

## REDIFINING SICKLE CELL ANEMIA IN AFRICAN AMERICAN COMMUNITIES

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Sickle cell disease (SCD) affects 1 out of 600 African American individuals at birth. More than 50,000 African Americans have it today. It is a genetic disorder that affects an individual's hemoglobin and has deleterious effects on an individual's life (Steinberg 1999). Many studies have been done to see the medical effects of sickle cell anemia yet it is interesting to unpack the disease and its relevance within a particular population. The primary objective of this analysis is the study of African-American mothers of children with sickle cell disease and the ways in which they react to the diagnosis and manage healthcare of their children. The mothers in the study are the primary caregivers for their children and they are active participants, creators, and definers of the social world in which they live. The meanings they construct and assign to the sickle cell disease experience develop from their own values, resources and life experience and thus differ from the meanings medical experts assign to the disease.

### **Data Collection**

The primary data for the research was collected in Hughes-Spalding Children's Hospital (a subset of Grady Memorial Hospital) and Egelston Children's Hospital, located in the metropolitan city of Atlanta Georgia, both which encompass a large population of African Americans. Hughes-Spalding Children's Hospital is located in downtown Atlanta and Egelston Children's hospital is in north-east Atlanta on the Emory University campus; thus both hospitals allow for a wide range of individuals in various classes to be comprised in the study. Both hospitals provide a broad range of medical care, primarily focusing on children under the age of twenty-one. I began my data collection by speaking socially to patients in the hospital, other key persons in the organizations that provide services for those with SCD, parents of SCD children and attending rounds made by hematology physicians at both hospitals. Interviews lasted anywhere from an hour to ten minutes and were based upon the willingness of the patients, parents, and healthcare providers to talk. The interviews were transcribed into a field notebook after the interviews had taken place. Great care was taken to protect the

confidentiality, feelings and the rights of the patients, doctors and parents involved. A few of the mother began to talk about sickle cell even before I could ask any questions. My approach was to be supportive and interactive and interested in listening. My research strategy drew upon the style of Berger and Luckmann, which viewed realities and meanings as socially created in an ongoing fashion by interacting individuals as they define and interpret events (Berger 1970). The approach was to understand the mother's definition of sickle cell anemia which places the diagnosis and management of the disease within their own cultural, racial, and class histories. I was specifically interested in learning about their knowledge and family history of the disease, their reaction to their child's diagnosis, the home care, the type of support, the type of medical care received, and finally the impact of the disease on the mothers and their families.

### **Sickle Cell Disease**

Sickle cell disease was first found prevalent in African American populations in 1910 (Durham 1991). Sickle cell anemia is a type of sickle cell disease in which there is a single point mutation on the  $\beta$ -globin gene. This single substitution mutation for the sixth amino acid on the hemoglobin molecule results in HbS. HbSS, or sickle cell anemia is an autosomal recessive trait and is commonly found in people with African ancestry. The probability of genetically transferring the gene is mathematically easy to predict. It is estimated that one out of every twelve black people carry the trait and therefore have the potential to have a child with the disease. The disease is an other- health impairment disease, meaning that it affects not one area but multiple areas within the body. It consists of periodic and unpredictable episodes of pain due to vaso-occlusive crisis, serious infections, respiratory difficulties and stroke. Sickle cell disease can be diagnosed prenatally or at birth. Symptoms do not appear until the child is six month old (Eldelstein 1986, Relethford 1997). Researchers have only recently begun to examine the impact of the disease on children and their families. The objective of this narrow study is to focus on care giving and management in non-traditional (female-headed) African American households with children that have sickle cell anemia.

### **Nontraditional Families**

The issues of race, gender, class and culture are crucial in the understanding of the organization of family. Racial exclusion, limited opportunities and poverty are common life experiences for many black families. High fertility rates, teenage pregnancy and single parent households often reflect Black families. Research rarely considers these types of situations. Traditional

healthcare studies have been performed in conjunction with traditional families, families that consist of two parents, namely a mother and a father, and their children; this is otherwise known as a nuclear family. Recent studies show that there has been a recent shift in the traditional family. Fewer than 25 percent of American families now conform to the nuclear model. The women in this study are more often than not multiple jeopardy families: they consist of families that face racism, sexism and classism. It is important to demonstrate how these families effectively and actively manage healthcare for their children.

### **Theoretical Perspectives**

It is put forth that the mothers primary method of handling care giving tasks, alleviating stress, and coping with the reproductive implications of having a child with a hereditary chronic disease is to reject, redefine, or modify the medical model of sickle cell disease. The medical model of the disease focuses on the transmission of the disease with the specific statistical probability that the parents will pass the trait onto their child, the treatment and prognosis of the disease and the elimination of the disease by selective reproduction. The women involved in this study did not alter their reproductive behavior in part because of inadequate medical information. Some mothers were skeptics of the medical responses. In coping with the disease they redefined sickle cell disease. African American mothers of children with sickle cell constructed and responded to their own interpretations, creating an alternative perspective of reality. The medical model of the disease focuses on the disease as an essentially discrete, biological event as opposed to reality and a painful life experience. Thus there is a divergence in the medical and lay response to the disease. The lay response is dependent upon the context of the individuals.

### **The Black Families in a Historical Context**

The African American women in this study are viewed in the larger historical context of the Black family, as well as socioeconomic factors that effect their values, lifestyles, and attitudes towards health and illness. Most of these mothers have some type of public assistance, welfare, or obtain Medicaid to help cover the costs of disease management. Many of the mothers come from single parent homes and live in predominantly black communities. Many of these mothers also have experienced poverty, homelessness and martial separation. The Black family has been a source of debate since analyst E. Franklin Frazier described Black families as undermined by the legacy of American slavery. Nontraditional Black families have their roots in historical experiences of Blacks in the

United States. Many African Americans came into bondage to provide for the growing agricultural economy of the United States by providing cheap labor. Undoubtedly, slavery has had a great effect on the lives of African Americans. Black families relative to white families have been deemed disorganized and inferior. Black women were and continue to be the target of blame for poverty, welfare dependence, and female-headed households. They are either the victims or the villains in the Black families.

### **Current Patterns of Motherhood in Black Families**

Teenage motherhood and female-headed households have been the focus of many recent studies. Early motherhood was common among the mothers within this study. Previous learned patterns in behaviors such as having grown up in a home with a single mother, may explain early motherhood and the phenomena of female-headed households. It may also be a cause of the desire to have something to love, meaning teenage girls have children to serve as an object of their affection. The other most likely reason for teenage pregnancy is the feeling of immunity to the consequences of sex. These Black females are stereotyped as being strong, emasculated, independent and self-reliant, yet there are burdens that are placed upon these women in society. It has been stated that Black men feel resentment towards these black women because of their inability to become involved and provide economic resources for a family. This thus leads to the status of single parent households. Women also tend to rely on other female kin ties. The mothers in this study relied more on kin ties than their men who either no longer exist or who are not willing to help. One young woman responded that her daughter's father was not really involved and that he was never around enough to be involved. This seems to be the overwhelming state of affairs. Some mothers do not want to admit that the father has no role or involvement in her child's welfare. One woman said that her son's father provides food and clothing periodically. Some mothers' attitudes lay in another extreme and have resentment towards the fathers, which is in part due to economic hardship. One mother said that her child's father does not care about the circumstances of their child and therefore she did not care for him. Most mothers in the study tended not to rely on the father of their child. More often than not, another male figure will take on the responsibilities of the father; it is most usually a boyfriend, maternal uncle (avunculate) or a stepfather. One mother was living with her boyfriend with whom she had gotten into a fight. The boyfriend had then thrown her and her child out of the house; the mother and her child were living in her car when her daughter had suffered a severe vaso-occlusive pain crisis. At this time the mother took her daughter to the hospital where she began treatment. The mother and her child have yet to be

discharged from the hospital due to their current living situation. It is not uncommon to see even the boyfriend abandon the burden of taking care of a sick child and a mother. Another case, that was quite disheartening, was a teenager who had neither mother nor father and is taking care of himself. He is administering his own drugs and responsible for himself. He has no kin ties to support him unlike many of the single mothers in the study.

### **Relying on Female Kin**

As previously stated, other men often fulfill the role of the biological father, yet mothers, in general, seem to turn to kinship ties to fill the void. The tradition of godmother and other mothers may be seen as a reflection of an Africanism, as seen from the Herskovitsian position. It may be an adaptation to cultural or racial oppression. Many of the mothers in the study relied heavily on female relatives or kin ties. Aunts and grandmothers were extensively involved in rearing children when their fathers were absent. One woman had disclosed that she, in fact, was not the child's mother but her aunt and that the biological mother had abandoned her child at birth. The biological father had died earlier of hemophilia and the child's brother had died of AIDS. This is a case of multiple jeopardy in which another female kin, in this case the aunt, takes on the role of mother. Another mother had said that while she was at work that the child's grandmother claimed responsibility as other. The child apparently seeks comfort only from her mother or her grandmother when she is sick, yet when she is in good health she seeks attention from her maternal aunt. In consequence the mother shapes her reality and her child's reality in order to better manage and cope with sickle cell anemia.

### **External Stress**

Many mothers live with constant stress. They stress about the well-being of their child and about their economy and livelihood. Each mothers had different living conditions that placed stress on their current predicament. One mother was living in her car and was being supported by her boyfriend. As of now, she is living in the hospital until she is allowed back home. Another mother was dependent on welfare to aid her. Another woman was completely reliant on Medicaid for the expenses incurred at the hospital. Each hospital visit can prove to be fairly expensive. One adolescent female with sickle cell who had suffered a stroke at a young age was frequently at the hospital for chronic blood transfusions, a process that is expensive for anyone let alone a single mother. The cost of one child spending three days in the hospital had cost one woman over \$3,000. This same woman is working at a part-time job trying to support herself and her sick child. Stress and social positions influence response to daily life events. These women all

manage to cope with these events yet use agents of experience of hardship to restructure their family life.

### **Diagnosis of Sickle Cell**

In 1970 there was a proliferation of public education and screening programs. The public education programs were initiated to increase awareness in the African American Community about the risk of sickle cell disease (Eldelstein 1986, Lewis 1970). This proved to not work as well as planned since women rarely consider SCD in their reproductive decision-making. This is yet another point that refutes the medical model. These screening programs and diagnoses provided limited information and not enough follow up care or continuity of health care services. One woman was not informed about routine follow-up appointments until her child had suffered a pain crisis. There is a discrepancy in the opinions of the diagnosis among the mothers and health care providers. The medical model of sickle cell disease sees SCD as a major health threat to Blacks, a serious disease that should be avoided if possible. These medical views focus on transmission of the disease with the specific statistical probability that the parents will pass the trait onto their child. It also focuses on the treatment and prognosis of the disease and the elimination of the disease by selective reproduction. Early detection is viewed as the key factor for control of the disease. Most mothers had never known a person with SCD before having their own child diagnosed with the disease. Furthermore, they do not seem to have a clear view on what it actually means to them or their children. In one situation, a mother had said that her child was not diagnosed with sickle cell until he was four months old and in the hospital with complications that arose from the disease. In spite of knowing about sickle cell, some mothers even knowing they are carriers of the trait only understood the repercussions of the disease after the child displayed unusual recurring symptoms. Some of the mothers were still not fully informed about the nature of the disease and some have trouble alerting doctors of the drugs and prescriptions their child is taking. A young mother had said that she was not fully explained the life threatening disease until she had learned about it through her own child's experience, who is now hospitalized with serious neurological disorders due to an episode of acute chest. One woman had struggled for a few minutes before she had given up and said that she could not remember what the name of her child's medication was. Not only dealing with diagnosis is important, but also reactions to diagnosis are important. Most women seemed very unaware of the effects of the disease so their reactions were mild. Some negative reactions were seen in biological mother who were aware of the sickle cell disease. A middle-aged mother had used the word "denial" to explain her feelings. Yet the same

woman still is strong and manages her child's health and well being by adjusting and reforming her reality.

### **Care Giving for Children with Sickle Cell**

Aside from hospitals, most health care is provided at home for children with sickle cell. Many of these women rely on their child's specific behaviors, attitude changes and feeling to distinguish the amount of pain and the treatment for it. One woman had explained that she could tell when her son is having minor pain and having major crisis just by his behavior. These women base their knowledge of their child's disease on their child alone. When an average child gets a cold, it is fairly common, yet when a child with sickle cell gets a cold it may be very serious and life-threatening. One woman had said that when her child was younger she would be in and out of the hospital yet as the child has grown up she has learned from first hand experience how to care for her child. Mothers tended to keep a careful watch on their child during pain crisis and to take note of what caused the onset of a pain crisis in order to avert them the next time; it varies from child to child. Each mother seems to develop her own personal lay theory to the explanation of the onset of pain crisis. The biological mother or another mother figure usually administers medical care at home. This support is usually necessary with families that have a child with sickle cell.

### **Social Support**

Outside of the kinship these mothers can find support in various places, although for some it is very difficult. It is suggested to the mothers that they find parent support groups or support through religion and through other friends. Some women even find support within the medical community and may even embrace the medical model. The latter situation is far less common. One woman is a Jehovah Witness could not turn to religion for her child's condition. Her child was a seven-year old boy who had suffered from an acute chest pain episode and was in desperate need of a blood transfusion. The mother's religion forbids blood exchange and therefore the boy had been taken custody by the state in order to save his life. She had said that it was very hard for her to reconcile her beliefs with her child's situation. She turns to friends that also have a young boy with sickle cell for support. Her family and her religion have proven to be of little help. Yet another woman says she turns to her church and her prayers to find sanctity. One very unique woman had decided, unlike most of the other mothers, to embrace the medical model and to supply her with the most amount of knowledge obtainable about sickle cell anemia.

### **Conclusion**

The African American mothers in this study tend to reject, modify or redefine the medical model of sickle cell disease that emerged in 1970's with the screening programs. Their responses to the disease reflects neither ignorance nor passiveness but the realities of their own lives and circumstances. The medical model states that the sickle cell trait is dominant in the African American gene pool, can be transmitted genetically, and can be easily diagnosed. It also states that the disease can be eliminated through careful planning, genetic screening, and selective mating. The medical model assumes that people diagnosed as being carriers of the trait will alter their reproductive behavior. However, the medical model does not offer a viable and coherent strategy for managing the disease. The mothers in this study reject or socially construct their own reality of the SCD in a number of ways. Mothers seem to have little interest in delving into the medical knowledge, origin, and transmission of SCD. Instead these women focus on first-hand experience on how to cope with the disease. Finally, women in their social position place a high value on the ability to have children and on motherhood as a role. They use the resources available to them in order to manage their child's disease.

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