

# **The Baby Fae Case: Treatment, Experiment, or Animal Abuse?**

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by Richard T. Hull, Ph.D.

Department of Philosophy

State University of New York at Buffalo

*On October 26, 1984, Dr. Leonard Bailey and the transplant team of Loma Linda University Medical Center in California operated on a five-pound baby girl born a few weeks earlier with hypoplastic left heart syndrome. In babies born with this defect the left side of the heart is much smaller than the right and is unable to pump sufficient blood to sustain life for more than a few weeks. This rare defect occurs about once in every 12,000 live births; it accounts for about a quarter of all cardiac deaths of newborns.*

*In an operation known as a xenograft, involving cross-species transplantation of an organ, Dr. Bailey removed the defective heart from the baby and replaced it with the heart of a baboon.*

(Carol Levine, "The Subject is Baby Fae," *Hastings Center Report* 15 (1)(February 1985): 8.

Baby Fae's mother, grandmother, and a male friend of the mother (at the time living with the mother, who was estranged from the father to whom she had never been married) had a conversation with Dr. Bailey over a 7 hour period (starting at midnight) on October 20. Bailey writes that he showed them a film and a set of slides that explained their research on cross-species organ transplantation. The mother, and later the father (who had not received the lengthy explanation), consented to the transplantation. Twenty days later, on November 15, 1984, Baby Fae died as a result of rejection complications. She had lived longer than any other human being who had received an animal's heart.

## **The Issues**

Three major ethical issues loom in the background of journalistic hype and public fascination with this gripping drama which drew us all to the evening TV news for the latest progress reports—ethical issues standing shyly at the coattails of thought, tugging for attention like shy children.

The first issue is the straightforward one of every medical intervention: was what was attempted in this child's interest? The second has to do with the ethics of research: were the canons of ethical research on humans strictly

observed or violated in this case? And the third has to do with the ethics of our treatment and use of animals: was the sacrifice of the baboon, Goobers, consistent with the obligations of humans towards creatures of other species?

I propose to explore these three issues in the context of simplified sketches of three different ethical theories or viewpoints. Just as, in science, our causal understanding proceeds in terms of a scientific theory's explanation of observed phenomena, so in ethics our moral understanding proceeds in terms of an ethical theory's explanation of the moral dimensions of situations and events of concern. A major difference is that we have not achieved the unanimity of theories in Ethics that has been approximated in science. However, I would argue that, as a meta-ethical principle of decision-making, we agree that if a significant proportion of often diverse ethical theories concur in a moral judgment, that judgment is well-confirmed.

The first ethical theory is that of John Stuart Mill's utilitarianism. In essence, this theory endorses the central principle to maximize the balance of pleasure or happiness over pain or unhappiness for any creature capable of experiencing in these dimensions. The ascendancy and influence of this central principle in medicine is marked by a number of features of medical reasoning and practice: the rule Do No Harm, the giving of anaesthesia for surgery, and risk/benefit ratios are all derivations in their justification from this central moral principle.

The second ethical theory is that of Immanuel Kant. A central moral principle of this view is that of respecting the autonomy of rational decision-makers in matters regarding their own welfare. This principle of autonomy serves as the justification for such medical rules as the requirement of informed consent to treatment or to participation in research.

The third ethical theory which will form a basis for our evaluation of the moral facets of this case is the Natural Law Theory. On this view, a central moral tenet is respect for individual human life, regarded as sacred and of inestimable worth. Proponents of this view emphasize in medicine the obligations of health professionals to preserve life where possible and dignity where life's preservation is not possible. It is, however, allowable for a moral agent to sacrifice his life in the course of pursuing a great good for others, but not allowable to impose such a sacrifice on another human.

A quick comparison of these three theories, or rather of their central tenets, reveals important differences. Let me review a few relevant ones, then return to our analysis of the Baby Fae drama.

First, for the utilitarian, sentience and its dimensions of pleasure and pain are critically important features of the beings to whom we owe moral obligations. Note that, qualitatively, the utilitarian maxim does not pick out humans as morally unique in deserving consideration, but may pick out cerebrally-endowed vertebrates as deserving of consideration.

Second, for the Kantian, it is the possession of a faculty of deliberative

reason and the consequent ability to make choices under rules of conduct that is possessed by the morally autonomous agent. The capacity to feel pleasure and pain is, on this view, of relatively little moral import.

Third, for the Natural Law theorist, humanity is the morally sacred quality to be identified and figured into our moral calculations. Creatures that are not human, whether possessed of primitive elements of reason or only sentience, do not lay claim to our efforts to preserve and protect, except insofar as their preservation and protection is one of the opportunities for exercise of human virtue. Mankind has, on this view, dominion over other creatures; and while there may be obligations of such stewardship, those tend only in the directions of conservation and humane treatment, since it is virtuous to be thrifty and non-wasteful and to refrain from causing gratuitous harm.

How, then, would each of these theories assess the Baby Fae case? Let me remind you of the three issues initially identified:

1) Was the xenograft, or transplant of a baboon's heart into a child with hypoplastic left heart syndrome, in Baby Fae's interest?

2) Were the canons of ethical experimentation observed or violated in this case?

3) Was the sacrifice of the baboon, Goober, consistent with our obligations toward creatures of other species?

A utilitarian, in seeking to maximize the balance of pleasure over pain, happiness over unhappiness, would take the following into account:

1. There is no standard, non-experimental therapy for hypoplastic left heart syndrome, a disorder which affects one in 12,000 live births.

2. The alternative paths that currently exist to deal with such cases range from

a. Allow the patient to die (the most common, coming from no known survival rate; i.e., the untreated condition is fatal);

to

b. Provide a heart xenograft (tried two times in humans with no survivors);

to

c. Provide a heart transplant (tried many times in adult humans, only a few times in children: fair success but of questionable long-term value and horrendously expensive;

to

d. a surgical procedure of repair developed by Dr. Norwood of Philadelphia (now with a success rate of 40-50% in children).

3. Assessment of alternatives involves specifying possible consequences, the degree of increase or decrease in the

balance of pleasure and pain associated with each, assessment of the likelihood or probability of each consequence and algebraic summation of the expected values (probability of outcome times degree of positive or negative effect) of each outcome for each act.

4. Assuming that the chief valuational factors are survival and normal life and suffering, the least suffering but non survival would result from non-treatment; the Norwood procedure would involve the suffering of 1 surgery but have a 50% chance of survival; the transplants have the suffering of at least 1 surgery plus a lifetime of risk of infection due to lifelong use of the immuno-suppressant drug, cyclosporin, together with a minimal annual drug bill of \$6,000, and the 5 year survival rate for human-to-human heart transplants is still only about 25%; the survival rate for heart xenografts is 0%.
5. The Norwood procedure would thus be the ethically preferable alternative.
6. The physicians did not correctly present this procedure.
7. Thus, on utilitarian grounds, the xenograft was immoral.

A Kantian would regard the consent issue as crucial, since requirement of a free, informed consent is the mark of rational autonomy.

1. The child is unable to give informed consent.
2. Hence, it is a proxy, parental decision.
3. The obligation of the parent is to act so that the child's potential for survival and maturation into an autonomous adult is maximized.
4. The Norwood procedure has the greatest likelihood for survival.
5. But the parents were not informed of this alternative adequately, and perhaps not at all.
6. Hence, the xenograft was immoral.

Finally, a Natural Law ethicist would have regarded the preservation of the human life, balanced by the preservation of human dignity, as crucial. Since the Norwood procedure had the best chance of the options, it would be morally permissible, with an accompany commitment to withdrawal of extraordinary means if survival appeared to be unattainable.

The xenograft was extraordinary treatment without any scientifically established probability of success. The child could not undertake, as a sacrifice, the experimental procedure, and no human has the moral right to impose such a sacrifice on another. Thus, the procedure that was adopted was not, relative to the alternatives, in the child's interest.

The second issue was the question of whether the procedure observed the canons of ethical research. Since this is a straightforward matter of identifying

the relevant requirements of ethical research and assessing the process that was followed against those canons, we should not expect the answers to differ for the different ethical perspectives.

Since there were alternative treatments each with a known measure of success, and since the empirical data regarding transgenic transplantation did not suggest comparable likelihood of success for the xenograft, and since the child was not able to make an informed choice to sacrifice herself for the advancement of science, the procedure did not follow the canons of ethical research.

Finally, there is the third issue of whether the sacrifice of Goobers, the baboon, was consistent with the obligations of humans toward creatures of other species.

Utilitarians generally accord great significance to sentient life, whether human or non-human. At the same time, they do generally recognize that we have the strongest obligations to our own species: given a choice between saving a cat and a human baby from a burning building, utilitarians would defend the preference of the human child.

However, sacrificing a specific animal to save a specific human as an act with a very low, if non-existent, probability is problematic for utilitarians. Where there is no alternative, or where the alternative would involve the human in a protracted, impaired life of suffering, and the loss of the animal's life can be achieved painlessly, most utilitarians would endorse such a procedure. But where a better alternative (better in terms of likelihood of quality survival of the human) exists, utilitarians have great difficulty preferring the experimental procedure over the alternative. In this case, they would declare the xenograft wrong.

Kantians do not generally regard animals (with some possible exceptions in the higher apes and dolphins and other cetaceans) as possessed of autonomy. Hence, our obligations to animals are derivative to our obligations to humans. We stop the child from pulling the wings off of flies, or torturing a cat or dog, out of concern that the results of allowing a streak of cruelty to go uncorrected will be eventual disrespect of humans. Provided that animals who are used in xenograft efforts are treated humanely and not caused suffering as sentient beings, Kantians would not be troubled by the treatment of Goobers in this case.

A similar observation holds for Natural Law theorists, although for somewhat different reasons. Being human holds the highest value; animals fall under the general characterization of beasts of the earth over whom humans have dominion. While we are not free to abuse animals, they do not warrant our self-sacrifice when it appears that a choice between an animal's life and a human's is at hand. Natural Law theorists would not object to the sacrifice of Goobers the baboon in this case.

As a final illustration of how these theories might operate, let us consider two new scenarios. Suppose you are on a hospital ethics committee and the

following cases come to you because their dimensions are regarded as troublesome by participants in the decisions or their implementation:

A. Baby Fae with her cardiac problems, and an anencephalic child born with no cerebral cortex. For this, assume the cerebral cortex is a crucial, necessary condition of consciousness and thus of autonomy, and assume that the anencephalic child's heart is healthy.

B. A chimpanzee that has developed a remarkable signing vocabulary but has developed a fatal heart condition, and an anencephalic child born with no cerebral cortex but a healthy heart. Assume that the chimpanzee has had previous chimp-to-chimp transplants and has developed hypersensitivity to further same-species transplants, but that a transplant from a human (98% shared genetic material) is more likely to succeed. Further suppose that the chimpanzee has signed that she wants to live.