

Human experimentation at Willowbrook Immoral?

Researchers said no

By ROBERT L. BENSON

Not since the discovery of the Nazi medical experiments in the aftermath of World War II has the subject of human experimentation been so much on the mind of thoughtful Americans as it is today. The reasons for this public consciousness and concern are many and evident, but no doubt most responsible is the succession of 'horror stories' to which we have been regularly treated over the past decade or so in the media.

Experiments by the military and intelligence services ended in at least one death. In a Manhattan hospital 22 seriously ill patients were injected with live cancer cells but were told only that they would be receiving "some cells." Syphilis was allowed to ravage the bodies of 200 black men so that scientists could learn more about the destructive effects of the disease. Retarded children at Willowbrook were infected with hepatitis. And so the stories go . . . on and on.

I have referred to these incidents as "horror stories" in the belief that the vast majority of us would, on closer study of these cases, agree in finding them grossly immoral. Yet these experiments were conducted by eminently respectable men and reviewed and approved by prestigious and responsible public and private agencies including in many cases ethics committees of medical centers and universities.

Further, after charges of immorality were voiced, those responsible for the experiments vigorously and unwaveringly defended the morality of what they had done.

In such a situation of moral confusion, or at least moral disagreement, it is not enough to simply "feel" one way or the other. It is necessary to *think*. This is never easy and the special complexity of moral problems makes it more than usually difficult to proceed beyond our "gut" feelings to reasoned argument. But reason is our only alternative to force and bureaucratic fiat.

What is the truth in the matter of the morality of human experimentation? Is it ever right to experiment on human beings? If so, under what conditions and subject to what limitations?



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I will attempt the beginning of an answer to these questions by discussing some of the more basic principles and lines of reasoning relevant to the problem. In an effort to minimize the generality and abstraction inherent in ethical argument, I will develop the line of thinking I wish to suggest in relation to a particular concrete case of questionable human experimentation, a case that also hits quite close to home: The hepatitis experiments at Willowbrook.

Hepatitis experiments had been conducted at Willowbrook for a period of some 15 years before a United States district court ruled in 1973 that "no physically intrusive, chemical, or bio-medical research or experimentation shall be performed at Willowbrook . . ." on residents.

It is not possible in this limited space to describe the experiments in their detail and sophistication. Some additional relevant data will be mentioned later, but for the moment three things should be mentioned: The research was extremely important; it was carried out in accordance with the highest scientific standards; and, most significant for the ethical question, it involved infecting newly admitted retarded children between the ages of 5 and 10 with hepatitis virus.

The physician-researchers at Willowbrook believed that their experiments were morally justified. They did not ignore the moral question and they did not proceed with their investigations with a bad conscience. In their very first published paper (New England Journal of Medicine, February 1958) they addressed the matter of morality and presented a number of considerations which they felt justified their undertaking. Their reasoning was no doubt persuasive to the numerous local, state and federal agencies as well as to the executive faculty of the NYU School of Medicine, which approved the project.

In the late '60s, when questions began to be raised about the propriety of the experiments, those responsible responded aggressively to their critiques and they were supported by many others in the medical community who had no role at all in the experiments. It will lead us to a deeper understanding of the complexity of the issue if we examine this justification in some detail.

1. Perhaps the most fundamental and widely accepted principle governing human experimentation is the consent requirement. If experimentation in man is ever morally justifiable, only then when the "free and informed consent" of the experimental subject has been obtained. But the retarded children at Willowbrook did not and could not consent. How then could the researchers and prestigious reviewing bodies find these experiments morally acceptable?

The answer is simple although, as I hope to show, not unproblematic: parental consent was obtained. No children without parents and no wards of the state were used. In fairness to the researchers it should also be noted that both the World Medical Association and the AMA have adopted ethical guidelines governing human experimentation.

which recognize the validity of "proxy" consent, even going beyond parental consent to accept the consent of more remote "legal representatives."

2. A second justifying element which can be distinguished in the moral reasoning of the researchers bears upon a second objection which the common moral sense might raise against what was done at Willowbrook, namely, that the experiments conferred no benefit on these subjects. They were infected with a disease, they were asked to make a sacrifice, and they got nothing in return.

It does not take a great deal of thought to see that experiments in man must be divided into two fundamental types: Therapeutic and non-therapeutic experiments. The former category comprises those experiments whose object is the cure or amelioration of the patient's own disease. Experiments of this sort, although they also, like all treatment, require consent, do not raise serious moral questions.

If an untried treatment, procedure, drug or operation is a patient's sole or best hope, then the moral problems raised by such "experiment" seem to be negligible, or at least of an entirely different kind from those posed by non-therapeutic experimentation. Questions which we might have had or still do have about the wisdom of kidney and dialysis, heart transplants, open-heart surgery, etc. do not turn on the fact that they are or were experimental but on other considerations.

Of course, the experimental procedure must really be the patient's best hope or at least it must involve no more risks than not participating in the experiment (as, for example, those who took the Salk vaccine in its experimental stages probably ran no greater risk of contracting polio than those who were naturally exposed to an epidemic situation each summer). It would be immoral to experiment on a patient even in treatment if another, tried remedy offered equally good prospects.

In non-therapeutic experimentation, on the other hand, the hazards to which the subject is exposed are not offset by any expected or even hoped-for benefits to him. The subject is asked simply to make a sacrifice, and there is never any question of a "therapeutic" result in his interest (especially since, as in the Willowbrook experiments, he is not sick). He must act out of personal idealism, whereas the subject of a therapeutic experiment acts out of self-interest.

Finally, we can see why in the case of therapeutic experimentation it is sometimes justifiable to experiment without obtaining consent or at least why proxy consent raises no questions: If the patient is unconscious, underage or mentally incompetent, his consent can be "constructed" or assumed since the experimental procedure is being carried out in his interest.

A number of the reasons adduced in justification of the Willowbrook experiments would seem to have their final rationale in the attempt to assimilate them to the model of therapeutic experimentation. First, it is pointed out that hepatitis had come to be a highly prevalent disease at Willowbrook and the conclusion is drawn that those artificially infected with the disease as experimental subjects would have gotten the disease anyway under the "natural" conditions prevailing at the institution.

Second, since the children participating in the study would have become infected in due course anyway, it is pointed out that it was to their advantage to have the disease under the favorable conditions prevailing within the experimental situation: special isolation quarters with special medical nursing personnel to provide close observation and extra care. The isolation feature carried with it the further advantage of protecting them from other infectious diseases prevalent at the institution. In the words of one of the leaders of the experiment: "Their exposure in the hepatitis unit would be associated with less risk than the type of institutional exposure where multiple infections could occur."

A third point made in justification brings out the "therapeutic" rationale most clearly: "It should be emphasized that the artificial induction of hepatitis implies a 'therapeutic' effect because of the immunity which is conferred." All of the reasons cited above, especially the last, draw their justifying force from the therapeutic model, from the principle that a human experiment is justified if it will benefit the subject or at least not harm him any more than he would be harmed under "natural" conditions.

3. We turn now to a third distinct reason advanced by the Willowbrook experiments in defense of their study: The mildness of the disease. Having obtained parental consent and established a "therapeutic effect," the experimenters now point out that hepatitis is a much milder disease in children than in adults and, further, that the particular strain endemic at Willowbrook was especially mild and even in adults did not produce severe illness. The effects of the disease consisted essentially of enlargement of the liver, lasting several weeks, and vomiting and loss of appetite, lasting usually only a few days.

When we ask ourselves why the mildness of the disease should be considered a justifying fact, we may be puzzled. Of course, it is a mitigating feature; it would certainly be heinous to inflict a severe illness on a child. But why should it count in favor of the moral acceptability of the experiment that the disease was not severe?

The only logic that occurs to me depends on a principle sometimes advanced in discussions of experimenta-

tion, namely, that an experiment is justified if there is "no discernible risk" involved. This principle has been appealed to especially in connection with children who cannot consent. One might feel no moral aversion to an experiment on a baby which involved a pin-prick to obtain a drop of capillary blood since such an experiment appears to involve absolutely no risk to the child.

4. Finally, the benefits to mankind which could be expected to follow from greater understanding of hepatitis are cited as a fourth justifying consideration. In the original paper, the researchers made reference to the possible benefits to the Willowbrook community: "A serious uncontrolled endemic situation existed in the institution, and knowledge obtained from a series of suitable studies could well lead to its control."

But since the control of viral hepatitis is one of the foremost problems in preventive medicine, the important research being done at Willowbrook promised benefits to adults and children everywhere. As one defender of the Willowbrook experiments put it: "Is it not proper and ethical to carry out experiments in children ... in which the parents as well as the physicians feel that a significant contribution to the future well-being of similar children is likely to result ... ?"

To sum up: The researchers and their defenders felt it was justified to infect retarded children with hepatitis 1) because they had obtained the consent of their parents, 2) because certain advantages accrued to the children as a result of participating which seemed to make a case for considering the experiments "therapeutic" in nature and hence less problematic, 3) the disease was extremely mild and, 4) the research was extremely significant and promised great benefits for humanity.

The question we must now ask is: Does this justification in fact justify? Do the facts put forward and the reasoning which connects those facts with morally acceptable principles really convince and yield the conclusion that the Willowbrook experiments were morally proper? What I will now try to show is that the answer is a clear and emphatic "No!"

Tomorrow: A critique of the Willowbrook justification.