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behalf of the patient-subject. Reading over the documents in the Barney Clark case, I have my doubts about the “informed consent” he gave to many aspects of what occurred, but at least some possibility of genuine communication and choice existed. Obviously, for Baby Fae, it was impossible.

This leads to the second, and more important, set of issues, which grow out of the role little Fae played in the drama that brought all that attention to Loma Linda University Medical Center. What was she: hero, victim, or patient?

The ancient dictum *primum non nocere* is simply inadequate guidance for those who treat very sick and dying patients. For them, the greatest kindness may not always be to avoid doing any harm, if they wish to risk harm for a chance at improvement. Indeed, some patients decide to join with physician-investigators in path-breaking research—almost as collaborators, as Renee Fox observed in *Experiment Perilous*. On such medical frontiers, they are rightly regarded as heroes.

A child who is “volunteered” for research is not in the same position, however. For this reason, some ethicists have opposed research involving children. Others have suggested that allowing children into experiments (on their parents’ consent, for example) serves to teach a moral lesson, that people in a community owe it to one another to behave altruistically, as by contributing to the discovery of new, useful knowledge.

Such arguments may be persuasive for low-risk studies, but certainly not for innovative therapy of the baboon-heart transplant sort. Here the choice to use a child must rest on the firmest scientific and ethical grounds. Regarding the first, I argued some years ago for a “model of successive approximations,” by which one would try to get down to the least vulnerable child-subjects for procedures designed and tested to involve the least possible risk (for example, only those that had first been proven on older subjects).

When a procedure cannot be tested first on other subjects because it is intended especially for infants (as is said to be the case for babies with Fae’s heart problems), there should be no ambiguity about the obligations of all involved toward the child as patient. For the physicians this means never advancing their research at the expense of the child by foregoing an alternative treatment that offers a better chance.

Did Dr. Leonard Bailey and his colleagues seek a human heart for Baby Fae? Apparently not. Was one available? So a transplant expert in Los Angeles has said.

Hence the concern that Baby Fae may have ended up—like the children in the Willowbrook hepatitis research—as a victim of well-meaning science. And like them, doubts linger not only about the adequacy of the information supplied to Baby Fae’s parents but about whether their personal difficulties made it possible for them to choose freely, and whether the

realization that their child was dying may have left them with the erroneous conclusion that consenting to the transplant was the only “right” thing to do.

More will have to be known about this case before these doubts can be answered. Until then, Baby Fae’s short life will remain with us as a reminder that certain good things—like biomedical research—sometimes go too far, and that others—like the publicity that so often now attends such experiments-in-process—need a very critical reexamination.

## 2 The Other Victim by TOM REGAN

**L**ike most people, my heart broke when Baby Fae died. It was no good my telling myself that thousands of babies die every day. Baby Fae was special. A member of our extended family, she was a child of the nation. When she died, we all grieved.

Others on this occasion will be drawn to debate the ethics of her treatment. I shall not here defend, only voice, my conviction that she was not treated fairly, that her interests were not uppermost in the aspirations of her principal caregivers. On this occasion I am pulled in another direction. For, unlike some people, my heart broke twice during Baby Fae’s public struggle. There were two victims, in my view, not just one, though, like the proverbial black cat in the dark room, the other victim was easy to overlook.

In grieving Baby Fae’s death, we were on familiar ground. She was *somebody*, a distinct individual with an unknown but partly imaginable future. If we allowed ourselves, we could share her first taste of ice cream,

feel the butterflies in her stomach before the third grade play, endure her braces. When we consider the other victim, the baboon, the landscape changes. That lifeless corpse, the still beating heart wrenched from the uncomprehending body: for some people that death marks the end, not of somebody, but of some *thing*. A member of some species. A model. A tool. A token of a type. After all, there were no braces, there was no junior prom, in that brute creature’s future.

Lack of empathy for the baboon is not easily improved upon. Even to note its absence or, more boldly, to suggest the appropriateness of our grieving over “its” death will meet with stiff incredulity in some quarters. When the choice is between a baby and a baboon, can there be any question? Really?

However natural it may seem to answer “no,” I think we must answer “yes.” It is true that Goobers (though seldom used, this was the baboon’s name) had a quite different potential, a quite different future form of life than Baby Fae. But no one, surely, will seriously question whether the duration and quality of his life mattered to that animal. Surely no one will seriously suggest that it was a matter of indifference to Goobers whether he kept his heart or had it transferred to another. Are we not yet ready to see that creatures such as baboons not only are alive, they have a life to live?

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The weary charges of "anthropomorphism" will fill the air. Baboons feel pain, it may be allowed. But their sentience exhausts their psychology. A twinge of discomfort here, maybe a warm stroke of pleasure there; that about does it.

This sparse view of baboon psychology will not stand up under the weight of our best thinking, neither philosophical nor scientific. Baboons not only feel pain, they *prefer* to avoid it, *remember* what it is like, *intentionally* seek to avoid it, *fear* its source. To describe and explain baboon behavior in such mentalistic terms is intelligible, confirmable, and defensible. As Darwin saw, and as we should see, the psychology of such creatures differs from ours in degree, not in kind. Like us, Goobers was *somebody*, a distinct individual. He was the experiencing subject of a life, a life whose quality and duration mattered to him, independently of his utility to us.

Suppose this is true. Where does it take us morally? Everything depends on how firm the moral status of experiencing subjects-of-a-life is believed to be. You are such a subject, and so am I. Morally, I do not believe that you exist *for me*, as my resource, to be used by me to forward my own or, for that matter, someone else's interests. And, of course, I do not believe that I exist as your resource either. Just as I would violate your right to be treated with respect if I forced my will on you in the name of promoting my own or anyone else's welfare, so you would do the same to me if you treated me similarly. This sort of strict equality between us, viewed as experiencing subjects-of-a-life, is, I believe, the fundamental precept in terms of which the morality of all our interactions ultimately must be gauged.

I would appeal to this precept to defend my opposition to using a healthy Baby Fae's heart to save the life of a sick Goobers. She did not exist as his resource. But I would insist upon equal treatment for Goobers. He did not exist as her resource either. Those people who seized his heart, even if they were motivated by their concern for Baby Fae, grievously violated Goobers's right to be treated with respect. That he could do nothing to protest, and that many of us failed to recognize the transplant for the injustice that it was, does not diminish the wrong, a wrong settled before Baby Fae's sad death. Fundamental moral wrongs are not alterable by future results. Or past intentions.

What, then, can we do when, as is cer-

tain, we face other Baby Faes whose life hangs by a thread? Morally and medically, we must do everything we may, balancing, as best we can, the vital interests present in health care contexts such as these against those we find in others. With limited resources, we cannot, alas, do everything it would be good to do. What

we must not do, either now or in the future, is violate the rights of some in order to benefit others. Our gains must be well, not ill, gotten. One measure of our medical progress will be the number of Baby Faes we are able to keep alive. But our resolve not to kill future Goobers will be one measure of our moral growth.

## 3 Clinical Urgency and Media Scrutiny

by KEITH REEMTSMA

I would like to comment on two questions that the Baby Fae case raises: First, when is it proper to move from the experimental laboratory to the operating room with new procedures? Second, what is the proper role of public information in cases such as this?

There is a widespread misperception that medical treatments and surgical procedures are easily classified as either experimental or accepted. In fact, all treatments have an element of experimentation, and new surgical procedures are based on extrapolations from prior work. Baby Fae was not the first baby to have a heart transplant nor the first person to receive a vital organ from a non-human primate.

When does a surgeon decide to apply a new operation to a patient? There is no simple answer to this question, but the decision is based on balancing, on the one hand, the experimental evidence suggesting the procedure may succeed, and, on the other, the clinical urgency—including alternate approaches. As the Baby Fae case shows, answers to these questions rarely are unambiguous. There is no single standard that permits a surgeon to guarantee that a laboratory experiment on an animal will be successful in a human. And there are mountains of evidence that procedures may

succeed in humans that were unsuccessful in animals. For example, in the 1950s, open-heart surgery was never proved to be consistently successful in animals before it was applied to humans.

What was the a priori evidence that a primate heart might succeed in Baby Fae? There is evidence from the 1963-64 studies that primate kidneys may function for months in humans. And Baby Fae had two advantages: as a newborn, she might have been more likely to accept a graft (although this is far from certain), and she received immunosuppressive drugs that were superior to those available two decades ago. These factors, and the clinical urgency, can be used to make a persuasive case for the physicians taking care of Baby Fae.

The second area for comment is the role of public information in the Baby Fae case. Science and news are, in a sense, asymmetrical and sometimes antagonistic. News emphasizes the uniqueness, the immediacy, the human interest in a case such as this. Science emphasizes verification, controls, comparisons, and patterns. Such scientific studies may not be possible in time for an afternoon press conference, and the uncertainties that scientists express may be misinterpreted as a lack of candor.

In evaluating the place of public information in the Baby Fae case, I believe the patient's and family's right to privacy takes precedence over the public's right to know, and I have sympathy for physicians and administrators who are involved in situations

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