

# Twenty Years of Followup Experience In a Long-Range Medical Study

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ONE OF THE longest continued medical surveys ever conducted is the study of untreated syphilis in the male Negro. This study was begun by the Public Health Service in the fall of 1932 in Macon County, Ala., a rural area in the eastern part of the State, and is now entering its twenty-second year (1-4). This paper is the first report dealing with the nonmedical aspects of the study. The experiences recounted may be of value to those who are planning continuing studies in other fields.

In beginning the study, schedules of the blood-drawing clinics throughout the county were announced through every available source, including churches, schools, and community stores. The people responded willingly, and 600 patients were selected for the study—400 who had syphilis and, for controls, 200 who did not. The patients who had syphilis were all in the latent stage; any acute cases requiring treatment were carefully screened out for standard therapy.

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At Tuskegee, each of the 600 patients initially was given a complete physical examination, including chest X-rays and electrocardiograms. Careful histories were taken and blood tests were repeated. Thereafter, each of the patients was followed up with an annual blood test and, whenever the Public Health Service physicians came to Tuskegee, physical examinations were repeated.

There have been four surveys: in 1932, 1938, 1948, and 1952. Between surveys contact with the patients was maintained through the local county health department and an especially assigned public health nurse, whose chief duties were those of followup worker on this project. The nurse also participated in a generalized public health nursing program, which gave her broad contact with the families of the patients and demonstrated that she was interested in other aspects of their welfare as well as in the project. The nurse was a native of the county, who had lived near her patients all her life, and was thoroughly familiar with their local ideas and customs.

A most important phase of the study was to follow as many patients as possible to post-mortem examination, in order to determine the prevalence and severity of the syphilitic disease process. Cooperation of patients with this plan was sought by offering burial assistance (through a private philanthropy, the Milbank Memorial Fund) on condition that permission be granted for autopsy. For the majority of these poor farmers such financial aid was a real boon, and often it was the only "insurance" they

could hope for. The Federal Government offered physical examinations and incidental medication, such as tonics and analgesics, but was unable to provide financial assistance on a continuing basis. The Milbank Memorial Fund burial assistance made it possible to obtain a higher percentage of permissions for post-mortem examinations than otherwise would have been granted.

Transportation to the hospital for X-rays and physical examination was furnished by the nurse. Her car was too small to bring in more than two patients at one trip; therefore, two men were scheduled for examination in the morning and two for the afternoon. During the early years of the study, when the county was strictly a rural one, the roads were very poor, some being impassable during the rainy season. Very often, the patients spent hours helping to get the car out of a mudhole. Now, with modern conveniences (telephones, electricity, cars, and good roads) the nurse's problems are fewer than in the early days.

Having a complete physical examination by a doctor in a hospital was a new experience for most of the men. Some were skeptical; others were frightened and left without an examination. Those who were brave enough to remain were very pleased. Only one objection occurred frequently: the "back shot," never again! There are those who, today, unjustifiably attribute current complaints (backaches, headaches, nervousness) to those spinal punctures.

### Followup

The patients have been followed through the years by the same nurse but by different doctors. Some doctors were liked by all the patients; others were liked by only a few. The chief factor in this was the length of time doctor and patients had to get to know each other. If the doctor's visit to the area was brief, he might not have time to learn and to understand the habits of the patients. Likewise, the patients did not have an opportunity to understand the doctor. Because of their confidence in the nurse, the patients often expressed their opinion about the doctor privately to her. She tried always to assure them that the doctor was a busy

person interested in many things, but that they really were first on his program.

It is very important for the followup worker to understand both patient and doctor, because she must bridge the gap between the two. The doctors were concerned primarily with obtaining the most efficient and thorough medical examination possible for the group of 600 men. While they tried to give each patient the personal interest he desired, this was not always possible due to the pressure of time. Occasionally, the patient was annoyed because the doctor did not pay attention to his particular complaint. He may have believed that his favorite home remedy was more potent than the doctor's prescription, and decided to let the whole thing go. It then became the task of the nurse to convince him that the examinations were beneficial. If she failed, she might find that in the future he not only neglected to answer her letters but managed to be away from home whenever she called. Sometimes the doctor grumbled because of the seemingly poor cooperation and slowness of some of the patients; often the nurse helped in these situations simply by bridging the language barrier and by explaining to the men what the doctor wanted.

Sometimes the nurse assisted the physician by warning him beforehand about the eccentricities of the patients he was scheduled to see during the day. For example, there was the lethargic patient with early cancer of the lip who needed strong language and grim predictions to persuade him to seek medical attention. On the other hand, there was the hypochondriac who overheard the doctor mention the 45° angle of rotation of his body during the X-ray examination; the next day, the entire county was buzzing with gossip about their remarkable friend who was "still alive, walking around with his heart tilted at a 45° angle."

Following a group of patients in a specialized field over a period of years becomes monotonous to patient and nurse, and both could lose interest easily. For the patients, the yearly visits by the "Government doctor," with free medicines, revived their interest. The annual blood tests and the surveys were always scheduled at "slack" times, between fall harvest and spring planting. The patients congregated in groups at churches and at crossroads to meet the nurse's

car in the morning. As the newness of the project wore off and fears of being hurt were relieved, the gatherings became more social. The examination became an opportunity for men from different and often isolated parts of the county to meet and exchange news. Later, the nurse's small car was replaced with a large, new, Government station wagon. The ride to and from the hospital in this vehicle with the Government emblem on the front door, chauffeured by the nurse, was a mark of distinction for many of the men who enjoyed waving to their neighbors as they drove by. They knew that they could get their pills and "spring tonic" from the nurse whenever they needed them between surveys, but they looked forward happily to having the Government doctor take their blood pressure and listen to their hearts. Those men who were advised about their diets were especially delighted even though they would not adhere to the restrictions.

Because of the low educational status of the majority of the patients, it was impossible to appeal to them from a purely scientific approach. Therefore, various methods were used to maintain and stimulate their interest. Free medicines, burial assistance or insurance (the project being referred to as "Miss Rivers' Lodge"), free hot meals on the days of examination, transportation to and from the hospital, and an opportunity to stop in town on the return trip to shop or visit with their friends on the streets all helped. In spite of these attractions, there were some who refused their examinations because they were not sick and did not see that they were being benefited. Nothing provoked some of the patients more than for a doctor to tell them that they were not as healthy as they felt. This attitude sometimes appeared to the examining physician as rank ingratitude for a thorough medical workup which would cost anyone else a large amount of money if sought at personal expense. At these times the nurse reminded the doctor of the gap between his education and health attitudes and those of the patients.

When a patient asks the nurse for help because he is a "Government patient" and she explains there are no funds for this, he may point out that he needs assistance while he is living, not after he is dead. Whenever the nurse

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## A Career in Nursing Service

Miss Rivers knows her patients well. She was born in Georgia and has lived in that vicinity her entire life. After graduation from the Tuskegee Institute School of Nursing in 1922, she joined the Alabama State Department of Health. There she was assigned to the bureau of maternal and child welfare where she helped farmers and their wives in the rural areas of Alabama with problems of home nursing and home hygiene. In a later assignment with the Alabama bureau of vital statistics, she assisted midwives in problems of rural nursing and in their vital statistics reports. After 8 years of work for the State, she returned to Tuskegee to be night supervisor of the John A. Andrew Memorial Hospital.

In 1932, Miss Rivers was offered a position as night supervisor in a New York general hospital. She chose, instead, to stay in Alabama as a scientific assistant with the Division of Venereal Disease of the Public Health Service. Miss Rivers still holds this position, in which she cooperates with the physicians and contact investigators on the Tuskegee untreated syphilis study. She also is the contact worker with the venereal disease control program in addition to assisting in the general nursing service of the Macon County Health Department.

Among her deepest convictions is the belief that rural areas desperately need good and sympathetic nurses to participate in and carry out effectively public health programs, as well as private medical care. She feels very strongly, on the basis of her own experience, that the girl who is trained in nursing in a rural area is much more likely to live and practice nursing in that area. Miss Rivers feels that, had she taken the offer to go to New York City many years ago, she probably would never have returned to the people with whom she is so familiar and for whom she feels she now can do her small part to contribute to better health and advances in public health.

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heard this complaint, she knew that there was danger of a lost patient. She appealed to him from an unselfish standpoint: What the burial assistance would mean to his family, to pay funeral expenses or to purchase clothes for his orphaned children. Even though a large number wished they might derive more benefits

from being "Government patients," most of them answered the call to meet the doctor, some willingly, others after much persuasion.

The study group was composed of farmers who owned their homes, renters who were considered permanent residents, and day laborers on farms and in sawmills. The laborers were the hardest to follow. Some of the resident farmers traveled to other sections seeking work after their own crops had been harvested, but they came back when it was time to start planting. An effort was made continually through relatives to keep informed of the patients' most recent addresses, and this information regularly has been placed in their records. During the 20 years of the study, 520 of the original 600 men have been followed consistently if living, or to autopsy. It is possible that some of the 80 now considered lost will at some time return to the county or write the nurse from distant places for medical advice.

### **Autopsies**

The excellent care given these patients was important in creating in the family a favorable attitude which eventually would lead to permission to perform an autopsy. Even in a friendly atmosphere, however, it was difficult for the nurse to approach the family, especially in the early years of the project, because she herself was uneasy about autopsies. She was pleasantly surprised to receive fine response from the families of the patients—only one refusal in 20 years and 145 autopsies obtained. Finally, the nurse realized that she and not the relatives had been hesitant and squeamish.

Sometimes the family asked questions concerning the autopsy, but offered no objections when they were assured that the body would not be harmed. If the patient had been ill for a long time and had not been able to secure any relief from his symptoms, they were anxious to know the reason. If he had died suddenly, they were anxious for some explanation. They also feared that some member of the family might have the same malady, and that information learned from the autopsy might aid them. Now, after many years, all of the patients are aware of the autopsies. When a member of "Miss Rivers' Lodge" passes, his sur-

living colleagues often will remind the family that the doctor wants "to look at his heart." Autopsies today are a routine; neither nurse nor family objects.

One cannot work with a group of people over a long period of time without becoming attached to them. This has been the experience of the nurse. She has had an opportunity to know them personally. She has come to understand some of their problems and how these account for some of their peculiar reactions. The ties are stronger than simply those of patient and nurse. There is a feeling of complete confidence in what the nurse advises. Some of them bring problems beyond her province, concerning building, insurance, and other things about which she can give no specific advice. She directs them always to the best available sources of guidance. Realizing that they do depend upon her and give her their trust, she has to keep an open mind and must be careful always not to criticize, but to help in the most ethical way to see that they get the best care.

### **Conclusions**

Experience with this project has made several points clear which may benefit anyone now engaged in planning or executing a long-range medical research study:

1. Incentives for maximum cooperation of the patients must be kept in mind. What appears to be a real incentive to an outsider's way of thinking may have little appeal for the patient. In our case, free hot meals meant more to the men than \$50 worth of free medical examination.
2. The value of rapport and sympathy between patient and physician, and between patient and nurse or followup worker never can be overestimated. Material incentives can merely supplement and support a basic feeling of good will. A kind word is often worth a carton full of free medicines. A single home visit is worth more than a dozen letters on impressive stationery.
3. Changes in key personnel over the years in a long-range project can seriously weaken the project by upsetting continuity and familiar routine. It is not amiss to start a long-

range study with young personnel who should then be around for the conclusion of the project. On the other hand, some new personnel may bring fresh ideas and energies to a lagging effort.

4. Teamwork between all members of the research staff is essential: doctor, nurse, investigator, technicians, and clerks all must work together for a common goal. They must appreciate the importance of each other's efforts to the success of the whole.

5. As difficult as it may be to maintain patient interest and personnel efficiency in a long-term study, there is still the advantage of momentum which gathers slowly but increasingly, until patient cooperation becomes so routine as to be habitual. Difficulties often can be anticipated due to previous experience, and thereby avoided.

6. The gains to medical knowledge derived from the horizontal, long-term study of illness and health are only just beginning to be real-

ized. As public health workers accumulate experience and skill in this type of study, not only should the number of such studies increase, but a maximum of information will be gained from the efforts expended.

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## Annual Symposium on Venereal Diseases

The annual symposium on Recent Advances in the Study of Venereal Diseases, sponsored by the experimental therapeutics study section of the National Institutes of Health, Public Health Service, will be held at the Federal Security Building in Washington, D. C., April 30 through May 1, 1953. The symposium will take place in conjunction with the 15th annual session of the American Venereal Disease Association.

All scientific workers interested in this field, including biologists, physicians, representatives of industry, epidemiologists, and public health nurses, are invited to attend. Further information may be obtained from Dr. Frederick W. Appel, executive secretary, experimental therapeutics study section, National Institutes of Health, Bethesda 14, Md., or from Dr. John C. Hume, secretary, American Venereal Disease Association, 615 N. Wolfe Street, Baltimore 5, Md.