Willowbrook Hepatitis Experiments

Background

Willowbrook State School in Staten Island, N.Y., housed and cared for mentally disabled children. Dr. Saul Krugman from the New York University School of Medicine and his coworkers began conducting hepatitis studies there in 1955 and continued for more than 15 years. Hepatitis was a major problem at Willowbrook for patients and staff, and Krugman believed that most newly admitted children became infected with hepatitis within the first year of residence in the institution. (More recent estimates put the risk of a child contracting hepatitis at Willowbrook at 30 to 50 percent.)

Hepatitis A is a relatively mild disease affecting the liver. Symptoms include jaundice, fatigue, abdominal pain, loss of appetite, nausea, diarrhea, and fever. It is usually spread from person to person when someone puts something in his or her mouth that has been contaminated with the feces of an infected person.

It was known at the time that the response to infection was milder in the younger children and that once infected, children were protected against the more damaging forms of hepatitis. Krugman was interested in using gamma globulin antibodies (taken from the blood of hepatitis patients) as a way to create immunity in others.

Antibodies are produced by the body's immune system in response to foreign substances. Krugman thought that if a child was infected with hepatitis after he or she had been injected with these protective antibodies, a *mild* case of hepatitis would result, and the child would have long-lasting protection against future, potentially more serious, infections. His goal was to find the best ways to protect children from hepatitis.

More than 700 children at Willowbrook were involved in the studies, which fell into two categories. The first used children who were already at Willowbrook. Researchers injected some with protective

antibodies (the experimental group) and did not inject others (the control group). Then, they observed the children's degree of immunity to hepatitis.

In another series of studies, researchers gave newly admitted children protective antibodies. A subset of these children were then deliberately infected with hepatitis virus (obtained from sick children). Those who had received protective antibodies but were not deliberately infected served as the controls. The children in this experiment were housed in a well-equipped and well-staffed facility where they could be given special care and be kept away from the other types of infections at the institution.

As the studies progressed, researchers noticed differing symptoms caused by different virus samples. They concluded that there are two strains of hepatitis, A and B. Hepatitis B is more difficult to pass on to others because it is spread through blood and sexual contact. Hepatitis B can lead to long-term (chronic) infection.

The children who were deliberately infected with hepatitis A virus had a mild reaction (a swollen liver, yellowing of the skin and eyes, and a few days of vomiting and not eating). The researchers noted that many children would become infected during their stay at Willowbrook, anyway. Children who naturally got hepatitis from other children had worse symptoms than those who got it from the study.

The researchers obtained consent from the parents of each child. Parents of children who participated early in the study gave consent after receiving information provided by Willowbrook orally and in writing. Parents of children who participated later could meet the research staff, tour the facility, discuss the program with the staff and other parents, and speak with their own private physicians. Then, after several weeks, researchers asked for the parents' consent.

Letter to Parents

This is the letter parents received from researchers in the Willowbrook Study.

November 15, 1958	Willowbrook Study Staten Island, New York
Dear Mrs:	
We are studying the possibility of preventing epidemics of hepatitis on a new principle. Virus is introduced and gamma globulin given later to some, so that either no attack or only a mild attack of hepatitis is expected to follow. This may give the children immunity against this disease for life. We should like to give your child this new form of prevention with the hope that it will afford protection.	
Permission form is enclosed for your consideration. If you wish to have your children given the benefit of this new preventive, will you so signify by signing the form.	

Source: Rothman, D., and Rothman, S. 1984. The Willowbrook Wars. Cambridge: HarperCollins, pages 265–266.