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Interview with Ellen Mosley

Ellen Mosley

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Abstract: In her June 1984 interview with Michael Cooke, Ellen Mosley detailed her experience working for the James R. Clark Memorial Sickle Cell Foundation and the problems with informing communities of sickle cell anemia. Mosley discussed the problems had with DHEC, funding the foundation, and aiding the communities in the Midlands area. She also discussed possible exploitation of the Black community, stigmas that the Black community had towards sickle cell, and the many misconceptions about sickle cell of all races. This interview was conducted for inclusion into the Louise Pettus Archives and Special Collections Oral History Program.

Keywords: Sickle cell anemia, James R. Clark Memorial Sickle Cell Foundation, James R. Clark, Richland Memorial Hospital, DHEC (Department of Health and Environmental Control)

Interview Session (June 14, 1984): Digital File

Time Keywords

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

00:00:26 Question: Could you give us a brief sketch of your life? Answer: EM was born on March 13, 1946 in Orangeburg, SC. She attended South Carolina State University for undergraduate and graduate work, where she received a Bachelor’s degree in Biology and a Master’s degree in Education. EM also attended the University of South Carolina.

00:01:02 Question: When did you first become interested in sickle cell and why did you become involved? Answer: EM learned about it during undergraduate and became interested because not much was available in her textbooks. When she moved to Columbia, SC in 1972, she met a physician, James R. Clark, who was very involved in the foundation. He pushed her into joining the foundation. After that, she started going to meetings and learning more about sickle cell anemia.

Question: Did you have any tasks assigned to you after you became a member? Answer: Initially, EM worked on an information and education committee, and then served as a volunteer for fundraising events.

Question: Can you tell us a little about these activities? Answer: EM said that it was difficult to get the community to come out. There was a fear of finding out about something that affected so many. The foundation contacted churches, schools, and social organizations. The foundation gave informational presentation to any of the groups that accepted them. The presentations were followed by testing and counseling. EM did not believe that they reached as many people as they should have.

Question: Once you joined the organization, the roles were fairly defined. What were the objectives of the foundation? Answer: The first objective was to provide education, counseling, and screening. That was the major goal in the Midlands area. The second objective was to raise funds.

Question: How did you raise funds? Answer: The foundation did a number of activities, including car washes, bake sales, raffles, annual banquets, and soliciting donations from churches and businesses.

Question: How successful were you in soliciting this type of support? Answer: EM said that success was not measured in the amount of money, but what one can do with the money versus the amount of money acquired. The foundation was not successful.

Question: Did you try going to pharmacies and asking for discounts for families with sickle cell? Answer: Yes, EM said the foundation tried to do that. They also asked doctors to reduce charges for sickle cell patients, but they were unsuccessful with both. Very few doctors knew anything about sickle cell anemia.

Question: You not only had to educate potential patients, but you also had to educate physicians? Answer: Yes. The foundation went to hospitals, especially Richland Memorial Hospital to talk to the nurses and admittance personnel to educate them. The sickle cell patients were often misdiagnosed and ignored. The foundation tried to improve attitudes toward these patients, so that the doctors and nurses would be more caring and understand what was happening.

Question: Did you see any progress in the campaign to educate the medical community? Answer: At that point, EM thought that the foundation had made a lot of progress in that area, but still had much to do. Many of the doctors in the program served as medical advisors, so they spoke to their peers about sickle cell anemia.
Some worked in research, as well as community outreach and education.

00:10:40  **Question:** Have you persuaded any people in the medical community to lower the cost of healthcare for people who suffer from sickle cell?  **Answer:** The foundation had been successful with that venture in the last couple of years. In the late 1970s, early 1980s, they began to receive money from the federal campaign. They were an affiliate of the national organization and could hire full-time staff.

00:12:29  **Question:** How have the parents of sickle cell anemia children responded to the foundation? What is the reaction of the sickle cell family to the foundation?  **Answer:** A number of volunteers had a relative or child with sickle cell anemia. EM said that on average, the foundation did not have enough direct parent involvement. They had tried a number of things, including group therapy for parents.

00:13:26  **Question:** When did you institute the group therapy?  **Answer:** Around 1978/79. The volunteers were from all different backgrounds and were properly trained in social work. However, the parents did not attend meetings and events as much the foundation had hoped. Transportation was an issue for many of them. EM said that in the Black community, it was difficult for them to admit to having sickle cell anemia.

00:15:08  **Question:** The 1970s were spent trying to make people comfortable with the diagnosis of sickle cell anemia—that it was not a disease to be kept secret. Genetic disorders are no one’s fault and nothing to be ashamed of.  **Answer:** Yes, that was the main focuses, and remained the focus during EM’s time as president.

00:15:43  **Question:** What are some of the misconceptions that people have had over the years?  **Answer:** One big misconception was that people would blame it on one side of the family. That would be impossible, since the child would have to inherit the gene from both parents. Another misconception is that sickle cell only affected Blacks, but that was also untrue.

00:18:00  **Question:** The fight is ongoing. MC spoke to someone in Orangeburg about the sickle cell foundation there, but the man was unaware of the foundation. He was unconcerned because he did not have sickle cell.  **Answer:** EM said that was a common problem, that attitude was what the foundations often ran into.

00:19:14  **Question:** Social acceptance of sickle cell is still a hard thing to achieve. What was the rapport between this foundation and DHEC (Department of Health and Environmental Control) during the 1970s?  **Answer:** In the 1970s, there was some money appropriated by DHEC. It was EM’s understanding that some of the money was lost and did not make it to the foundation. The foundation was still waiting for the money.
00:21:30 *Question:* During the time that you were associated with the foundation, what is your impression of the role of DHEC and the community organizations that had an interest in sickle cell. *Answer:* EM thought that DHEC could do more for the health organizations, in the 1970s to the time of the interview.

00:22:11 *Question:* Where do you think they’ve been deficient? *Answer:* DHEC was controlled by legislative bodies, which were controlled by people not affected by sickle cell anemia, so sickle cell organizations were not a concern. In more recent times, the legislative bodies had more people of color and cared more for sickle cell organizations. EM thought that the foundations possibly could have done more to make the foundations more visible and to get more information out to the people in charge.

00:23:30 *Question:* Did you have a number of DHEC employees who worked for the foundation over the years? *Answer:* Yes, and it proved to be very beneficial for the foundation because of their knowledge of DHEC’s resources and tools.

00:24:14 *Question:* Are you saying that DHEC is a political bureaucracy? *Answer:* It is a state agency, which makes it political. EM said that any state agency became a political bureaucracy, in her opinion.

00:24:34 *Question:* Do you think that sickle cell has become a political football within DHEC over the years, especially during the 1970s? *Answer:* EM did not think so because if it had become one, the foundations would be in better shape to have sickle cell clinics with financial aid.

00:25:23 *Question:* How have the objectives of the foundation changed over the years? *Answer:* EM said there were topics that they were more concerned with originally, but had become less important. For example, sickle cell awareness was very important in the beginning. At the time of the interview, the foundation was looking into treatment and research for a possible cure. They were also looking into appropriate services for people with sickle cell anemia. There was some research going into prenatal screening.

00:27:22 *Question:* Thinking about exploitation, have people who suffered from sickle cell trait and sickle cell anemia been victimized by the publicity of disease? *Answer:* EM said that the general community had to be educated. There were a number of people in the community who thought that the trait had the same effect as sickle cell anemia. EM was concerned about prenatal screening because of the possible of Black exploitation. The public would have to be more informed about the trait versus the disease. EM said that some people thought that sickle cell anemia affected the mind.
00:29:52  *Question:* Is there anything else you would like to add or elaborate on? *Answer:* No, but EM was delighted that someone was interested in studying sickle cell like MC. EM wanted MC to spread whatever information he gathered.

00:31:07  *End of interview*