

I think this other way of "knowing" is beneficial in making truly informed decisions, is a parental right, and is the best safeguard against arbitrary or frivolous decisions. The physician-counselor's role, then, is to encourage independence and autonomy. He should allow the parents themselves to decide whether to touch and hold the baby, but should encourage them to do so. Our aim should not be easy choices, but real ones.

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COMMENTARY

by ERIC J. CASSELL

The birth of this child is a tragedy. No matter what decision is made, or whether the child lives or dies, sorrow and suffering will follow. Therefore, there are two immediate problems: first, to make a decision about treatment and second, to minimize pain and suffering, because such relief is a necessary and legitimate object of medicine.

There are two alternative decisions to be made about her care. Either the infant should be permitted to die from the complications of her genetic defect and given care that will comfort her and relieve her suffering; or she should be kept alive until, beyond the limits of technological rescue, she ultimately dies, usually, we are told, within a year. If she is to be kept alive, the tools to be used—respirators, cardiac drugs, resuscitation—are merely technical details.

The case offers four alternative treatment levels, suggesting some ambivalence in the medical staff. Physicians may say, for example, "I believe she should be kept alive, but only if resuscitation for apnea is sufficient," or "only if therapy for heart failure is sufficient." This ambivalence makes the baby's failure to survive beyond a certain level of technologi-

cal support the factor that determines outcome. Such decisions merely extend the wheel of fortune from conception into the neonatal intensive care unit and seemingly remove human agency—an understandable strategy, but an illusion nonetheless.

The parents have two choices. Either life is to be saved at all costs, or the decision to treat the baby is based on the infant's individual characteristics. If the parents believe life must be preserved at all costs, then their decision to treat is obvious. We would all sympathize with them and should do what is necessary to minimize their pain whether the infant survives or dies.

But if the decision is to be made on the basis of what the infant will become—her quality of life, her ultimate length of survival, economics, their ideas about parenthood, the effect on siblings or other family members, and future child-bearing—then clear thinking and as much information as possible will be necessary. Clear thinking is the ability to weigh the evidence and the sets of competing needs and feelings as objectively as possible—to sort out wishes and desires from the facts of this infant's existence now and in the future.

This kind of thinking may be difficult for the mother who has given birth, just three days earlier, to a child that probably bitterly disappoints her nine months of dreams and wishes. Clear thinking will be made even harder by the inevitable feelings of guilt that accompany such a birth. The mother will wonder whether she did something to bring on the defects. Indeed, it is often easier to accept blame and guilt than to accept one's helplessness in the face of a capricious fate.

Now we come to the more pernicious question. Should the parents be encouraged to nurture the child—to touch her and to hold her—before making their decision?

If their decision is to save her life at all costs, what harm could come from not nurturing? The child will not lack such attention in the intensive care unit where nurses will hold and fondle her without the aversion that the inexperienced first feel with a defective child. What good would come from the physician encouraging the parents to hold and

touch the infant before making the decision? They could ask to do so if they wished.

If the decision is to be based on a careful weighing of the baby's individual characteristics and the therapeutic possibilities, I cannot conceive how nurturing would clarify the mother's painful thinking or provide her with more "information." If the child lives there will be time enough for nurturance.

And if the child dies? Recent research confirms what even the most primitive people know: the bonding of parent and child occurs through the mother's nurturance and the child's response. If an infant is adopted at birth and after a period the biological mother wants the child returned, we feel sympathy for the adopting parents. Why? Because nurturing experience has formed a bond between the parents and their adopted child, so that the loss of the child is not merely the loss of a desirable object, but the loss of a loved one.

Why do pediatricians sometimes want the parents with newborns like Baby S to nurture the child? Does the physician wish to teach them, starting here, how to be good parents? Or is there possibly something punitive in encouraging the parent to touch and hold? Does the staff share the magical beliefs on which the parents' feelings of guilt are based? Nurturing this infant will not change her defects or the conditions upon which a decision must be based. But nurturance and the establishment of a bond may make a decision to save the life a selfish one based on the parents' unwillingness to lose a loved one. Furthermore, nurturance will only add to the parents' suffering after her death. Is either a selfish decision or further suffering desirable?

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