

Baby K – A Classic Case Study in the Debate on Futile Medical Care

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Abstract

Baby K, an anencephalic child born without a cerebral cortex in 1992, became the central figure in a landmark legal case of special importance to medical ethics because of the complex issues the case raised with respect to the notions of dignity and personhood, the definition of brain death, and the concept of medical futility. At issue was whether it was clinically and ethically inappropriate to artificially ventilate Baby K. instead of letting nature to take its course, and whether doctors should be required to provide treatment that is futile. This case is used as a starting point to explore the problem of medical futility.

Key Words

Anencephaly

Baby K

Medical ethics

Medical futility

Organ transplantation

Baby K was born in an anencephalic state on October 13, 1992, at Fairfax Hospital in Fairfax , Virginia. That is, she was born missing almost all of her brain. In fact, all that remained of her brain was the “brainstem”, that primitive part of the brain responsible (in part) for autonomic and regulatory function, such as the control of respiration, the heart beat and blood pressure [1-3].

About 1000 anencephalic infants are born annually in the United States. The condition, a form of neural tube defect, can often be diagnosed prenatally, for instance by ultrasonography. About 95% of women who learn that they will have an anencephalic baby choose to have an abortion. Of the remaining 5%, about 55% are stillborn. The rest—the remaining 1000—are said to be "born dying" [4-7].

The maternal serum alpha-fetoprotein (MSAFP) test is useful for screening for neural tube defects such as spina bifida or anencephaly, but the gestational age of the fetus must be known for proper interpretation. The frequency of neural tube defects has been shown to be reduced if women supplement their diet with folic acid, especially during pregnancy [8,9].

In more technical terms, anencephaly is an extreme neurological condition where the victim suffers from the congenital absence of any cerebral cortex or cerebellum, and consequently has only a reflexive, unconscious, brainstem existence. Lacking all cortical function, the victim lacks awareness and consciousness, cannot feel, see or perceive, and can neither suffer nor feel pain. Some clinicians would describe the situation as a form of

permanent, irreversible, general anesthesia, and, in fact, it is generally supposed that anencephalic babies would not need anesthetic drugs to allow surgery to take place.

The diagnosis of anencephaly is almost always obvious on initial clinical examination of the neonate, because the skull is so small and misshapen, not having had the usually amount of internal brain substance to influence normal in utero skull development. Still, confirmation of the diagnosis by MRI or CT imaging studies can occasionally be helpful.

Management of Anencephalic Infants

In almost all cases anencephalic infants are not aggressively resuscitated since there is zero chance of the infant ever achieving a conscious existence. Instead, the usual clinical practice is to offer hydration, nutrition and comfort measures and to “let nature take its course.” Artificial ventilation, surgery (to fix any co-existing congenital defects), and drug therapy (such as antibiotics) are usually regarded as being pointless.

Some clinicians see no point in even providing nutrition and hydration, arguing that withdrawal of nutrition and hydration is morally and clinically appropriate in such cases, as is sometimes done in the case of adults in a persistent vegetative state (e.g., the well-known case of Paul Brophy [10-12]).

One should understand that anencephalic babies are technically not brain dead, as they usually have intact brainstem reflexes. Yet there is a strong clinical consensus that valiant

efforts should not be employed to keep these infants alive. In fact, anencephaly and brain death may be the only two clinical situations that all virtually knowledgeable clinicians agree are futile to treat (except possibly to the extent necessary to allow organ harvesting).

Occasionally parents want clinicians to use all available means to keep anencephalic infants alive as long as possible. However, in most of these cases parents eventually come to realize that there is no possibility of a good outcome from such efforts, and end up agreeing with the clinical team.

But not always. In the case of Baby K., Ms. H., the mother, wanted the hospital to continue with advanced supportive care (primarily ventilatory support) against the wishes of the clinical team, and sought legal support for her position. Ms. H. knew of her baby's condition from the second trimester of her pregnancy, but, motivated by a strong religious conviction that "all life is precious" and that God alone should decide how long the baby would live, she remained adamant that Baby K. be kept alive as long as possible.

The hospital's position was that such care would be futile. At the trial [*Matter of Baby K.* 16 F.3d 590 (4th Cir. 1994), n. 9 at 598.], expert testimony was given to demonstrate that provision of ventilator support for anencephalic infants goes beyond the accepted standard of care. The legal team for Baby K's mother adhered to a religious sanctity-of-life principle as the basis for their case. In the end, in a particularly controversial

decision, the U. S. District Court ruled that the hospital caring for Baby K must put her on a mechanical ventilator whenever she had trouble breathing. In particular, the court interpreted the Emergency Medical Treatment and Active Labor Act (EMTALA) to require continued ventilation for the infant. The wording of this act requires that patients who present with a medical emergency must get "such treatment as may be required to stabilize the medical condition" before the patient is transferred to another facility. The court took the position that "it is beyond the limits of our judicial function to address the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants. We are bound to interpret federal statutes in accordance with their plain language..." As a result of the decision, Baby K was kept alive much longer than most anencephalic babies, living to age 2 ½ .

The court decision had more than mere clinical implications – as noted by Ronald M. Perkin, the decision stripped away the treating doctor's prerogative to act as a "moral agent" and turned the health care team into mere "instruments of technology".

The Case Against Futile Medical Care

Arguments against futile care generally center on two issues. First, futile care has no possibility of achieving a good outcome and serves only to prolong death. No physical or spiritual benefit comes from such care. Futile care also prolongs the grieving process and frequently raises false hope. Also, futile care can be very difficult on caregivers, who may see themselves as forced to act against the best interests of their patient [13].

Secondly, in a setting of limited resources, futile care involves the expenditure of resources that could be used by other patients with a good likelihood of achieving a positive outcome. For instance, in the case of Baby K, attempts to transfer the infant to other centers were unsuccessful because there were apparently no unoccupied pediatric ICU beds in the region. Note also that the medical costs for Baby K.'s care has been pegged at \$500,000. Such an amount of money might have been better spent, some ethicists would argue, on prenatal care aimed at preventing such neural tube defects (for instance, by encouraging the wide spread use of folic acid supplements in women).

The issue of futile care in clinical medicine generally involves two issues. The first issue concerns the identification of those clinical scenarios where the care would be futile. The second issue concerns the range of ethical options when care is determined to be futile.

Let us consider the first issue. While scenarios like providing ICU care to the brain dead patient or the anencephalic patient when organ harvesting is not possible or practical are easily identifiable as being completely futile, many other situations are less clear. For instance, should surgeons attempt a heroic clinical rescue in a 99 year old unconscious patient with a ruptured abdominal aortic aneurysm, even though survival with a good outcome would be so very unlikely as to warrant publication of the case as a clinical case report? What is actually true is that various bleak clinical scenarios will vary in their degree of futility. Another example: when elderly patients sustain large third degree

burns, mortality can be very high. This is similarly true for elderly patients sustaining massive trauma.

The last four decades has seen the clinical community make impressive efforts at improving the quality of their prognostic efforts. As a result, simple but imprecise rules of thumb like “percent mortality = age + percent burn” have now given way to very sophisticated algorithms based on multiple linear regression and other advanced statistical techniques. These are complex clinical algorithms that have been scientifically validated and have considerable clinical predictive value, particularly in the case of patients suffering severe burns [14, 15].

While one intent of such algorithms is to provide high-quality prognostic information to aid patients and families in making difficult decisions, it takes little imagination to see how they could be used to guide resource allocation in a setting of limited resources [16].

Usually such prognostic algorithms produce an estimate of the probability of the patient surviving. While clinicians faced with difficult clinical scenarios where the probability of survival is, say, 30% might be expected to mount a valiant effort, when the chance of survival falls well below 1%, most clinicians would be expected to focus on palliative and comfort measures rather than attempting aggressive clinical measures. In a study of patients so severely burned that survival was clinically unprecedented [17], during the initial lucid period (before sepsis and other complications set in) patients were told that survival was extremely unlikely (i.e., that death was essentially inevitable) and were

asked to choose between palliative care and aggressive clinical measures. Most chose aggressive clinical measures. This suggests that the will to live in patients can be very strong even in hopeless situations.

As another practical clinical example that occurs very frequently in large hospitals, it can sometimes be problematic to decide whether or not to continue resuscitation when the resuscitation efforts following an in-hospital cardiac arrest have been prolonged.

Clinicians often want to know when continuing resuscitation in such settings is futile. A study in JAMA [18] has validated an algorithm developed for these purposes.

The second issue in futile care theory concerns the range of ethical options when care is determined to be futile. Some people argue that futile clinical care should be a market commodity that should be able to be purchased just like cruise vacations or luxury automobiles, as long as the purchaser of the clinical services has the necessary funds and as long as other patients are not being denied access to clinical resources as a result. In this model, Baby K. would be able to get ICU care (primarily ventilatory care) until funding vanished.

However, this market-oriented viewpoint is naïve in several respects. First, in almost all such cases the funding comes from insurance carriers, who must avoid “wasting” funds to ensure that adequate funds are available for other clients. Secondly, competition for ICU resources can be intense, and providing ICU resources to patients who will not benefit from them only makes access more difficult for patients for which ICU care would prove

to be clinically beneficial. Finally, to view clinical care as a mere market commodity or service is to detach it from its underlying dignity and humanity, akin to those who would view sexual liaisons from a purely physiological perspective. (My apologies to those commercial sex workers who might disagree).

Organ Harvesting from Anencephalic Infants

Sometimes the parents of an anencephalic infant want clinicians to harvest their infant's organs to donate to other infants in need of new organs. This way, their grief can lead to another family's joy. This is especially important given that at the moment the only suitable organs for most infants are those from other infants.

However, as noted earlier, anencephalics are not brain-dead. While debates have raged about whether it is appropriate to make an exception in such cases, this has not occurred to date. For instance, in 1992 the parents of an anencephalic baby called Baby Theresa wanted to donate her organs to a needy infant. However, the Florida Supreme Court would not declare her dead. When she died 10 days later, her organs were not suitable for transplantation. That day Baby Theresa's parents and a transplant surgeon appeared on the Phil Donahue Show to talk about the need to change the law.

Perhaps some day the law will change. Some philosophers such as Joseph Fletcher and Peter Singer regard the possibility of a conscious existence as a prerequisite for attaining “personhood”. By such criteria Baby K was never a person and would not be granted the

same moral standing as normally granted to conscious, self-aware, sentient persons. In such a setting anencephalic infants as well as patients in a persistent vegetative state would be suitable as organ donors even though they are technically not brain-dead [19].

For more information on the varied issues involved in organ harvesting from anencephalic babies, the interested reader is referred to discussions from the Committee on Bioethics, American Academy of Pediatrics [20], the Bioethics Committee, Canadian Paediatric Society (CPS) [21] and The Standing Committee on Ethical Aspects of Human Reproduction of the International Federation of Gynecology and Obstetrics (FIGO) [22].

It is of interest to note the extent to which these authoritative bodies disagree. For instance, the Bioethics Committee of Canadian Paediatric Society takes a very cautious stand on the matter. Referring to the problems associated with waiting for anencephalic infants to meet formal brain death criteria, they note [21]:

An alternative approach that has been suggested would be to allow the removal of organs before the anencephalic infant reaches a stage equivalent to conventional brain death. However, we strongly oppose this proposal on the following grounds.

- It might be extended to other groups of "near-dead" patients, including those in a persistent vegetative state, those with other major abnormalities of the central nervous system and those who are chronically comatose.

- It would lead to negative effects on people's confidence and trust in physicians in general and pediatricians in intensive care units in particular.
- It would have negative effects on staff otherwise committed to caring for these patients.
- |
- It would be a further step toward the consideration of anencephalic infants simply as a means to an end.

Compare this stand to that of the FIGO Standing Committee on Ethical Aspects of Human Reproduction [22]:

There have been reports on the use of organs from anencephalic infants for transplantation. It is recognized that the ethical principles of beneficence and protection of the vulnerable can conflict. On the one hand, the principle of beneficence, the imperative of doing good, can apply to a person in need of organs. On the other hand, the principle of protection of the vulnerable newborn might apply in that an anencephalic infant might need protection against being treated as a means to another's advantage.

In view of the potential ethical issue the following guidelines have been developed by the Committee.

1. It is recognized that the purpose of organ donation constitutes an ethical ground for a woman to choose to maintain an anencephalic pregnancy, provided she is fully informed and counseled.
2. When an infant is born with signs of life but has no forebrain (anencephaly) and hence has no prospect of survival, this infant may be declared brain dead, and with parental permission may be placed on a ventilator for the purpose of organ donation. Local legal definitions of death are binding but it is felt that these have to be reviewed to catch up with scientific development.

Conclusion

The case of Baby K. is of particular importance to clinical bioethics because of the rich variety of issues it raises: defining death, the nature of personhood, the notion of moral stranding, medical futility concerns, caregiver issues, resource allocation concerns and much more.

At a personal level, I cannot escape the feeling that in the case of Baby K., the court got it all wrong. Apparently, others share my opinion. In this respect, perhaps Ronald M.

Perkin stated it best:

“Prolonging the dying of Baby K was wrong. This was not a case of factual uncertainty, conceptual ambiguity or moral perplexity. The certainty of the fate of

Baby K was so great among health care providers that there was no room for compromise. The decision to continue to provide care for this child was at the expense of the nurses' and other health care providers' integrity, and resulted in great suffering.”

“The moral crisis in contemporary medicine is not the explosion of technology, but our failure, as a society, to have a sufficient sense of the physical and moral limits involved in any attempt to help and care for one another. Society is not providing medicine with guidance, and this lack of moral consensus to guide medical care intensifies its tragic character. The tragedy involved in the case of Baby K extended far beyond her birth defects.”

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