

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.