

*I already knew I had it  
[the sickle cell trait] . . .  
but I didn't check into  
anything. You just don't  
think about these things.  
—A forty-year-old single  
mother of two children*

# Introduction

## 1

Being diagnosed with the sickle cell trait really did not mean much to Doris Jacobs, a single Black mother who gave birth to her first child, a son, when she was eighteen years old. The baby was born during the 1970s, when advances in medical technology and the civil rights movement had converged to define sickle cell disease (SCD) as an important national health-care issue. Doris and her son were both screened for SCD and were found to be among the more than three million African Americans who carry the sickle cell trait. Because Doris was informed that the sickle cell trait was common among Blacks and did not, in itself, cause illness symptoms, she never equated carrying the trait with the possibility of transmitting a serious disease to her children. A few years later, she had a second child, a seemingly healthy girl. By this time the medical-political emphasis on preventing SCD had waned, as had the policy of testing newborns for SCD. When her infant daughter began to experience persistent symptoms of illness, neither Doris nor her doctors suspected SCD.

Before her daughter's first birthday, however, Doris's life had become a continual series of clinic visits seeking medical care for her child's innumerable colds, fevers, and infections and insisting that something was seriously wrong. Finally, the diagnosis of SCD was made:

*How old was she? . . . She was a baby still in arms, probably eight to nine months old. I know she wasn't walking, but she wasn't a tiny baby either. She would cry a lot, and she'd have a lot of fevers, a lot of high fevers. And if you touched her she didn't like it. She was so sick—I was working near [a clinic] and I was taking her there so much they finally discovered it [SCD]. They did a blood test and told me she had it.*

The diagnosis of SCD in her daughter generated a great deal of uncertainty and distress. Although she had been exposed to educational programs about SCD and had discovered that she and her son carried the sickle cell trait, Doris never thought that she could pass a serious disease on to her child. Intellectually, she accepted the hereditary nature, of SCD; based on her own family history, however, it just did not make sense. Within of a large family of eight sisters and brothers and numerous nieces and nephews, no one had ever been diagnosed as having SCD. Yet medical wisdom held that the trait may have been in her family for generations. An even greater source of distress was that she had little idea of what to expect as a result of the diagnosis of SCD, and she was given no instructions on how to manage her daughter's health care:

*I don't know what I thought. I was kind of sad about it. I didn't really know much about it. . . . And I felt kind of bad*

*about it, with her sick and everything. They told me the only thing they could do was to treat whatever the symptoms are—if they had trouble with their heads, their stomachs, they would try to fix that because there wasn't really anything that they could really do. Just work on whatever the problem was at the time you brought them in.*

During the first year after the diagnosis, Doris "ran a lot, back and forth to the hospital," seeking medical care for the many minor illnesses and pains that jeopardized her daughter's health. Still, the full implications of having and caring for a child with SCD did not become clear until her daughter reached the age of three and had the first of many life-threatening pain crises. A few years later, her daughter underwent a splenectomy—the removal of her spleen—as a result of SCD complications, and Doris's concerns over her daughter's health were exacerbated by anxiety over how to pay the medical bills. Now, both Doris and her daughter worry about the reproductive implications of having the sickle cell trait.

For thirteen years, Doris, a single mother with two children and a full-time clerical job, has managed the numerous tasks involved in the care of a chronically ill child—accepting the diagnosis, finding social support, learning about the disease, providing home care, obtaining and paying for medical care, and dealing with the psychological impact of SCD on her child and family. Her experiences confirm the contention that the discovery and management of childhood chronic illnesses are stressful life events. Yet the ways in which low-income and/or single parents provide care for their chronically ill children with SCD have rarely been

examined by the vast literature on family caregiving or by Black family studies. The present research focuses on caregiving within the context of nontraditional families, and in doing so it highlights the roles of race, class, culture, and gender in shaping perceptions of and responses to illness and caregiving options.

The primary objective of this analysis, based on in-depth interviews with thirty-two low-income African American mothers of children with SCD, was to give voice to Black mothers who managed the day-to-day medical and home care of children with SCD. So, while my understanding of SCD was enhanced by talking with laypersons and professionals (see Appendix) who worked in the SCD field, the primary data for this research are from mothers who are the major caregivers for children with SCD. As a group, these mothers belonged to nontraditional families—families that do not fit the highly idealized traditional model of family as a Eurocentric, two-parent, nuclear, gendered, child-centered, affluent unit (Baca Zinn and Eitzen 1987). Most of the mothers in this study, who ranged in age from twenty-one to seventy-two, were modestly educated, employed single parents who headed their own households or lived in extended families. Twenty-nine were biological mothers of a child with SCD; two had informally adopted a relative with the disease, and one had formally adopted a foster child with SCD. The children with SCD ranged in age from two months to twenty-two years, with an average age of 10.4. The mothers had a total of eighty-six children, thirty-six of whom had SCD.

Sickle cell anemia, the SCD most likely to affect Blacks (see Chapter 2), was first reported in 1910, but not until nearly sixty years later did it gain much publicity from

medical experts and the public. Underlying SCD's rise to national attention were advances in medicine's ability to detect the sickle cell trait and the political activism of the late 1960s, which condemned the sparse resources devoted to eliminating SCD and implied that a serious, debilitating, and preventable disease had been ignored by the medical system primarily because of racism. The deaths of four Black military recruits with the sickle cell trait during high-altitude basic combat training (Jones, Binder, and Donowho 1970) challenged the notion of the sickle cell trait as harmless and led to demands for testing Blacks for the trait. The efficacy and implications of massive screening of Blacks for a racially inherited genetic trait sparked as much comment and controversy as did accusations that SCD had been historically neglected (Bowman 1977; Sullivan 1987; Wilkinson 1974), but these concerns waned after early coercive policies supporting mandatory screening gave way to educational programs and voluntary testing. Virtually ignored in the politics of SCD was the impact of the disease on persons who had it and on their families. Millions of African Americans have been tested for and diagnosed with the sickle cell trait, and as many as eighty thousand have SCD. Yet we know little about how African American families cope with the diagnosis of sickle cell trait or SCD or how these families manage the health care of their children.

The literature on families and medical crises has essentially ignored how race and social class influence notions of illness and the resultant strategies of caregiving, and only recently have researchers begun to demystify the concept of "family caregiving" by noting that women, rather than families, perform most of the caregiving labor. My research looks

explicitly at the caregiving labor of African American women in nontraditional families. I have chosen the management of SCD in children not only because the disease usually affects Black families but also because its management encompasses a broad array of health issues, such as the role of politics in setting health-care priorities, the efficacy of genetic screening in preventing the transmission of diseases, the impact of race and culture on health-care attitudes and behaviors, how social class affects access to medical care, the role of women as caregivers, and the viability of the Black family as a caregiving institution.

### **Nontraditional Families**

Race, class, and culture are crucial factors in shaping the organization of family life and in explaining the differences found between white and nonwhite families. Racial exclusion, restricted opportunities, and poverty are common experiences for many Blacks and, in some Black families, are reflected by high rates of fertility, teenage parenthood, and single-parent households, as well as low levels of education and income. Poverty also helps explain why Black family members have higher rates of illness than whites do; yet, while the viability of Black families has become a perennial issue, rarely has research focused on Black family responses to medical crises. Family diversity is largely ignored in family caregiving studies; instead, the assumption of a traditional family has shaped the framing of issues since the early works of Parsons and Fox (1952) and Hill (1954), who saw the nuclear family as ill equipped to care for its sick members. More recent studies have accepted the shift in medical care

from hospitals to families, but most still view the family as a nuclear entity formed by marriage. Studies have examined the impact of childhood illnesses on the marital relationship (Hymovich and Baker 1985; Lansky et al. 1978; Venters 1981) and have noted the need for two parents in home caregiving (Patterson 1985). Optimal coping has been attributed to spousal support (Barbarin, Hughes, and Chesler 1985), spousal intimacy (Hobfoll and Lerman 1988), and the father's occupation (Kupst and Schulman 1988) and income (McCubbin et al, 1983).

During our nation's industrialization, a shift in the nature and the location of labor undermined the family-based economy (Tilly and Scott 1978) of colonial America (and Western Europe) and, many felt, challenged the resilience of and need for the family. The emergence of the family wage system reorganized family life by assigning men responsibility for economic support and relegating women to full-time roles as wives and mothers. The dominance of this family structure was asserted in the 1950s, when families conforming to the public-private, gendered division of labor were idealized as functional and the norm, while others were seen as inadequate. In fact, this pattern was never universal, so its designation as "traditional" is misleading. Fewer than 25 percent of American families now conform to the nuclear model (Baca Zinn and Eitzen 1987; Skolnick 1991), yet the literature reflects a narrow definition of family that suggests that nonconforming families are less likely to provide adequate caregiving for the sick. Such analyses reduce the caregiving issue to individual traits and virtues of families, while ignoring cultural and structural issues that affect attitudes toward illness and access to medical resources.

The low-income African American mothers in this study, despite the multiple jeopardies of racism, sexism, and classism (King 1988), effectively and actively manage the health care of their children with SCD. I argue that their primary method of handling caregiving 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 SCD—the "objective, scientific" facts about SCD. The medical model of SCD focuses on the etiology and transmission of the disease, the specific statistical probability that parents with the trait will pass SCD on to their children, the treatment and prognosis of those who have it, and the elimination of SCD by early detection of the trait and selective reproduction. In this model, SCD is described as a serious, debilitating, and incurable disease arising from a recessive trait that has existed in Blacks for generations. Illness episodes are seen as unpredictable and often life-threatening, and treatment as capable of managing only the symptoms of the illness. The medical model guided the public information efforts and screening programs brought to the Black community during the 1970s.

Although most of the mothers in this study learned about SCD from these programs, and many were diagnosed with the sickle cell trait prior to having a child with the disease, their perceptions of and responses to SCD were often at odds with the medical model of SCD. Genetic screening for the sickle cell trait rarely led mothers to alter their reproductive behaviors, in part because they received inadequate medical information about the disease but also because they valued their ability to have children. Mothers evinced little interest in the etiology and genetic transmission of the disease; they often

had difficulty tracing the sickle cell trait in their own families and occasionally doubted that their children really had the disease. Some brought to the SCD experience a history of doubting medical authority and regimens—their skepticism often reinforced by medical responses to SCD. Unable to reconcile medical descriptions and prognoses of SCD with their own firsthand experiences, mothers emphasized their children's normality rather than their illness. They devoted their energies to managing illness episodes as they arose and developed caregiving strategies that helped alleviate the stress and uncertainty of the diagnosis. Mothers were often more tolerant of illness symptoms than health professionals were, which helped them minimize the impact of the disease on their children. Like many low-income Black women, mothers of children with SCD placed a high value on motherhood yet lacked enough power in their relationships with the men in their lives to insist that they be screened for the sickle cell trait. In coping with SCD they redefined unmanageable aspects of SCD as manageable, obfuscated the reproductive implications of carrying the trait, and used stress-reducing normalization and denial as coping strategies. They defended their perceptions of reality, protected their reproductive autonomy, and gained greater control over managing SCD by rejecting the medical model of the disease.

### **Theoretical Perspective**

African American mothers of children with the sickle cell trait constructed and responded to their own interpretations of SCD—creating alternative perspectives on reality. The emergence of a framework that acknowledges and respects as

legitimate a distinctive Black female consciousness can be found in the work of Patricia Hill Collins, who suggests that Black women have a "self-defined standpoint on their own oppression":

Black women's political and economic status provides them with a distinctive set of experiences that offers a different view of material reality than that available to other groups. The unpaid and paid work that Black women perform, the types of communities in which they live, and the kinds of relationships they have with others suggests that African American women, as a group, experience a different world than those who are not Black and female . . . [and that] these experiences stimulate a distinctive Black feminist consciousness concerning the material reality. (Collins 1989, 299-300)

This framework meshes with the social constructionist view, which understands meanings and realities to be socially created based on human perceptions and interpretations (Blumer 1969). The race, class, and gender positions of the African American mothers in this study, who constitute a marginalized segment of the population, fostered a view of reality that led them to question conventional medical knowledge about SCD. The divergent views of low-income African American mothers and health professionals stem from the social positions of each group. P. Berger and H. Kellner (1970) note the crucial role power plays in determining the prevailing view of reality and the discrepancy that often exists between a macrosocial (dominant) view of reality and microsocial (subjective) realities of subordinated groups. Health experts constitute a dominant group, and their views, although socially negotiated and often disputed, prevail at the macrosocial level as the objectified, correct response to

SCD. At the microsocial level, however, these mothers did not share the medical model's view of SCD, as it did not coincide with their realities, life experiences, and values. Their world differed from that of most health authorities; as Berger and Kellner note, the "socially constructed world must be continually mediated to and actualized by the individual, so that it can become and remain indeed his world as well" (1970, 51).

The social constructionist perspective is broadly applicable to the field of medical sociology and has been used to understand the allocation of medical resources, the overall structure of the American health-care system, and the attitudes and behaviors of individuals toward health care; Theoretically, a disease gains the public's attention through the deliberate activities of individuals who organize and campaign to bring the reality of the disease before the public. The advent of new medical technologies (Conrad 1975; Conrad and Schneider 1980; Mishler 1981) and a politically mobilized, affected population (Fox 1989) are often key factors in the amount of medical attention a disease receives. The support of physicians, health professionals with the authority to "create social meaning of illness where that meaning or interpretation was lacking before" (Friedson 1970, 252), is a crucial element in the process.

The rise of the medical model of disease—a focus on disease as essentially a discrete, biological event—often creates a credibility gap between physicians and patients in their views of illness. In his critique of the medical model, E. G. Mishler (1981) offers an alternative sociomedical approach, which recognizes the social and economic factors that influence perceptions of and responses to illness. Ac-

According to Mishler, "whether or not a particular behavior or experience is viewed by members of a society as a sign or symptom of illness depends on cultural values, social norms, and culturally shared rules of interpretation" (p. 141).

Even within the same culture, differences in physician and patient responses to symptoms of illness often occur. Freidson (1970,252) notes that physicians "are permeated by the tendency to see more illness everywhere around and to see the environment as being more dangerous to health than does the layman." This discrepancy between physician's and patient's views of illness is best described by David Mechanic's distinction between illness, a "scientific concept denoting a constellation of symptoms or a condition underlying them," and illness behavior, "the manner in which persons monitor their bodies, define and interpret their symptoms, take remedial action, and utilize the health care system" (Mechanic 1982,1).

Doctors focus on illness and, Mechanic notes, lack viable strategies for measuring health and well-being; thus, basing their conclusions on medical tests, they are likely to diagnose illness even when no physical symptoms are present. Conversely, patients "conceive of health status in terms of an overall sense of well-being and the extent to which the symptoms they experience disrupt their ability to function or interfere in some significant fashion with their life activities" (Mechanic 1982, 1).

The divergence between professional and lay responses to illness is accentuated when physicians and patients are from different cultures or social classes. R. Angel and P. Thoits (1987, 465) note that "culture constrains the perceptual, explanatory, and behavioral options that individuals have at

their disposal for understanding and responding to illness", an argument also advanced by other medical sociologists (Zborowski 1981; Zola 1966). Social class can be viewed as a subculture because it is "associated with differential prevalence of various symptoms and influences the extent to which symptoms are viewed as atypical and noteworthy or as normal and part of everyday life" (Angel and Thoits 1987, 485).

The mothers interviewed for this study are active participants in and creators and definers of the social world in which they live, a world that leaves them ill equipped to manage SCD in a way consistent with the medical model of the disease. While the alternative perspectives of marginalized groups tend to be viewed as evidence of either pathology or the need for further education, I accept the perspectives of these mothers as derived from their past experiences with illness and health-care experts, as well as their social position in American society. Thus I see their responses to the challenge of SCD as legitimate within the context of their own realities and family resources.