

Withholding and Withdrawing Neonatal Therapy: An Alternative Glance Arlov Bellieni, MD

Neonatal care has greatly improved in recent years and it has become possible for very low birth weight or asphyxiated newborns to survive. Until a few years ago, many of these babies inevitably died early. Now we can prolong their life, but with handicaps in many cases. A recent debate centred on whether it is ethical to withhold or withdraw therapy, sometimes in an active way, allowing newborns, presumed unable to lead a normal life, to die. ^{1,2,3,4,5,6}

Attitudes on this ethical question in neonatal intensive care units of four Western countries, ⁷ France, ⁸ The Netherlands, ⁹ and other states ¹⁰ have been published. Guidelines have been proposed for withholding or withdrawing therapy from high-risk newborns, ¹¹ actively hastening death, ^{12,13} suspending parenteral feeding, ^{14,15} and seeking parents' advice. ^{12,10,16} To justify this practice, has been proposed that newborns need not be regarded as persons ¹⁴ and that such intervention is in the interest of the baby, otherwise unable to lead a normal life, ⁶ or in the interests of parents, unable to accept a handicapped child ⁷ as broadly defined to consider physical harm as well as social, psychological, and or financial harm to related third parties: "*there are firm ethical norms that should serve as the basis for coherent and consistent perinatal policy. These include 1) a grant of full moral and legal status to the newborn but only partial moral and legal status to the late-term fetus, 2) a general prohibition against feticide unless to save the life of the mother or prevent the birth of a fetus facing certain death or severe pain and suffering and 3) a general endorsement of neonaticide subject to a parent's assessment of the newborn's interest.*" ⁷

I believe another view that has not received much space in the literature, but which in some countries ¹⁷ motivates reluctance to withhold therapy not to dying babies, but also to babies with a high risk of brain damage, can be taken.

Realism: The Problem of Brain Damage

Brain damage, and how severe it is, become clear as time passes. ⁸ In most cases it is not possible to obtain a certain prognosis at birth. Echographic periventricular hyperechogenicity with EEG evidence of positive Rolandic spikes considered a highly sensitive index of cerebral palsy) in a newborn indicates a risk, not a certainty. However, the same criterion is often used to suspend therapy.

A recent study ¹⁸ compared the results of two different attitudes: that of interventist" NICUs where all sick children are actively resuscitated and that of selective" NICUs where babies to be resuscitated are selected on the basis of risk of brain damage. There was no statistically significant difference in the percentage of healthy and handicapped babies in the two groups. In other words, selecting who should live reduced the number of both handicapped and healthy survivors. This sacrifice can hardly be justified. Prudence is always advisable: before acting, one should have a clear aim and avoid harming third parties.

Rationality: All Factors Considered

a) It is a widespread principle that parents should always be consulted, ^{12,14,16,19} but in practice this does not happen. ^{4,18,19} Consulting parents means giving them an almost unbearable weight which can lead to a personal or family crisis, possibly worse than raising a handicapped child. Not consulting them is paternalism, which is unacceptable in Western society. Although our aim is parents' well-being, proposing their offspring's survival as their own or doctors' choice risks creating the opposite effect, similar to a depressive syndrome. ^{20,21}

b) Parents' reaction depends on the way the news is disclosed.

In Western society, mishaps are viewed as definitive and unforeseen events are unacceptable: both are associated with the idea of death. Western women "*cannot accept the possibility that their pregnancy may end with the birth of a baby whose condition may make normal motherhood impossible.*" ²² When a birth anomaly is announced, their world comes crashing down, as if "drama" and "tragedy" were the same thing. They do not understand that tragedy is a one-way road in darkness, whereas drama is suffering, but not the end of the world. Parents can be helped to see this difference in the manner in which the news is communicated by caregivers, by the way the physician looks at the baby. There are guidelines on how to break the news of birth abnormalities. All insist that the newborn must be present, ²³ because parents' acceptance of the baby is shaped by the physician's attitude and how the parents perceive that. "*If the physician is incapable of elaborating positive representations of the baby, the risk is to identify with the parents, to take extreme positions from scientific detachment to a critical empathy, from rejection to over-protectiveness.*" ²⁴ Caregivers who fail to highlight the potentialities of the newborn, lose their supportive role, ²⁵ because despite handicaps, the newborn has moods and humour and these must be supported and encouraged from the outset. ²⁶

How Much Does It Concern the Doctor?

A flaw of modern Western medicine is that it has increasingly become a mere rendering of services. Once medicine could not avoid the idea of solidarity, which sprang from recognition of physicians' and patients' limits. There has been a shift from the ethics of solidarity in facing troubles to an ethic of escape and fear, escape from relationship and fear of losing the mask that everybody creates when faces someone's pain, withholding therapy in a sick baby is an easy shortcut: maybe too easy to be effective. The feeling of anguish experienced by doctors withholding life support (*"Anguish invades us and leaves its mark. We baptise him and then we kill him"*; *"On days of withholding care I don't feel good: they are heavy, they are not like other days"*⁸) arises from this point. But one cannot always escape from the unknown, i.e., what he cannot manage: *"Modern western medicine is 'scientific', in the sense that it presumes to control and dominate things. But death is unavoidable."*²⁷ Thus withholding or withdrawing life supportive care on the basis of fear of a future handicap is also ominous for caregivers. It is a negation of the desire and wonder of existence, however imperfect; it means negation of the wonder and desire of our own existence, however flawed: *"The caregiver's dialectic is identical to the patient's dialectic. To what extent is the caregiver able to accept a person who is suffering, especially where he is suffering?"*²⁸ The caregiver here falls prey to sentimentalism: *"He who participates in another's pain so deeply as to be crushed by it is capable of compassion but lacks force. He cannot care for the other, because he cannot give him comfort. . . . This temptation grows in the field of loneliness."*²⁹ We cannot forget that eugenic selection is often masked by compassion.

Conclusion

It is well worn practice to withhold or withdraw therapy from seriously ill neonates. I propose another approach that I call the "ethics of wonder": *"We suggest that one source of both moral and intellectual renaissance for the contemporary physician lies in recapturing a sense of wonder for the human body, its place in the natural realm, and its miraculous functioning as the fount, and the medium, of embodied human experience."*³⁰ Let us not exclude the possibility of diagnostic errors, let us not identify drama with tragedy a priori, let us stop and ask the baby, our patient, "Who are you?": our patient will always be more than the sum of his parts and more than the suffering that oppresses him. **E&M**

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