 1 minute was introduced in 1952. The Apgar score did away with the fiction of labeling marginal neonates as "stillborn" in our institution, and this change spread quickly when the scoring system was published in 1953.<sup>8</sup> In the mid- and late 1950s the number of persons present, and the levels of intervention in delivery rooms and in premature infant nurseries, began to escalate. This also marked the beginning of the ongoing controversy about what shall, and what shall not, be considered "overtreatment."

I can illustrate the abrupt change in attitude and in action by a dramatic incident that took place in a delivery room on our obstetric service. It occurred when a new chief of obstetric anesthesiology was called to be present at the delivery of an extremely small baby at about 23 weeks of gestation and weighing roughly 500 g. The neonate did not breathe spontaneously and had no pulse. The new anesthetist asked for a scalpel, opened the chest with one stroke, and began to squeeze the heart directly, as he yelled for someone to intubate the baby immediately. No one prior to this had ever dreamt of using open-chest cardiac massage for resuscitation of the newborn. Needless to say, this incident had an electrifying effect on the crowd of open-mouthed young people in the room. This was a very loud signal indicating how far resuscitative efforts were now prepared to go. The fact that the neonate died a few hours later was dismissed as an irrelevant detail.

Although I was horrified by this act, I had to admit it differed very little from my never-say-die action 10 years earlier. It was soon clear, in the next few years, with increasing interest and with increasingly bold action, that an exciting new field of medicine was, in fact, inventing itself. The timid notion of a "natural limit of viability" vanished.

I want to call attention to the team-action as a significant feature of the new rescue program. "Team-think" provided a self-validating stamp of approval: What we all agree to do must somehow be right. Freeman Dyson<sup>9</sup> has pointed out this dynamic in teams of physicists who worked on the atom bomb project. "We did things together," he wrote, "that none of us would think of doing alone." He became convinced that it is this diffusion of responsibility that allows people to put aside disturbing questions about the horrendous consequences of their acts.

It was easy to get swept up in the exciting development of neonatal medicine, so long as you did not ask too many questions about overarching goals. And, I must say, I did sweep my second thoughts under the rug. Now, as I look back at those exciting times, I am reminded of the Alice-in-Wonderland-like Principle: "If you don't know where you are going, any road will take you there."

The dramatic increase of technical power in neonatal medicine has made possible an unprecedented form of extremism. This change, I suggest, is nothing less than a radical social revolution. When the fulfill-

ment of an eager team's dream of rescue brings about the real-life enactment of a family's worst nightmare, something momentous has happened to the unwritten rules of common decency. In commenting on who does what to whom, Lewis<sup>10</sup> noted, "Of all tyrannies, a tyranny exercised for the good of its victims, may be the most oppressive. Those who torment us for our own good, will torment us without end, for they do so with the approval of their own conscience."

We failed at the outset of the journey of discovery in neonatal medicine to make a clear distinction between the exciting search for understanding the biology of human procreation, as separate from the sober, practical application of the new knowledge in delivery rooms and in the new neonatal intensive treatment units. In preclinical research, real progress depends heavily on freedom from limits of any kind. There should be no requirement that the work be targeted at a specific clinical goal. On the other hand, I have argued repeatedly, there must be a sharp restriction at the threshold of bedside applications. Now the operative question is, "How do we transform new medical information into something of social value?" Here, I suggest, we are on very shaky ground, because the decision involves a subjective weighing of personal and societal values. The process is far removed from the hypothetico-deductive approach we use in searching for substantive knowledge.

As we wrestle with a definition of the social aim of modern antenatal and neonatal medicine, parents and the community remind us that this activity is never a solitary enterprise. Medical action is always carried out within some broader social and cultural context. Parents and communities are beginning to make their wishes quite clear: they must be active players. It is slowly but surely dawning on all concerned that unrestrained intensive treatment of the smallest and most severely malformed babies is unreviewed and unlegislated social policy. No extensive and continuing communication between doctors and the rest of society has taken place to find out whether or not "reduce mortality," the clear, but overly simple goal set out in the 1940s, makes any realistic sense half a century later. Tocqueville warned that "human institutions are, by their nature, so imperfect, that to destroy them it is only necessary to carry out the underlying ideas to their logical extreme."

Stahlman<sup>11</sup> reminds us that as the momentous changes were taking place in this new field of medicine, there has been a striking increase in the complexity of American society. We have experienced an increase in the numbers of young families of high-risk babies living below the poverty line. There has been an increase in the number of single-parent families. Many live amid appalling conditions of poor housing, violence, and substance abuse. Large waves of immigration have brought a sharp increase in cultural diversity. There has been an increase in the variety of religious beliefs and value systems in families of high-risk babies. The disparity between intensive efforts at rescue and the social circumstances of the family is greater now than at any time in the past. How much of our resources, communities are now asking, should we invest in social interventions like

jobs, food, and housing for the families at higher risk of pregnancy complications, and how much in the technologies of medical rescue? Has the extremely costly neonatal industry (a 1992 estimate places the cost at 5.6 billion dollars per annum<sup>12</sup>) increased or decreased the amount of social chaos in this country? How have we come to use such exorbitant means, the severest critics ask, for such limited ends? What are the biologic consequences, scientists are asking, of the large-scale, radical experiment in which we keep compromised infants alive, who never before survived in the several-million-year-old history of our species?

The intense debates, in recent years, have focused on setting limits for neonatal treatment and on the question of *who* has the authority to define the boundary. Swan<sup>13</sup> has commented on the wide gulf separating those who believe all decisions about intensive neonatal treatment must be taken in the child's best interest (with parents and society secondary), as opposed to others who believe that in ambiguous situations, the wishes and interests of the parents must be given first consideration. The difference is highlighted when parents are convinced that touching, caressing, and avoiding pain and trauma for their baby, even for a brief span of life, is a humane alternative to the physical suffering and the uncertainties of life-prolonging intensive treatment. Swan comes down squarely on the side of parents in this debate. So did a President's Commission,<sup>14</sup> and so did the New York Court of Appeals<sup>15</sup> in a case involving parents who elected conservative rather than surgical treatment for their infant born with a severe neural tube defect. The court affirmed that a "most private and most precious responsibility [is] vested in parents for the care and nurture of their children."

The more I speak to parents away from the hospital setting, that is to say, on their own "turf," the more I agree with the Appeal Court's words. For the past 20 years, I have been interviewing families of adults blinded in the original retrolental fibroplasia disaster, and, more recently, parents of seriously damaged ex-premature infants. I have been told how some families feel about their fate to provide lifelong care for a blind, deformed, or brain-damaged child kept alive by heroic medical interventions. Some families are ennobled, but too many are boiling with anger. Parents of a badly damaged baby<sup>16</sup> often resent the implied demand that their family is required to pass a "sacrifice test" to satisfy the moral expectations of those who do not have to live, day after day, with the consequences of a diffuse idealism. It is easy, some parents say, to demand the prolongation of each and every new life that requires none of one's own or the community's resources to maintain that life later. This isolation of the right to prolongation of a frail earthly existence is frightening, and, as Churchill and Siman<sup>17</sup> have pointed out, "profoundly anti-social." The unequal sacrifice seen by parents recalls the story of a chicken and a pig, who walk down a road and find a starving man. The chicken says, "This is terrible, we must give him something to eat." The pig says, "You're right, what shall we feed him?" and the chicken replies, "Ham and eggs."

I have used a Venn diagram (Fig 2) to suggest that the right to personhood granted by law to a newborn infant is an empty gift—only parents or equally committed surrogates can make this right meaningful. When some families refuse highly visible specific medical treatment, they strongly resent the implication that this means the end of meaningful *care* for their child. Moreover, many prefer to carry out their intensely personal ministrations in private; away from the trappings of intensive treatment; surrounded by friends, relatives, and religious advisers, not by strangers on the hospital staff, no matter how well-meaning.

A discussion of "overtreatment" of neonates, in our notoriously litigious country, is incomplete without mention of the awful legacy of actions that led to our "Baby Doe" legislation. The federal child-abuse amendments were passed because of a perception that damaged babies were undertreated. Now the rules are often misinterpreted: they are seen, mistakenly, as the legal prods forcing overtreatment of such infants. Weil<sup>19</sup> has pointed out, "If physicians decide to opt for the 'safe' route and treat every infant, that is a course of their own choosing and not one imposed upon them by government." Nelson<sup>20</sup> is even more forceful in his condemnation of what he terms the "Baby Doe Myth." "Unnecessary legalism, improper disenfranchisement of parents, simplistic reliance on a single popular standard of questionable meaning, and rejection of 'quality of life' considerations are, in my view," he writes, "the deepest and most insidious traps into which physicians and nurses fall . . . today."

There is, to put it mildly, a pervasive suspicion that overtreatment of seriously compromised neonates is now widespread in this country. Note, however, the question mark in the title of this article. Although there is no shortage of highly charged opinion about the issue, there is little more than anecdotal evidence and the results of opinion polls to support the judgment.<sup>21</sup> We are largely ignorant, I suggest, about the

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full social consequences of abandoning the time-honored notion of a limit in prolonging the lives of extremely small or other seriously compromised newborns. I think we will continue to thrash around in a morass of conflicting opinion until we undertake concrete studies to narrow the uncertainty about a "life at any cost" policy in these baffling situations.

Let me be clear about the question I think needs to be addressed: Do arbitrary decisions, made at the time of impending birth of a seriously compromised neonate, result in improved long-term social outcomes, as compared with discretionary decisions? The contrast here lies between the presumption to initiate all-out rescue in most cases, as opposed to a discussion with parents and *based on their wishes*, initiate either all-out treatment or neutral care. The relevant outcomes are looked for in families whose infant did, and in others whose baby did not, survive. The subgroup questions are, "What is the relative impact of death or survival of a marginally viable neonate on families living in poor circumstances, in single-parent families, in drug-addicted families, in unwanted pregnancy, in different cultures, in different social classes. . . ?"

I emphasize the need for follow-up studies of the impact of neonatal death and survival, because the argument for all-out rescue hangs in thin air if it takes into account *only* the outcome in families of survivors. These are the data, I suggest, needed to determine the extent to which an arbitrary, as opposed to a discretionary, rescue policy is sensitive to a complex balance of interests (Fig 3). Churchill and Siman<sup>17</sup> argue that any morality that treats individuals as autonomous units is incoherent—rights are social in origin. The equation of fairness involves not only the best interest of the neonate, but the *competing* interests of the family and the community, who must, at some sacrifice, provide for a completely dependent new child.

Legal scholars discuss these issues<sup>22</sup> in terms of the difference between abstract and concrete rights: whereas abstract rights, like justice and the right to

survive, are considered to belong to every person, concrete rights take into account the possibility of a conflict of claims. The rigid requirement of adherence to an abstract standard, like the "child's best interest" as the sole ethical criterion for decision-making, cannot be supported, because an appeal can be made to the competing interests of others whose rights will be sacrificed, if the abstract right is made concrete. In a family's hierarchy of values, the priority assigned to severely damaged offspring has always been influenced heavily by consideration of its resources, the effect on other family members, and the effect on future childbearing. In the present day, we need to know the extent to which these traditional priorities have changed in the United States. More specifically, we need to find out in each instance whether a family is or is not willing to place the welfare of the severely damaged child ahead of all others. I suggest that a Procrustean, "one-size-fits-all," approach to decision-making often results in what can only be called "the destructiveness of thoughtless benevolence." It describes the enormity of the problem when the value domains of "victims" and "rescuers" are incongruent.

In another context, Lewis Mumford<sup>23</sup> once commented about our endless pursuit for the best guide to regulate human behavior. He said, "In so far as ethics provides a sound guide for living, it must have life's own attributes, its pliability, its adaptiveness to the occasion." The advice in this thoughtful reflection is not new. Theognis of Megara, a Greek poet who lived in the 6th century BC, said, "Wisdom is supple, folly keeps to a groove."

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