Black Women And Sickle Cell Disease: Implications For Mental Health Disparities Research

Portia L. Cole

Virginia Commonwealth University

Abstract

This qualitative study sought to center the personal experiences of Black American women affected by Sickle Cell disease (SCD) within the broader policy discussion of mental health disparities. Previous research suggests that stress may serve as a trigger for painful episodes which may contribute to increased rates of psychiatric morbidity in this population. The sample consisted of 10 women who perceived disease related stress in various social settings. Data was collected via tape recorded interviews using a semi-structured interview guide. The findings shed light on the role of perceived social stressors as potential determinants of mental health disparities among SCD women. The development of a gender and race specific psychosocial screening instrument which measures the social correlates of stress in this population is warranted. Amelioration of the social conditions that place SCD women at risk for poor mental health outcomes should be the ultimate policy goal.

Introduction

In recent years, the terms "health disparities" and "mental health disparities" have become buzzwords within conversations among academics, policymakers, community activists, and citizens who are concerned about health care and health outcomes. Two documents are responsible, in part for bringing these issues to the fore of the nation's health policy agenda. The Institute of Medicine (IOM) Report Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care (Smedley, Stith & Nelson) published in 2003 found that minorities were more likely to encounter quality of care, access, and affordability issues when interacting in the health care system. The U.S. Surgeon General's Report Mental Health: Culture, Race, Ethnicity commissioned by Dr. David Satcher in 2001 cited the following "Ethnic and racial minorities in the United States face a social and economic environment of inequality that includes greater exposure to stressors such as racism, discrimination, violence, and poverty, all of which take a toll on mental health" (p. 13). It is hypothesized that the health of African Americans in particular, has

suffered greatly because of these social stressors. The terms "African American" and "Black" are used interchangeably throughout the paper to refer to Americans who share a common ancestral descent from people historically indigenous to sub-Saharan Africa.

Although the literature suggests an "interconnectedness" between stress and physical health outcomes among African Americans (Mechanic, 2005; Satcher, 2006), it is also believed that the cumulative effects of social stress may partially explain why African Americans have a greater burden of mental illness than Caucasians. Blacks are more likely than Caucasians to use the emergency room for mental health problems. Research findings suggest that Black women are most vulnerable to mental illness and their self-reported distress tends to be higher than Caucasian women, Black men, and Caucasian men. At any given time, 16 percent to 28 percent of women in this group have psychological distress that is indicative of clinical depression (Brown & Keith, 2003, p. 46). Phobia appears to be the most frequently occurring anxiety disorder among Black women

in large scale psychiatric studies such as the Epidemiologic Catchment Area Survey (Robins & Regier, 1991) and the National Co-Morbidity Study (Magee, 1993). Furthermore, Neal & Turner (1991) contend that Blacks are less likely to receive appropriate treatment for anxiety disorder because symptoms of anxiety may be manifested differently in Blacks than in Caucasians.

In general, women of color are less likely to report excellent or very good perceived mental health status (Agency for Healthcare, Research and Quality, 2001). Black women are most likely to report fair or poor mental health (Clark, Fong, & Romans, 2002). Research on appropriateness and outcomes of mental health services finds that Blacks may metabolize psychiatric medications more slowly than Caucasians with Blacks often receiving higher dosages than Caucasians, leading to more severe side effects (Lawson, 2004). On a positive note, while few clinical trials have evaluated the response of Blacks to evidence based treatment, the limited data available suggest that, for the most part, Blacks respond favorably to treatment (DHHS U.S. Surgeon General's Report, 2001 p. 68).

The present study seeks to describe and analyze the chronic illness experience from the viewpoint of Black women affected by Sickle Cell disease (SCD). Another aim is to explore the perceived relationship between disease related stress and mental health among SCD women. I place the various descriptions into the context of our existing knowledge base regarding risk factors for mental health disorders among Black women. By examining the relationship in this manner, I hope to clarify underlying risk processes e.g., stress emanating from perceived racism and/or unfair treatment in settings such as the health care system and the workplace which may predispose Black women in this population to experience depression and/or anxiety. As suggested by Smith, Bovbjerg, Penberthy et al. (2005):

> Since African Americans are on average poorer, have more limited access to health care services and die sooner than

Caucasians, understanding health services for SCD may yield unique insights into the relationship between symptoms and illness on one hand, and access, quality, healthcare utilization and costs for the poor and underserved on the other. (p. 183)

In general, Black women may be exposed to more stressful circumstances than other women because of a particular set of role expectations. Black women have historically combined employment, childbearing, and family roles, thus increasing the likelihood of role overload and role conflict, particularly in circumstances where coping resources are limited. It is likely that SCD women may bear a "triple burden" – in that they may receive unfair treatment in the workplace or educational institutions due to race, sex, and socioeconomic status on one end of the continuum, and then face the same possibility [of unfair treatment] in the health care system given that the disease is accompanied by unique genetic, racial, and clinical markers. Lydia K. Anderson, former President and Chief Operating Officer (COO) of the Sickle Cell Disease Association of America (SCDAA) echoes this sentiment in the Sickle Cell Newsletter:

> Far too many sickle cell patients are having their self-esteem, integrity and health compromised when they need emergency care. All too often, they face accusations of seeking treatment under false pretenses. There is a prevailing misunderstanding within the health care system about the unique physical challenges and social needs of patients. (Summer, 2000, p. 3)

Epidemiology of Sickle Cell Disease

SCD disorders are characterized by abnormal hemoglobin production, hemolytic anemia, and vascular damage caused by trapped abnormal red blood cells resulting in acute and chronic tissue damage (Dauphin-McKenzie, Gilles, Jacques, and Harrington, 2006). The disease is named "sickle" cell because of the abnormally shaped red blood cells that resemble the sickle, a farm tool with a curved, sharp edge that is used for cutting wheat (Kenny, 2005). Persons with SCD may experience fatigue, poor appetite, infections, growth retention, incontinence,

damage to bodily organs, strokes, paralysis, and early death (Whitten, 2001). Painful episodes vary in frequency and severity and many are managed at home with oral analgesics. SCD pain can be as intense as post-operative pain (Walco and Dampier, 1990), and severe painful episodes are treated in hospital with parenteral opiates, usually intramuscular injections or intravenous infusions of pethidine, morphine, or dimorphine.

To date, there are about 70,000 Black Americans in the United States who are homozygous for the sickle cell gene (NHLBI, 2007). The condition predominately affects people of African ancestry. It affects 1 in 400 Blacks and has a carrier rate (sickle cell trait) of 1 in 12 and 1 in 100 for Black and Latino populations respectively (NHLBI, 2002). Other populations may be affected because the gene is widely distributed and is present in the Mediterranean and Caribbean regions, the Middle East, and South America (Alleyne & Thomas, 1994). In 1970, the estimated median survival for patients with SCD was 20 years (Smith, Bobverg et. al., 2005, p. 184). Life expectancy is now estimated at 43 years for males and 48 years for females while some people with sickle cell disease live into their 60s and beyond (Dauphin-McKenzie, Gilles et al., 2006, p.344).

Some gender based differences have been noted as SCD women living in India express more seasonal variation in the frequency of painful episodes (Dash & Das, 1998). Another study conducted by Mohanty & Mukherjee (2002) reported that menarche is delayed to an average age of 15.8 years as compared with 13 years in the non affected population of India. Women with SCD also experience multiple complications as each organ system can be adversely affected. For example, more than one third of pregnancies in women with sickle syndromes terminate in abortion, stillbirth, or neonatal death (Smith, Espeland, Bellevue et al., 1996, p. 200). In contrast to what has been reported by some in the literature, McClish, Levenson, Penberthy et al. (2006) found no gender differences between men and women in a longitudinal cohort of 226 SCD patients who were followed for six months as it related to

reported sickle cell pain, distress, and interference in daily activities. The authors found no differences in health care utilization with a trend toward women using slightly less health care resources.

Psychosocial Aspects of Sickle Cell Disease

Psychological complications in patients with SCD mainly result from the impact of pain and symptoms on their daily lives and society's attitudes toward them (Anie, 2005). SCD can be a stigmatizing condition, associated with negative labels or social meanings that are attached to negative behaviors (Joachim & Acorn, 2000). There may be physical differences such as lower weight, short stature, and delayed sexual development when compared to a matched control group which could exacerbate the process of stigmatization (Cepeda, Allen, Cepeda, & Yang, 2000). Psychological research findings among individuals affected by SCD have been mixed; some studies have reported high rates of depression (Belgrave & Molock, 1991; Hasan, Hashmi, Alhassen, Lawson & Castro, 2003; Wilson-Schaeffer, Gil, Burchinal et al., 1999) although a clear pattern of clinical depression and anxiety has failed to be established (Alao & Cooley, 2001; Molock & Belgrave, 1994) which may be in part due to small sample sizes, culturally insensitive instruments or instruments that are unable to disaggregate depressive symptomatology or anxiety and SCD disease related symptoms. Individuals with a chronic illness such as SCD are at risk for depression. Moreover, they are at risk for untreated depression (Jenerette, Funk, & Murdaugh, 2005).

Health problems and resulting complications such as repeated hospitalizations, interruptions in daily living schedules, and anxieties associated with decreased life expectancy increase SCD individuals' chances for experiencing social and psychological distress. Difficulties in these areas negatively influence the individual's overall sense of well-being and life satisfaction (Comer, 2004). These findings speak to the following: 1) A broader public health issue of racial and ethnic disparities in terms of quality of and access to mental health

treatment as noted in the 1999 and 2001 Surgeon General reports and 2) Suggests the potential for SCD as an exemplar to further expound the complexities of race, socioeconomic status, gender, and psychosocial implications of chronic illness. This insight may inform health care professionals, social workers, and psychologists in the development of psychosocial screening guidelines for SCD, which may have a significant impact on rates of psychiatric morbidity and mortality in this population.

Pain Management

Patients often report that their pain is poorly managed when they are in the hospital, or that staff are not responsive to patients' reports of pain (Maxwell, Streetly & Bevan, 1999). Another common complaint by SCD patients is that staff unjustly suspect or accuse patients of drug dependence (Shapiro, Benjamin, Payne & Heidrich, 1997). A study conducted by Waldrop & Mandry (1995) revealed that the estimated prevalence of opioid dependence was twice as high for patients with SCD compared with patients with other painful conditions.

Perceptions by hospital staff of substance dependence may affect patients with other painful conditions, but patients with SCD may be at greater risk for several reasons. First, in Europe and North America, SCD patients are all members of ethnic minority groups, which may adversely affect their treatment in health care settings (Dyson, 1998). In a study conducted by Chestnut (1994), race was perceived by SCD patients and their families as the most influential factor affecting health care delivery and there is evidence that hospital pain management is poorer for ethnic minorities by comparison with other patients.

Advances in the care of people affected with SCD include genetic counseling, neonatal screening, early initiation of prophylactic penicillin therapy, closer medical monitoring, and newer medications such as hydroxyurea (which has been found to decrease the severity and frequency of painful episodes by at least 50% in some patients). The only cure for SCD at this time is bone marrow transplantation, which is not an option for most people with SCD due

to either a shortage of compatible donors or the inherent risks posed by the drug regimen required before transplantation (Chakrabarti & Bareford, 2004). Given that SCD individuals are living longer due to medical advances, psychosocial intervention strategies must be identified and implemented to help them cope with the challenges that often accompany this disease. But in order to develop these intervention strategies, I argue that social sources of stress inherent within various institutions such as the workplace, schools, and health care must be understood from the perspective of SCD women and targeted with their insights in mind.

Methods

This qualitative analysis was part of a larger dissertation project that examined the causal processes of depressive symptomatology and anxiety in 30 SCD women. The American University Institutional Review Board provided ethical approval March, 2002.

Sample

A sample of 30 women was recruited between April 16, 2002, and October 17, 2002, from various locations in the Washington, D. C. Recruitment locations included: a sickle cell clinic hospital waiting room; a monthly sickle cell support group held at a local church; study announcements at three local churches; postings on the Sickle Cell Association of the National Capital Area web site; a snowball method in which participants informed friends and relatives about the study); and fliers mailed to 253 individuals on a list provided by the Armstead-Barnhill Foundation, a sickle cell advocacy organization in Crofton, Maryland.

The first 10 persons recruited participated in the interviews after completion of survey instruments that explored role strain, depressive symptomatology, anxiety, mastery, and disease severity in Phase 1 of the study. There was no systematic method or criteria used to select Phase 2 interview participants. Due to the chronic, unpredictable nature of this disease [from a research standpoint], time was of the essence. Oftentimes, participants were available for the survey Phase 1 of the study and then

hospitalized the following week. Additional delays would result as it would take up to a month to reschedule with some participants. The most logical way to interview the women was to conduct interviews with those women who were interested and were feeling well enough to participate in both phases on the same day.

The 10 participants ranged in age from 27 to 66 years, with a mean of 41.2 years. The women self described as being Black, African American, or of African descent. Two of the participants were married, seven were single or divorced, and one was widowed. Half (50%) of the participants were gainfully employed in occupations ranging from medical technologist, nurse, college financial aid counselor, and computer programmer.

The women's annual incomes ranged from $30,000 to $70,000. One participant was retired and received monthly Social Security checks. Three participants had intermittent work histories in the service sector e.g., restaurants, domestic work and were no longer able to work based upon their doctors' recommendations. These women reported that they were encouraged to apply for Supplemental Security Income (SSI) which provided them with annual income totaling $9,000.00 per year. One participant was able to work but her employer determined that she was unable to fulfill her duties, and was subsequently fired. This participant reported unemployment insurance payments as her primary source of income in the amount of $500.00 per month.

Each participant was required to read and sign a consent form which explained the purpose of the research, procedures involved, risks and benefits of participating in the study, and my contact information. Each participant was paid $20.00 for one structured interview. Interviews ranged from 1.5 to 2 hours and took place at participants' homes in the Washington, D.C. metropolitan area. Participants responded to open–ended questions about disease related stress, the experience of stigma, stressful life events, and perceived impact on their mental health.

Data Analysis

Participants were allocated a randomly selected number and referred to by this number throughout the interview process. Interviews were recorded and then transcribed. Transcripts were reviewed for consistency with audio recordings, then shared with participants for accuracy and corrected accordingly. I used Atlas/Ti software to store all interview texts, field notes, codes and code definitions, and categories. Data collection and analysis occurred simultaneously which is consistent with grounded theory methods as described by Strauss & Corbin (1990). Inter-rater reliability was assessed by comparing the transcript coding between myself and a colleague to facilitate a more robust analysis.

Inductive, open coding techniques were used to identify initial categories and concepts that emerged from the transcripts. I used axial coding techniques to refine initial categories and relate categories to one another as commonalities regarding perceived social sources of stress emerged. A constant comparison method was utilized to identify any additional common elements of stressful experiences which led to generation of broader categories that were consistent across interviews. Memos were also generated to capture the textual "flesh" of the study findings and were an integral component of theory building. I constructed memos to distinguish between physical/mental signs of stress which helped identify the multiple meanings/interpretations of stress for the participants. I also used memos to explore ways in which categories were linked with the existing literature on the stress process e.g., the significance of stressful life events versus ongoing daily hassles. This process is consistent with basic tenets of qualitative data analysis that suggest these memos may be organized into conceptual networks (Tesch, 1990). The use of qualitative software allowed me to track changes made to the coding of the interviews overtime. In this way, a clear audit trail added to the trustworthiness and completeness of the research (Lincoln & Guba, 1985). Finally, I kept a reflexive journal to assess my own biases and described how those biases might have impacted the study.

Findings
The findings will be presented in relation to four categories:

1. Stressful Experiences during Hospital Care
2. Stigma and SCD
3. Stressful Events Precede Painful Episodes
4. Disease Related Stress Impacts Perceptions about Mental Health

Experiences of Hospital Care
This category describes women's experiences: 1) with pain assessments made by physicians; 2) difficulty in obtaining analgesics; and 3) health care professionals' responses to the patient in pain. The testimonies of the women attest to an apparent lack of understanding of pain particularly among those within the lower socioeconomic status group (less than $19,999.00) per year. The emergency room was a source of stress for eight of the women. One participant reported negative experiences in the emergency room, but reports a satisfactory relationship with her primary care physician. Another participant, a nurse, did not report stress because she was trained to understand the treatment process. The major concerns among the eight women who reported health care related stress were the following: 1) health care providers did not take patients' pain seriously; 2) health care providers thought the women just wanted drugs; 3) health providers thought the women had exaggerated the severity of their pain; 4) Patient satisfaction varied and was contingent upon one's degree of "health literacy" e.g., basic doctor-patient communication skills, understanding of the biopsychosocial aspects of SCD.

Pain Not Taken Seriously (Drug Seekers)
The following participants suggest that doctors do not take pain seriously because patients are seeking drugs for their own pleasure. At times, there is incongruence between doctors' pain assessment tools and patients' perceptions of pain.

> I am fortunate where I don't go into a pain crisis that often…when I did have to go in to the emergency room, there was one doctor

who gave me my pain medication and an hour later he comes and asks me "So are you ready to go home?" And that just turned me off so I just left…..It's very far and few between where I get a doctor who is really concerned with what I feel, what medicines I usually take, how I handle it. Because a lot of them [doctors] just have this preconceived notion that you are an addict because you have sickle cell and that bothers me.

This participant suggests her racial/ethnic background plays a role in faulty assumptions made by physicians.

> Because pain medication a lot of the time is addictive, doctors make false assumptions about the patients and also because sickle cell patients are Black, doctors think we are addicts, lying, cheating, stealing. It is a contradiction…doctors are here to help, you [doctors] have tests that prove I have this disease. If I weren't in pain, then I wouldn't be in here. And so why are you going to assume that I am lying, when you have already tested me to prove that I have a disease that produces pain as a symptom.

Delays in the Provision of Pain Medication
These two participants acknowledge delays in receiving pain medication and blame doctors and nurses for exacerbating their levels of stress:

> It can be stressful in that sense that we have to wait hours in the waiting room… in pain and nobody understands that. It's just so stressful. Doctors put us through the trauma of crying….

Another participant said:

> The emergency room… that could give anybody stress… Once I got to my hospital room, about an hour went by and nobody came in to see about me …. I was having a fit.

One participant believed that losing one's temper with health care workers may speed up treatment.

…..they will tell you to go back out to the waiting room and sit down until they call you. Now that's what you call stress, I become angry, and then I begin to argue with the nurses until I get some attention.

Patient satisfaction with pain management may be influenced by degree of "health literacy" such as familiarity with the health care system, basic doctor-patient communication skills, understanding of physiological processes associated with SCD.

In contrast to previously described experiences, participants who worked in the health care field tended to report satisfaction with pain management. One participant states:

I haven't experienced a lot of stress not in relation to physicians or health care. I understand the treatment process due to my training in the nursing field.

Another participant said:

When it comes to healthcare, I am in the health field…. so I have a lot of background knowledge about the way my body works and about medications. There are certain medications that I intend to take and I make clear what I do not intend to take. I have learned a lot about SCD itself and things that can really affect me in an adverse kind of way. Because I have a knowledge base, I have not had a bad experience in the health care system…because I am very vocal in my own care and I ask for what I need.

This participant goes on to talk about steps that persons with SCD can take to advocate for themselves.

The people with the disease, they have to become more vocal, make complaints, write complaints to the hospital administrators who like to get good ratings in this area…they don't want people to stop coming to their hospital. Well, you know you have a voice, and you can use it.

It is important to note that six out of the ten women had either undergraduate and/or graduate degrees. Women with higher levels of education were empowered by various experiences in health care and felt that they would have to be actively involved in order for change to take place. The four participants who had completed some high school or had high school diplomas were more likely to feel powerless when interacting with health care professionals. Three out of the four participants with high school diplomas or some high school were also at risk for Major Depressive Disorder and Generalized Anxiety Disorder as evidenced by high scores on the Center for Epidemiologic Studies Depression Scale (CES-D) and the State Trait Anxiety Inventory (STAI) instruments completed in Phase 1 of the present study. There was only one participant with a college degree at risk for Generalized Anxiety Disorder as evidenced by high scores on the STAI. This participant did not score at risk for Major Depressive Disorder in Phase 1 of the study.

The participant with the highest annual salary among the other women recounted a unique experience which was vastly different from others in the study. Her primary care doctor allows her to come in to the office for intravenous fluids if she feels a painful episode is about to occur. This strategy seems to lessen the need for emergency room visits as she is able to leave work and spend the day at the doctor's office. Her perspective also differs from other participants because she says "in her mind, she does not have an illness." The participant labels this way of thinking as "reverse psychology."

I really like the fact that I can come in…get some intravenous fluids and pain medication as opposed to the emergency room because before I worked out this arrangement, my experience in the emergency room was ridiculous.

Doubts about the genuine nature of pain
This participant suggests that to some extent, doctors may be unknowingly questioning the veracity of medical tests when they doubt the magnitude of SCD pain.

Apparently what is lacking a lot in the health care system is physicians and nurses that know about SCD. And generally because it is in the Black community and a lot of times when they [white doctors] see patients they are not sure how to react to pain. I think there is a contradiction in the medical community concerning their own tests and what the tests say the patient should be experiencing when they have a certain illness yet in the doctor's mind there is a fear the patient is going to be addicted….yes to some extent there is dependency… what do you call that if you don't rely on something to relieve your pain. You depend on your job to pay you so you can pay your bills, well a person that has pain must depend on something to relieve the pain ….well what do you [doctors] think they [SCD patients] are going to depend on.

This participant suggests that gender may influence the doctors' pain assessment.

I have managed over the years to deal with doctors. They [doctors] don't like it when you come in crying, they just can't handle a woman in tears. Because doctors can be so intimidating and if you don't know how to express yourself [being a woman] ….like how bad your pain is…. you may get run over.

Stigma and SCD

In this section of the interview, I focused on participant perspectives regarding stigma in social institutions such as the family, education, workplace, health care system.

Women affected by SCD may have to endure the stress that accompanies stigma and/or discrimination. The responses to this question fell into two categories. There were two participants who chose not disclose their health status and in turn, avoided stigma. The remaining eight participants chose to disclose their disease status. As a result, they reported the experience of stigma and perceived discrimination in the workplace, schools, and by health care professionals. For example, one participant reported that she was fired from her

job because of SCD. Another participant had to endure the ignorance of her co-worker who wondered if SCD was contagious.

Two participants recount how delayed body development led to being labeled as "different." Two participants talked about interactions with educators who either equated SCD with cognitive deficits or lowered their academic expectations of them (because they were students with SCD). Two participants felt discriminated against in the health care system because SCD predominately affects Black Americans.

No Disclosure of Disease Status

One woman who works in the health care field, chose not to reveal her disease status to co-workers.

I didn't tell because I never wanted to be 'that worker with SCD'. And I don't like to be cast typed and I don't like labels. I don't like people to put me in a box. I just wanted to be normal like anyone else and regarded on my own merits as a health care worker and on my skills and what I did.

Another woman chose not to reveal her disease status because she does not feel that others need to know:

I can honestly say 'no.' Because one, I don't tell people I have sickle cell. Some people are able to tell because they know the symptoms like jaundice or yellowing of the eyes. I think I heard somewhere that you have the longer legs shorter torso. I don't know if that is a sickle cell characteristic or not, if someone is familiar with that they may say something to me. I am not going to lie but I will tell them that I would rather it not be public knowledge. So I don't feel as though I have been discriminated against.

Disclosure of Disease Status

The following participants discuss the emotional implications of disclosure:

One woman discussed SCD and effects in the workplace.

There were jobs I worked at that made me feel uncomfortable because of my sickness. They would make smart remarks like 'What is that?' 'Can we catch it?' People or co-workers [also African American] on the job would ask stupid questions like that.

Another woman states she was fired from her job and subsequently filed a lawsuit:

Recently I was fired for having sickle cell because I told them I could not go to Denver, Colorado because of the high altitude [this is known to cause painful attacks among persons affected by SCD]. My boss accused me of lying and said I didn't disclose that I had a disability…I told him that I don't have a disability. He told me that I couldn't do the work…he was very angry at me and very rude. He treated me like I was the bad guy and caused problems for the company.

Another woman talks about perceived discrimination in the health care system.

The only time I was treated differently was with the health care professionals. There are some things with the health care profession that really bother me basically because sickle cell affects the majority of African Americans. ….you would think that doctors would be a little bit more open or receptive going through schooling and learning about various illnesses that they would be more compassionate. It is also sad that in some instances, white doctors tend to have a little bit more compassion than Black doctors.

Another woman said:

Because sickle cell is a disease of predominately minorities, I think it carries a certain stigma with it. The vast majority of minorities afflicted with this disease are low income. And in this country people of low income are treated differently than people of moderate to upper incomes. You know they try to pigeon hole you and they think that everyone who is low income is illiterate or uneducated. I have seen many doctors

approach me as if I were uneducated, illiterate or somewhat less articulate than others.… because I am a Black person with sickle cell disease.

Another participant questions her delayed development.

I never got my menstrual cycle until I was a senior in high school and I asked myself 'Am I normal?'

Stigma can also surface within the family especially if there are no other siblings with the disease as reported by another woman.

I had a brother of mine tell me after my mother died, after we buried her 'Oh you know poor _____. All we ever heard about was poor _____ is going to die from sickle cell.' She can't do this or that because of sickle cell. And it's been all these years and you haven't died yet.

Stressful Events Precede Painful Episodes

I explored the role of stress in the occurrence of painful episodes after listening to the women's definitions of stress, and experiences of stigma and discrimination. I wondered if they thought stressful periods tended to precede painful episodes. Among the 10 women I interviewed, eight women expressed agreement with the hypothesis that stress triggered painful attacks. One participant saw a link between parenting stress and frequency of pain. Another participant was able to recount an upsetting interaction with her teenaged son that precipitated a pain attack. The experience was frightening for the participant and she says it led to a subsequent hospitalization in the intensive care unit. Another participant identified a link between stress and pain during her elementary and middle school years. She also believes that her low self-esteem during that period increased her vulnerability to the negative effects of stress. Two participants saw no link between stressful life events and pain. One participant reported that cold air seemed to trigger pain attacks.

Stressful Life Events as Triggers for Painful Episodes

When asked about the relationship between pain and stressful periods, a participant offered this perspective.

> I stayed in the hospital every day. I was in a pain crisis almost every single week. It wasn't until I got to know who I was, got into environments where I felt comfortable about myself, got out of stressful environments that pain is not even an issue for me. I have not been hospitalized in 13 years and I think it's because I have not been in a real stressful role. It was then that I determined that I was going to do….what I need to do to stay out of the hospital.

I asked a participant if she observed a relationship between her level of stress and pain. She admitted earlier in the interview that stressful events did not have a negative impact on her mental health. She felt that stressful periods were challenging and made her stronger. I was intrigued by her response that stress had just the opposite impact on her physical state:

> I can say with 100% accuracy that it is a true and correct statement. That is why I work hard to eliminate stress from my life because I know that it will trigger an attack. In other stressful situations, I start worrying and my body feels tight. If my body is not in a relaxed state, my cells will not flow smoothly and all I need is to not drink some water or not get some rest…my body is tight because of the stress, an attack is coming, guaranteed…I would try to say to everybody that has sickle cell, you have to eliminate stress.

Another woman noted the following:

> I have always tried to see what makes me go into a pain crisis…and a lot of time I would figure that it was due to a lot of stress from home. My family expects me to live a normal life like they do…care for my son…care for myself, they expect me to do that.

No Trigger for Painful Episodes - Unpredictable

In contrast to other participants, one woman was not aware of a relationship between stressful periods in her life and painful attacks.

> There is nothing that turns this thing on, pain just comes on by itself. This is the only disease I know of that pops out of the blue. It doesn't give you any warning.

Another participant states:

> I can't really say there is a relationship between my normal everyday stress and pain.

Disease Related Stress Impacts Perceptions about Mental Health

Out of the 10 women interviewed, eight believed that disease related stress impacted their mental health in a negative sense. For one participant it was the additional strain of her son's illness that stressed her out and forced her to seek out psychiatric services. Another participant sought out formal mental health services due to complications of SCD. Another participant reported that lack of employment had a negative impact. Two participants reported that stressful life events presented challenges that affected them in a positive manner and made them stronger.

Disease Related Stress and Perceived Negative Impact on Mental Health

One woman spoke of the disabling nature of SCD which led to her unemployment:

> I think it has taken a great toll on my mental health. Because sometimes I find myself really depressed, worn out, and crying.

Another woman elaborates on how the stress associated with her leg ulcer (complication of SCD) led to utilization of mental health services.

> I am taking an anti-depressant medication. I have a pretty high stress level and a high tolerance. But I do have my breaking point. I went to a therapist…..my primary doctor suggested that I see someone.

In contrast, one mother said the experience of her young son being diagnosed with cancer forced her to seek mental health services with a psychiatrist. She had never sought out formal mental health services to cope with the stress of SCD.

> I was stressed at the time. At the time my son was sick and I had to go back to work and he still hadn't come home from the hospital…hoping and praying that I wouldn't get sick from worrying so much. So that was the only instance that I really had to see a psychiatrist.

Adversity as a Motivator with Perceived Positive Mental Health Benefits
Two participants felt that the stressful experiences related to the disease did not have adverse effects on their mental health. Examples of comments made in this regard follow:

I think I am fine mentally. I have to do more to break down some of the myths about SCD patients. To make the medical physicians or the medical community more educated. Stressful experiences as a person with SCD gives me more drive….more perseverance.

Another woman said:

> These experiences have impacted my health in a positive manner. Because I am a competitive person and I like to win. So I have used these negative experiences to make me stronger…it's almost like a challenge. When my husband and I divorced, he just assumed that I would fall apart. I showed him. So I've used this attitude not only with sickle cell but if anyone challenges me…I will just use that as an incentive to better myself.

Discussion
In this study, the relationship between disease related stress and perceived impact on mental health for Black women was explored. This study sheds light on the complex ways in which Black women understand, live with, and respond to unpredictable attacks of pain characterized by SCD. This study also pays attention to the

mental health status of SCD women given that they are more likely to experience stress and to exhibit depressive symptomatology than SCD men (Schaeffer-Wilson, Gil et al., 1999). In addition, eight of the participants recognized the role of stress in the occurrence of painful episodes. This awareness is consistent with the framework advanced by Bloom (1995) that persons with SCD should avoid stress as it could trigger painful episodes.

The present study demonstrates the resilience of women who have faced many challenges in part, due to their health status, race, and gender within various social settings. It is clear from the findings that multiple sources of stress place these women at risk for depressive as well as anxiety disorders. Hence, the present study sought to get at the "root" of social stress and how it manifests itself in the form of a risk process for anxiety and depression among SCD women.

The health care system, specifically emergency room departments, emerged as major stressors for eight of the participants. The women perceived health care as a burden in their lives rather than an opportunity to get physical and mental health needs addressed. The literature suggests that SCD patients may have difficulty in obtaining proper health care and appropriate treatment for painful episodes (Barbarin & Christian, 1999). Three participants noted that they often try to manage their pain at home to avoid emergency room visits. Sickle cell patients may be treated rudely, or may experience delays in care. As a result, some may actually try to avoid the emergency room department until extreme need provokes utilization (Murray & May, 1988).

My investigation reveals a vicious cycle whereby social stressors might bring about painful episodes in this population. Upon entrance into the health care system, an SCD woman may encounter additional stress due to the perceived insensitivity of health care professionals. This, in turn, might exacerbate the physical and emotional pain associated with the treatment of SCD. Cumulative effects of disease related stress (specifically perceived unfair

treatment) on frequency of pain has yet to be explored by researchers in the areas of sickle cell and among minorities in other chronic illness groups. In addition to addressing the misinformed personal beliefs of health care providers, efforts to improve pain management services should also seek to identify and address barriers that prevent readily available medical technology from being fully utilized to relieve pain (Mendenhall, 2003).

Another notable finding was that women who were highly educated, worked in the health care field, and possessed "health literacy" tended to be satisfied with their care as compared to those women with lower levels of education. An abundance of information and knowledge acquired by women regarding pain medications, sickle cell therapies, and biological/ physiological processes associated with SCD, seemed to increase the likelihood of taking on the role of "patient advocate" for themselves. This suggests the need for health education among SCD patients given that access to information might equate to higher levels of empowerment and increased satisfaction when interacting with providers in the health care system. Moreover, Carr- Copeland (2003) notes that patient satisfaction among African American women is one of many missing links among health services research investigations.

In terms of stigma, two women felt that they had not been stigmatized or treated unfairly because they did not disclose their SCD status. Although the two participants perceived this as a positive action, they did not seem to have an awareness of the emotional toll this could take on their mental health by what is referred to as "passing" (Goffman, 1963). Passing involves deliberate concealment of the illness. The goal of passing is to become part of the "normal" group. Individuals who utilize this strategy can impose additional stress on themselves due to worry about the risk of discovery and the embarrassment of being caught. Should one be caught lying, the SCD individual may be stigmatized and discredited. The discredited individual then suffers the same fate as the person with a visible defect (Joachim & Acorn, 2000).

The majority of the women chose to disclose their status. It appears that two of the women perceived being penalized in various ways for their disclosure e.g., being fired from one's job, blocked opportunities for advancement in the workplace. Stigma associated with chronic illness, and the resulting discrimination discourages individuals and their families from getting the help they need (Jenerette et al., 2005). Furthermore, Snowden (2001) suggests that in general, African Americans tend to deny the threat of mental illness and strive to overcome mental health problems through self reliance and determination. Health care providers can lessen the stigmatization of adults with SCD by gaining a better understanding of SCD, educating others, and screening for depression and anxiety (Smith et al., 2005; Schaeffer-Wilson et al., 1999). I would also argue that a gender and race specific psychosocial screening instrument which measures the social correlates of stress among SCD women is needed.

Disease related stress appeared to impact the majority of participants in a negative sense. It is important to note that women's perceptions of mental health correlated with objective measures of depression and anxiety in Phase 1. In other words, those women who did not perceive being in a healthy mental state, scored high on either the CES-D, STAI or both. The scores met the Diagnostic Statistical Manual (DSM) criteria for diagnoses of Major Depressive Disorder and Generalized Anxiety Disorder (American Psychiatric Association, 2000). Conversely, two participants who had positive perceptions of mental health scored low on the CES-D and STAI. To my knowledge, there is no literature that tracks SCD women's perceptions with objective measures of depression and anxiety in a single study.

There are also some study limitations that must be highlighted to ensure that findings are interpreted in an accurate context. First, the study is cross-sectional; hence causation could not be inferred. Second, because of the small sample, findings cannot be generalized to others and apply only to a similar population. Third, given that women self-selected (participants

volunteered after completing Phase 1 of the study) the potential for bias is possible, because women were not selected randomly.

In this article, I place SCD in a broader discussion of mental health disparities which up to this point has been largely absent (because it predominately affects patients of one race). The fact that four participants in this study met the DSM criteria for Major Depressive Disorder and Generalized Anxiety Disorder is alarming. These participants also talked about behaviors that place them at risk for these mental disorders e.g., withdrawing from others and keeping things bottled up inside. It is also striking that these women did not perceive a need to consult with a mental health professional. The two participants who sought out mental health treatment were referred by primary care physicians in light of either family related crisis or emotional distress communicated by the patient to the primary care physician. There seems to be a striking contradiction between the goal of improving access to mental health treatment and the multiple realities experienced by the participants in this study.

The Surgeon General's Report (DHHS, 2001) suggests that in order to improve access to mental health care, strong links must be developed between primary care providers and community mental health centers. Demonstration projects and research programs need to be created to encourage the delivery of integrated primary health care and mental health services for SCD women.

In order to help patients with SCD deal with depression and anxiety, we need to know the source of stress: Is it the disease, the living conditions of the patient or both? (Molock & Belgrave,1994). Sources of stress were identified in this study but critical unanswered questions remain regarding the pathways leading to positive mental health and factors associated with help-seeking processes for formal mental health services among SCD women. It is these same questions that still remain unanswered for Black women in general. These concerns are consistent with the Surgeon General's Report (DHHS, 2001) regarding the expansion of our

science base. The mental health community will benefit from a better understanding of how factors such as help seeking behaviors and stigma provide protection against or risk for mental illness in minority populations and specifically among SCD women.

Expansion of our science base and improved access to mental health treatment for SCD women must take place within a health care system described in recent years as "broken" (Gingrich & Kennedy, 2004). The reality is that there are too many unknowns specific to health system changes and no mechanisms in place within the sickle cell community to address or study problems specific to these changes (Telfair, 2004).

The next step for me is to generate research that sheds light on ways of coping, sources and perceived meaning of social support, and SCD women's suggestions for interventions to alleviate stress in their lives. An exploration of perceived psychological resources coupled with the findings of the present study, will reveal a total picture of the sickle cell disease experience from a Black woman's point of view. As noted by Telfair (2004) "having a chronic condition such as SCD, while struggling with issues of being African American or a person of color in this society, compounds the already complex task of day to day functioning" (p. 136).

The findings from the present study will not only strengthen our existing knowledge base regarding biopsychosocial issues facing persons affected by SCD but also highlight the way in which qualitative research could influence the policy process. The passage of the Sickle Cell Treatment Act in October, 2004, designed to substantially expand specialized sickle cell treatment programs, offers a remarkable opportunity to significantly improve health outcomes for individuals with SCD if the legislation is implemented with a specific focus on the distinct but related issues of equity and quality (Smith, Oyeku, Homer & Zuckerman, 2006). The present study enabled Black women to give priceless gifts in the form of their voices. Policy makers should be made aware of these voices. In addition, policy makers must be

mindful of the ways in which race, class, and gender shape the disease experience if elimination of disparities in health care and mental health treatment are to transcend from "policy goals on a national agenda" to realities in the lives of Black women.

References

Agency for Healthcare Research, & Quality. (2001). In B. M. Altman & A. K. Taylor (Ed.), Women in the health care system health status, insurance access to care. Rockville, MD: Agency for Healthcare Research and Quality.

Alao, A. O., & Cooley, E. (2001). Depression and sickle cell disease. Harvard Review of Psychiatry, 94(4), 169-177.

Alleyne, J., & Thomas, V. J. (1994). The management of sickle cell crisis pain as experienced by patients and their carers. Journal of Advanced Nursing, 19, 725-732.

American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.). Washington, DC: Author.

Anderson, L. (2000, Summer). In the spotlight. Sickle Cell Newsletter(Summer), 3. National Sickle Cell Disease Association of America.

Anie, K. A. (2005). Psychological complications in sickle cell disease. British Journal of Haematology, 129, 723-729.

Barbarin, O. A., & Christian, M. (1999). The social and cultural context of coping with sickle cell disease: I. A review of biomedical and psychosocial issues. The Journal of Black Psychology, 25(3), 277-293.

Belgrave, F. Z., & Molock, S. D. (1991). The role of depression in hospital admissions and emergency treatment of patients with sickle cell disease. Journal of the American Medical Association, 83, 771-781.

Bloom, M. (1995). Understanding sickle cell disease. Jackson: University Press of Mississippi.

Brown, D. R., & Keith, V. M. (2003). The epidemiology of mental disorders and mental health among African American women. In D. R. Brown & V. M. Keith (Eds.), In and out of our right minds The mental health of African American women (p. 46). New York: Columbia University Press.

Cepeda, M. L., Allen, F. H., Cepeda, N. J., & Yang, Y. M. (2000). Physical growth, sexual maturation, body image and sickle cell disease. Journal of the National Medical Association, 92(1), 10-14.

Chakrabarti, S., & Bareford, D. (2004). Will developments in allogeneic transplantation influence treatment of adult patients with sickle cell disease? Biology of Blood & Marrow Transplantation, 10(1), 23-31.

Chestnut, D. E. (1994). Perceptions of ethnic and cultural factors in the delivery of services in the treatment of sickle cell disease. In K. B. Nash (Ed.), Psychosocial aspects of sickle cell disease Past, present and future directions of research (pp. 215-242). New York: Haworth Press.

Clark, A., Fong, C., & Romans, M. (2002). Health disparities among U.S. women of color. An overview. In A. Clark, C. Fong, & M. Romans (Eds.), Proceedings of the Jacobs Institute of Women's Health (pp. 1-21). Washington, DC: Jacobs Institute of Women's Health.

Comer, E. W. (2004). Integrating the health and mental health needs of the chronically ill A group of individuals with depression and sickle cell disease. Social Work in Health Care, 38(4), 57-76.

Copeland-Carr, V., & Scholle, S. H. (2000). Patient satisfaction and African American women. A missing link in health services research. African American Research Perspectives, 6(2), 48-56.

Dash, B. P., & Das, R. K. (1998). Age sex and seasonal variations of sickle cell disorder cases in Orissa. Journal of Human Ecology, 9, 281-284.

Dauphin-McKenzie, N., Gilles, J. M., Jacques, E., & Harrington, T. (2006). Sickle cell anemia in the female patient. Obstetrical and Gynecological Survey, 01(5), 343-352.

Dyson, S. M. (1998). "Race", ethnicity and haemoglobin disorders. Social Science and Medicine, 47, 121-131.

Gingrich, N., & Kennedy, P. (2004, May 3). Operating in a vacuum. The New York Times.

Goffman, E. (1963). Stigma. Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice-Hall.

Hasan, S. P., Hashmi, S., Alhassen, M., Lawson, W., & Castro, O. (2003). Depression in sickle cell disease. Journal of the National Medical Association, 95, 533-537.

Jenerette, C., Funk, M., & Murdaugh, C. (2005). Sickle cell disease: A stigmatizing condition that may lead to depression. Issues in Mental Health Nursing, 26, 1081-1101.

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. Journal of Advanced Nursing, 32(1), 243-248.

Kenny, J. (2005). Sickle cell anemia. Retrieved August 16, 2006, http://www.edhelper.com/ReadingComprehension_29_143.html

Lawson, W. B. (2004, May). Pharmacogenetics of racial and ethnic minorities. Psychiatry and Race presented at the Race Medicine and Public Policy Conference, Washington, DC. Retrieved August 15, 2006, American Enterprise Institute web site http://www.aei.org

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Magee, W. J. (1993). Psychosocial predictors of agoraphobia, simple phobia, and social phobia onset in a U.S. national sample. Unpublished doctoral dissertation, University of Michigan, Ann Arbor.

Maxwell, K., Streetly, A., & Bevan, D. (1999). Experiences of hospital care and treatment seeking for pain sickle cell disease Qualitative study. British Medical Journal, 318, 1585-1590.

McClish, D. K., Levenson, J. L., Penberthy, L. T., Roseff, S. D., Bovbjerg, V. E., Roberts, J. D., et al. (2006). Gender differences in pain and healthcare utilization for adult Sickle Cell patients The PiSCES project. Journal of Women's Health, 15(2), 146-154.

Mechanic, D. (2005). Policy challenges in addressing racial disparities and improving population health. Health Affairs, 24, 335-338.

Mendenhall, M. (2003). Psychosocial aspects of pain management: A conceptual framework for social workers on pain management teams. Social Work in Health Care, 36(4), 35-51.

Mohanty, D., & Mukherjee, M. B. (2002). Sickle cell disease in India. Current Opinion in Hematology, 9, 117-122.

Molock, S., & Belgrave, F. (1994). Depression and anxiety in patients with sickle cell disease Conceptual and methodological considerations. Journal of Health and Social Policy, 5(3-4), 39-53.

Murray, N., & May, A. (1988). Painful crisis in sickle cell disease - patients' perspectives. British Medical Journal, 294, 452-454.

Neal-Barnett, A. M., & Turner, S. M. (1991). Anxiety disorders research with African Americans: Current status. Psychological Bulletin, 109, 400-410.

NHLBI. (2007). The National Heart, Lung and Blood Institute Diseases and Conditions index. Retrieved May 5, 2007, http://www.nhlbi.nih.gov/health/dci/diseases/sca/sca_summary.html

Robins, L. N., & Regier, D. A. (Eds.) (1991). Psychiatric disorders in America. The Epidemiological Catchment Area Survey. New York: Free Press.

Satcher, D. (2006). Securing the right to healthcare and well-being. In T. Smiley (Ed.), The covenant with Black America (p. 5). Chicago: Third World Press.

Shapiro, B., Benjamin, L. J., Payne, R., & Heidrich, G. (1997). Sickle cell related pain: perceptions of medical practitioners. Journal of Pain and Symptom Management, 14, 168-174.

Snowden, L. R. (2001). Barriers to effective mental health services for African Americans. Mental Health Services Research, 34(4), 181-187.

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2003). Unequal treatment: Confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press.

Smith, W. R., Bovbjerg, V. E., Penberthy, L. T., McClish, D. K., Levenson, J. L., Roberts, J. D., Gil, K., Roseff, S.D., & Aisiku, I.P. (2005). Understanding pain and improving management of sickle cell disease The PiSCES study. Journal of the National Medical Association, 97(2), 183-193.

Smith, J. A. (1996). Pregnancy in sickle cell disease. Experience of the cooperative study of sickle cell disease. Obstetrical and Gynecological Survey, 87, 199.

Smith, L. A., Oyeku, S. O., Homer, C., & Zuckerman, B. (2006). Sickle cell disease: A question of equity and quality. Pediatrics, 117(5), 1763-1770.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research Grounded theory procedures and techniques. Newbury Park, CA: Sage.

Telfair, J. (1994). Sickle- cell disease Biosocial aspects. In I. L. Livingston (Ed.), Praeger handbook of Black American health (Vol. 1, pp. 129-146). Westport, CT: Greenwood Publishing Group.

Tesch, R. (1990). Qualitative research Analysis types and software tools. London: Falmer.

U. S. Department of Health and Human Services. (2001). Mental health: Culture, race, and ethnicity. A supplement to mental health: A report of the Surgeon General (Executive Summary, p. 13). Rockville, MD: U.S. Department of Health and Human Services.

Walco, G. A., & Dampier, C. D. (1990). Pain in children and adolescents with sickle cell disease A descriptive study. Journal of Pediatric Psychology, 15, 643-658.

Waldrop, R., & Mandry, C. (1995). Health professional perceptions of opioid dependence among patients with pain. American Journal of American Medicine, 13, 529-531.

Whitten, C. F. (2001). Sickle cell anemia. In R. L. Braithwaite & S. E. Taylor (Eds.), Health issues in the Black community (2nd ed., pp. 242-262). San Francisco: Jossey Bass, Inc.

Wilson-Schaeffer, J., Gil, K., Burchinal, M., Kramer, K., Nash, K., Orringer, E., et al. (1999). Depression, disease severity and sickle cell disease. Journal of Behavioral Medicine, 2(2), 115-126.

Acknowledgements

Author Information

Portia L. Cole, M.S.W., Ph.D.
Assistant Professor
Virginia Commonwealth University, School of Social Work
1001 West Franklin Street
P.O. Box 842027
Richmond, Virginia 23284-2027
Ph.: 804-827-0998
Fax.: 804-828-0716