6-15-1984

Interview with Edward Bynum

Edward Bynum

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Abstract: In his June 1984 interview with Michael Cooke, Edward Bynum described his time with the James R. Clark Memorial Sickle Cell Foundation and his work with hematology and sickle cell anemia research. Bynum covered topics of hematology and training, the CDC, DHEC, sickle cell anemia and trait, and thalassemia. This interview was conducted for inclusion into the Louise Pettus Archives and Special Collections Oral History Program.

Keywords: Sickle cell anemia and trait, thalassemia, James R. Clark Memorial Sickle Cell Foundation, CDC (Centers for Disease Control and Prevention), DHEC (Department of Health and Environmental Control), hematology, Dr. James R. Clark

Interview Session (June 15, 1984): Digital File

Time          Keywords

00:00:00  Start of Interview/Interviewer’s Introduction

00:00:20  Question: Could you give us a brief biographical sketch of your life? Answer: EB was born in Washington, D.C. in 1933. Went into the U.S. Navy after high school and performed duties on a hospital ship. Went to the United States Medical School and received his certificate from the Bureau of Medicine and Surgery in another hospital. He was discharged from the navy and lived in Long Beach, California, where he went back to school. He returned to Washington, D.C. and worked at Freedman’s Hospital, then went back to school and moved to D.C. General Hospital. He worked with the hematologist in charge of the hematology blood bank department. The hematologist had been working with children with sickle cell anemia. After leaving D.C. General, EB worked at Princeton University Hospital and also worked in the hematology department. In 1970, EB went back to D.C. and further worked with children with sickle cell anemia. In 1972, EB moved to Columbia, S.C., where he met James R. Clark and worked alongside him at the
foundation (what would be the foundation). In 1975, EB left to go to Baltimore and did further testing on hemoglobin. When EB returned to Columbia, he continued to help set up the James R. Clark Memorial Sickle Cell Foundation.

Question: When did you return? Answer: EB returned in 1981 and started back with the foundation in 1984. In 1983, EB worked with setting up a laboratory in Columbia. The laboratory was officially setup in 1984. EB’s job, at the time of the interview, was to educate, counsel, and teach various topics about hematology and related subjects at the University of South Carolina.

Question: How many tests have proved positive that you’ve conducted so far? Answer: Approximately 65 of 400 proved positive.

Question: Positive with sickle cell anemia? Answer: About 30-35% tested positive for traits, the others were fetal hemoglobin. EB explained that people with sickle cell anemia with fetal hemoglobin could live longer lives. Their complications would not be as great because their sickle cell levels were lower than usual. There was one test that was positive for thalassemia.

Question: What were some of the early problems that the foundation had? Answer: Mostly to educate people, Black and White, about what sickle cell anemia was. People were frightened of it and thought it was contagious. People were not supportive of the foundation and testing because they did not understand sickle cell anemia.

Question: Did this foundation receive any support? Answer: Yes, it received funds.

Question: But in the beginning, did they receive any funds? Answer: No. The funds were received from various Black sororities, fraternities, and churches.

Question: How would you characterize the success of the foundation in the first couple of years? Answer: The first couple of years were very difficult.

Question: Did you spend a large majority of your time trying to educate rather than screening? Answer: EB said his job consisted of both tasks.

Question: Did you have a lot of people willing to be tested or did you find a lot of reluctance in the part of the community to be tested? Answer: EB said approximately 20% of the community was reluctant because they did not know what it was, even the highly educated members of the community. Sickle cell anemia was not taught until the early 1980s in medical schools.

Question: This is a really complex problem. It is not simply educating the “sicklers”;
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it is educating the medical community and the general community. **Answer:** Yes. EB went on to say that there was a myth that White people did not have the trait. However, some Whites did have sickle cell or thalassemia trait, but it was not a high percentage of people.

**00:15:00 Question:** When you look at the Black population, what is the percentage like? **Answer:** EB said that about 5% out of 1,000 had the trait or were sicklers.

**00:15:18 Question:** Did you ever work with the foundation members? You did a lot of the technical work, but did you attend the meetings? **Answer:** Yes. EB was on the screening board in 1984 and met with the members.

**00:15:50 Question:** That's today, though? What about in the past when you were here in the 1970s? **Answer:** At that time, EB was working directly with Dr. Clark.

**00:16:14 Question:** But what was your contact with the other members? Did you actually attend meetings in the ‘70s? **Answer:** Yes, EB attended meetings in the ‘70s because that was when they were trying to set up the foundation.

**00:16:28 Question:** What were some of the goals/objectives of the organization? **Answer:** EB could not answer because he left before the goals were developed.

**00:16:53 Question:** When you left the foundation, you continued to work in sickle cell research? **Answer:** Yes.

**00:17:03 Question:** How much time did you spend in sickle cell research? **Answer:** Approximately 75% of his time; examining patients, screening, educating various people, etc.

**00:17:50 Question:** Was there a Baltimore sickle cell organization? **Answer:** Yes, there was a Baltimore chapter that had three locations.

**00:18:17 Question:** Did you volunteer any of your times to work with those groups? **Answer:** Yes. Much of EB’s time was spent doing volunteer work. His work at the community level was all volunteer work.

**00:18:37 Question:** It’s not like you left sickle cell organizations behind. You were still active. **Answer:** Yes.

**00:18:49 Question:** You left the Baltimore area when? **Answer:** EB left the Baltimore area in 1981 and returned to Columbia, where he contacted people at the James R. Clark foundation. EB met the new people on the board and introduced a plan to set up a laboratory in Columbia, which the board and doctors at DHEC approved. EB’s
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credentials were sent out, proving him eligible to work at the laboratory.

00:20:56  Question: Have you proposed a standard procedure for setting up laboratories?  
Answer: EB wanted to do that, but the training was difficult and the people had to already be very experienced.

00:22:23  Question: Who is qualified to be a technician testing for sickle cell? Is there specific training?  
Answer: EB said someone would have to have specific training and expertise.

00:22:49  Question: Who would be the type of person who would be competent to have a small lab in South Carolina?  
Answer: The person would have to train with a hematologist or a pathologist, first of all. That person would also have to have knowledge of chemistry. That person could also go to the CDC.

00:23:41  Question: Do they have a program for technicians?  
Answer: Yes, there were programs at the CDC (located in Atlanta, Georgia). They also had a program in New York and California. Those were advanced courses.

00:24:38  Question: You can’t simply come out of medical technology training and understand what’s going on?  
Answer: No.

00:25:27  Question: Do you think that the state and the federal government have done everything they can to help? Do you think there should be some help by the state or the federal government?  
Answer: EB thought that the funds should go to the leader, not the community itself. EB said the money was sometimes misunderstood.

00:26:28  Question: What do you mean by that?  
Answer: EB meant that sometimes communities stray for the goal. He was saying that the money was misused and was incorrectly distributed in other organizations.

00:28:28  Question: When you think back to the 1970s, was that a big factor? The Black Awareness of the civil rights movements was prevalent at the time so people rallied to the cause of sickle cell anemia?  
Answer: EB thought that was one of the reasons, along with the Nixon administration.

00:29:31  Question: What is your impression about the relationship between the foundation and the Department of Health and Environmental Control? Did they provide adequate support for the foundation?  
Answer: EB was not sure; he was not present when DHEC was working with the foundation.

00:30:12  End of interview