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Controlling crises in Sickle cell anemia: A biopsychosocial perspective

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CONTROLLING CRISES IN SICKLE CELL ANEMIA: A BIOPSYCHOSOCIAL PERSPECTIVE

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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Assigned Responsibilities

This was a two person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:
   - Assigned Leader: Denita Grant
   - Assisted by: Cynthia Alexander

2. Data Entry and Analysis:
   - Assigned Leader: Cynthia Alexander
   - Assisted by: Denita Grant

3. Writing Report and Presentation of Findings:

   a. Introduction and Literature
      - Assigned Leader: Denita Grant
      - Assisted by: Cynthia Alexander

   b. Methods
      - Assigned Leader: Cynthia Alexander
      - Assisted by: Denita Grant

   c. Results
      - Assigned Leader: Denita Grant
      - Assisted by: Cynthia Alexander

   d. Discussion
      - Assigned by: Cynthia Alexander
      - Assisted by: Denita Grant

ABSTRACT

Environmental and social stressors complicate sickle cell anemia (SCA). Individuals suffering from SCA are at greater risk of experiencing stress more intensely. Social stressors may relate to housing, employment, health, relationships and self-esteem. Through semi-structured interviews, a small sample of adults with SCA was studied to determine if their life experiences with stress are associated with reported SCA pain crises. The results of the study were used in considering a biopsychosocial framework in treatment alternatives.

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To our families and friends, thank you for your understanding and thoughtful deeds that helped make this journey more complete.

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INTRODUCTION

Sickle Cell Disease (SCD) is an illness that affects approximately 1 in 400 African-Americans in this country (Thompson, Gil, Abrams & Phillips, 1996). SCD is one of the disease entities grouped under the umbrella term of "genetic chronic illnesses" and is a blood disease characterized by the production of hemoglobin S (Hb S). The three most common types of hemoglobin abnormalities are, Hb SA, Hb SC and Hb SS. Hemoglobin SA occurs when one abnormal gene (Hb S) and one normal gene (Hb A) are inherited from each parent, producing sickle cell trait, or a person who is usually asymptomatic. Hemoglobin SC occurs when one abnormal gene (Hb S) is inherited from one parent and another abnormal gene (Hb C) is inherited from the other parent, causing mild hemolytic anemia (Burdick, 1994). When an abnormal gene (Hb S) is inherited from each parent, the outcome will be Hb SS. This person will have sickle cell anemia (SCA). The two abnormal genes cause the red blood cells to appear as a "crescent shape" and is commonly referred to as "sickle." This sickling prevents red blood cells from effectively flowing through the arteries, clogging the arteries and blocking oxygenated blood from

reaching other parts of the body. The lack of blood supply to the parts of the body can cause mild to excruciating pain, also known as sickle cell crisis (Famuyiwa & Akinyanju, 1998).

The physical effects of SCA and rate of fatalities vary from case to case. Some people with SCA have few painful crises and live essentially normal lives, while others have dozens of crises each year and/or die within the first few years of life. Those suffering from SCA live with a degree of pain each day. As part of their daily lives, they may require pain medication to alleviate the pain. At times the pain becomes intense and the person frequently requires hospitalization. Not only is it important to understand the effects SCA has on the individual physically, but it is also important to understand how SCA affects the person psychologically and socially.

The literature on the psychosocial effects of SCA has developed over the past decade, but SCA is discussed more commonly within the chronic illness literature. Most diseases (e.g., cystic fibrosis, diabetes) surpassed sickle cell in terms of empirical research (Hurtig & Viera, 1986). Yet, SCA is one of the most common and serious genetic diseases in the United States (Abrams, Phillips & Withworth,

1994). With the consideration of how narrowly this disease has been studied, even less research has been done which addresses the complications associated with SCA.

Attention to the emotional factors associated with chronic illness and physical disorders has always been an essential part of good medical practice. Although in the era of managed care, many non-essential, non-medical psychosocial components to good health care and maintenance go untreated, in reality, the SCA client struggles with a chronic, life-long debilitating illness in which he/she will experience episodes of crises, which could effect the emotional stability of the client.

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity" (Shannon, 1989). With SCD, SCA in particular, attention must be given to the client's "social well-being" if the goal is to maintain good health and control crises. The literature suggests that stress is a contributing factor of crisis for the SCA client (Thompson, Gil, Abrams & Phillips, 1992). This, in effect, means that psychosocial evaluations should constitute a part of the diagnostic process of every client and should be considered in the implementation of treatment

or rehabilitation (Abiodun, 1993). Therefore, the successful health management of SCA clients can best be accomplished through a biopsychosocial perspective with an interdisciplinary team.

Furthermore, in today's society where so many people are vulnerable to the stressors associated with inadequate housing, inadequate and/or lack of employment opportunities, access to proper healthcare, and the dismantling of the family system, it is the individual with SCA who may experience these stressors with greater significance. The significance of these implications will affect their health and their emotional adjustments.

The effects and impact of chronic illness on an individual have been increasingly studied over the years. Chronic illness, or long-term illness is defined as a treatable, but not curable, illness or disease (Sayger & Bowersox, 1996; Johnson, Muyskens, Palmer, Bryce & Rodman, 1985). The illness or disease, often progressive in nature, is characterized by impaired physical or mental functioning. There are often variations in severity and level of medical care needed. It has been found that the incidence of chronic illness has also increased. However, improvements in health care have increased survival rates (Gaudet &

Powers, 1989; Gonzalez, Steinglass & Reiss, 1989; Sargent & Liebman, 1985). SCA is categorized as a chronic illness. Currently, there is no cure for this genetic disease which may cause major tissue damage and is manifested by bouts of chronic pain. Individuals who live with SCA must do so for a lifetime.

Numerous research studies have been conducted on the topic of SCA. Much of this research addressed the medical aspects of SCA, in terms of diagnosis, treatment modalities and preventive education, while other research addressed the physical characteristics of the illness. There has also been some research conducted on the psychosocial effects of SCA on the individual, but the majority of the psychosocial research has been conducted on children and adolescents (Abiodun, 1993; Barbarin, Whitten & Bonds, 1994; Hurtig, 1994). Relatively little research has been conducted on the psychosocial effects of SCA in adults. Some of the research compared adult patients who have SCA with other chronic illnesses, such as, diabetes, chronic pain, obesity and respiratory ailments. The limited research that has been completed indicates that the disease can have a significant impact on psychosocial adjustment (Barrett, Wisotzek, Abel, Rouleau, Platt, Pollard & Eckman, 1988). Whitten and

Fischhoff (1974) suggest that long-term physical disorders may lead to a psychosocial disability much more serious than the illness itself. There was virtually no literature found in which the research indicated whether or not psychosocial issues/problems have a direct effect on the number of crises the patient experiences. The lack of information found in this area would indicate there is a need to continue to assess the level of psychosocial functioning of patients with SCA, and its effect on crises to help us better predict psychosocial problems and to develop better methods of treatment.

Of the studies completed on psychosocial aspects of SCA, one study compared 30 sickle cell patients with 30 diabetes patients in psychosocial development (Damlouji, Kevess-Cohen, Charache, Georgopoulous & Folstein, 1982). This study looked at three areas: social disability, psychiatric morbidity and physical complications. This study found that 73% of patients with SCA were exhibiting high levels of social disability, as compared to 57% of the diabetes patients. Sixty-three (63%) of the SCA patients had high levels of psychiatric morbidity as compared to 50% of the diabetes patients. There was no relationship found between psychosocial impairment and the presence or absence

of physical complications for either group.

In contrast, Leavell and Ford (1983) found a relationship between medical complications and psychopathology. Although there were no specific personality or behavior problems found to be associated with the disease, men were found to have greater psychiatric impairment than women and stress was found to be associated with a marked increase in development of disease symptoms (Leavell & Ford, 1983).

Another study was conducted in 1996 at the Duke University of North Carolina Comprehensive Sickle Cell Center. This study focused on the stability of psychological adjustment of adults with SCA over a 20-month period (Thompson, et al., 1996). The study was conducted to meet three objectives: 1) To assess the stability of the classification of psychological adjustment based on self-reported distress; 2) To identify adaptational processes at baseline that differentiate those with stable good adjustment, as compared to those with stable poor adjustment and 3) To assess the independent and combined contribution of baseline adaptational processes to psychological adjustment at follow-up 20 months later (Thompson, et al., 1996).

Although there has been research conducted which addresses some of the issues with SCA, a limitation of the research on the psychosocial impact of the disease is that few studies have addressed issues of adults, 21 years of age and over. In addition to this, there is large variability in how psychosocial functioning is assessed. Many studies have relied on structured interview techniques or case report methods, whereas, this study would focus on gathering information from settings other than a clinic or hospital. What is needed is a more objective and quantifiable assessment of psychosocial functioning, with a special emphasis on identifying the problems associated with chronic medical illnesses.

In a study by Barrett, et al. (1988), the Chronic Illness Problem Inventory (CIPI) was used to gather empirical data on the nature of psychosocial functioning in a large sample of patients with SCA. The goal was to determine the applicability of the CIPI in assessing the nature of these problems and to determine the additional treatment needs of this population beyond the well-documented need for medical treatment. Traditional medical interventions have not been found to address psychosocial problems, therefore, additional treatment interventions are

needed. The results of the Barrett, et al. (1988) study reveal that there is a need for vocational rehabilitation services and job training programs such as those developed by Azrin and Besalel (1980). Other non-medical interventions include training in communication, assertiveness and social skills, which may help the client establish closer interpersonal relationships.

Theoretical perspectives which have guided past research vary greatly, depending upon the topic within SCA. These theories include family systems theories (Sayger, et al., 1996), for those working with families of sickle cell clients; ecological theory (Kramer & Nash, 1995), when working with sickle cell clients and groups; social learning theory if considering coping, behavior and self-efficacy (Thompson, et al., 1996); and lastly, the biopsychosocial theory, if addressing issues of human growth and development or if addressing the problem from a multi-focus perspective.

This study will differ from others because it will look at the biopsychosocial perspective as it discusses SCA, and the effects of environmental and psychosocial stressors on sickle cell crises. Within this biopsychosocial theory of practice the interplay between environmental, physical, behavioral, psychological and social factors and their

effects on health (Shannon, 1989) will be addressed. The biopsychosocial theory applies a balanced and multidimensional approach to health promotion and illness prevention which addresses the total needs of the clients. It is hypothesized that the psychosocial issues of clients with sickle cell disease encompass more than one aspect of the clients' lives, and because these issues often overlap, there is not one clear method or one direction to pursue when developing plans of treatment and finding more appropriate ways of coping with the psychosocial stressors. Dealing with these issues may potentially reduce the number or incidence of crises, which in turn could reduce the number of hospitalizations and the cost of health care.

This study will also build upon other studies of the biopsychosocial perspective with chronically ill clients and specifically, clients with SCA. It will build upon studies which describe the need for social work in the health care setting and the social work profession's role in the primary care setting (Shannon, 1989). Social workers can also provide services by educating the community, health care professionals, social service employees and others. This study might also assist with increasing funding for additional medical treatment and research, and to create

policies to generally improve the quality of life for clients with SCA.

This research project will address environmental and psychosocial stressors and how the stress contributes to the crisis experienced by adults with SCA. To that end, it is the goal of this study to gain a better understanding of SCA from an eclectic framework that encompasses the entire person. Additionally, possible interventions from a biopsychosocial model will be discussed in an effort to develop treatment plans for the adult SCA client.

In conclusion, the purpose of this research project is to determine the extent to which problems in environmental life stressors, defined in terms of housing, employment, health, relationships and self-esteem have an association with the occurrence of sickle cell pain crises in adulthood.

METHOD

Subjects

The subjects were recruited from the Sickle Cell Organization of the Inland Counties located in Riverside, California. The study sample consisted of 12 adults (n=12) with sickle cell anemia, who resided in both San Bernardino and Riverside counties. All of the subjects described themselves as African-American and all of the subjects

reported having Hb SS (sickle cell anemia). Eight (67%) of the subjects were female and 4 (33%) were male. The subjects ranged in age from 22 to 49 years old. The mean age was 32 years (SD= 7.76). Ten (83%) of the subjects were single and 2 (17%) were married. The range in age of diagnosis was birth (0 months) to 72 months. The mean age of diagnosis was 29.8 months (SD= 26.6). The number of crises requiring hospitalizations ranged from 1 to 10, with a mean of 6.00 (SD= 3.13). Eleven (92%) of the subjects were unemployed. Of those 100% reported not working due to SCA.

Instruments

A 27-item questionnaire (Appendix A) was developed by the researchers. The questions were designed to obtain data relating to the 5 independent variables, addressing environmental and psychosocial stressors related to sickle cell crisis: housing, employment, health, relationships and self-esteem. The questions were asked using a six-point Likert scale ranging from Strongly Disagree (1) to Strongly Agree (6). A separate information form was attached to gather demographical data. The questionnaire was pretested for reading level on junior high school students.

Procedures

Initially, each subject was informed that their responses would be confidential and informed consents (Appendix B) were obtained. The questionnaire was administered individually to each subject during a scheduled 90-minute personal interview. Four (33%) of the interviews were conducted in the subjects' homes. Eight (67%) of the interviews were conducted at the Sickle Cell Organization office. The questionnaire took approximately 25-40 minutes to complete. To conclude the interview, the debriefing process allowed the subjects the opportunity to share their personal experiences, ask questions, and each was given a community resource guide (Appendix C).

RESULTS

The data were initially screened to ensure that the proper assumptions were met for conducting parametric statistical tests. Histograms indicate that the variables were approximately normally distributed and linearly related. For each of the 5 subscales, the following questions (questions #4, 6, 8, 12, 15, 16, 18, 20, 23, 24, 25) had to be recoded to ensure that responses were obtained in a standardized form.

The following section will present means and standard

deviations for the number of crises and each of the 5 subscales (Table 1); and correlations between the number of crises and the independent variables (Table 2).

Housing

The questionnaire contained four questions (questions #2, 3, 4 and 5) designed to determine how SCA influenced the subjects' choices in where they lived and whom they lived with. The mean score for the housing variable was 14.4, (SD= 6.11), out of a possible range of 4-24. While there was no significant association between housing and the number of sickle cell crises (r= .195, p= .272), during the interview process, many subjects reported experiencing limitations with regards to where they lived and whom they lived with due to SCA.

Employment

Three questions (questions #6, 7 and 8) were asked regarding whether or not sickle cell affected the subjects' ability to work. The mean score for the employment variable was 12.4, (SD= 2.68), out of a possible range of 3-18. The association between employment and sickle cell crises was not significant (r= -.141, p= .331). However, it is of interest to note, the lack of significance between employment and the number of sickle cell crises, considering

the high representation of unemployed subjects (92%).

Health

The questionnaire contained four questions (questions #12, 13, 14 and 15) to determine how the subjects perceived health professionals' interaction with them in the management of their health. A higher score on this variable indicates an increased perception that they were not treated well within the healthcare system. The mean score for the health variable was 15.3, (SD= 3.20), out of a possible range of 4-24. The correlation between health and number of crises was significant (r=.508, p= .046) indicating that individuals who reported more crises, also reported an increased perception that they were not treated well within the healthcare system. This phenomenon became more apparent during the interviews as many subjects reported open interaction with their physicians, but felt overall treatment was poor.

Relationships

Questions were also asked concerning interpersonal relationships. A total of eight questions were designed to ascertain whether or not sickle cell disease was a factor in establishing and/or maintaining healthy relationships (questions #16, 17, 18, 19, 20, 21, 22, 27). The mean score

for the relationship variable was 24.8, (SD= 8.84), out of a possible range of 8-48. No significant association was found between relationships and number of sickle cell crises (r= .266, p= .202). Many of the subjects reported enjoying healthy relationships.

Self-esteem

There were a total of four questions asked to identify the subjects' perception of themselves in relationship to SCA (questions #23, 24, 25 and 26). The mean score for the self-esteem variable was 15.5, (SD= 5.04), out of a possible range of 4-24. No significant association between self-esteem and sickle cell crises was found (r= .478, p= .058), although it was approaching significance.

Additionally, bi-variate correlations which showed significant associations between the variables housing and self-esteem (r= .746, p= .003) and the variables relationships and self-esteem (r= .707, p= .005), indicate that the subjects' housing conditions due to SCA would impact upon their self-esteem. The same as the subjects' poor self-esteem would negatively impact upon their personal relationships.

To determine whether gender or having children shared a relationship with reported sickle cell crises, two

independent T-tests were conducted. Results indicate that there was no significant difference in the number of crises between males and females (t= 1.69, p= .122) (Table 3). Similarly, there was no significant differences in the number of crises among individuals who reported having children versus those without children (t= -.928, p= .375) (Table 4).

DISCUSSION

The major assumption of this study was that adults diagnosed with SCA who experience difficulties with psychosocial stressors would report higher incidences of sickle cell crises. While all of the independent variables did not prove to have a significant association with sickle cell crises, there are several common themes that surfaced during this study.

The trends found in the study were obtained during the interviews with the subjects. The most notable of these findings was in the subjects' perception of themselves as patients. The common theme with regard to crisis management was the lack of understanding on the part of the healthcare provider in administering appropriate pain medication. Many reported being treated with suspicion, as if they were drug addicts as opposed to patients managing a life-long illness.

One subject reported having to attend a weekly 12-Step program, in order to continue receiving appropriate pain medication.

Another common theme perceived by the researchers was the overwhelming feeling of incompletion. Many subjects reported being unable to maintain employment because employers lack understanding about the frequency of their illness. The one subject who was employed worked in a nontraditional job which afforded her the opportunity to work at her leisure. Additionally, many of the subjects reported having to repeatedly withdraw from classes, thus, being unable to complete educational goals.

A refreshing commonality found was that the majority of the subjects were involved in intimate relationships and sustained healthy familial relationships.

Notwithstanding, the overall assumptions of this study, there were several significant correlations found. The relationship between reported crises and healthcare ($p = .046$) was significant. This positive correlation lends itself to a better understanding of how sickle cell patients view their treatment by acute healthcare professionals. Those subjects who experienced more hospitalizations related to crises would have increased interaction with healthcare

professionals and thus be exposed to treatment that they consider inadequate. The pervasive "ill-treatment" notion was also expressed during the interview process. The data support the assumption that the more frequently the subjects reported being in the hospital, the higher their belief was that they received poor treatment.

In regards to housing and self-esteem, this correlation was most interesting. It would stand to reason that having to live within certain housing situations because of SCA would have an effect on one's self-image. Many of the subjects reported living with roommates, family members and spouses who served as caregivers. Furthermore, many of the subjects reported being concerned with where or with whom they would live in the future. It is evident that living with SCA has a strong association with housing and or living options for adults who suffer with this illness. This in turn directly affects their self-esteem and is an added stressor in their lives.

The final correlation among the independent variables is more of a natural assumption, the significance between relationships and self-esteem. It is reasonable to conclude that poor self-image adversely affects positive relationships. Interestingly enough, our subjects all

expressed having positive healthy relationships during the interview process. When asked about intimacy in relationships (except for the two married subjects) fewer subjects reported experiencing intimate relationships. We concluded that the affirmation of positive relationships speaks to family and friendship bonds.

Limitations

A major limit of this study was the sample size (n=12). With such a small sampling from this population, it would be difficult to generalize any findings to the larger population of adults with SCA. Also, the sample size weakens the reliability of the results and does not lend itself to having enough subjects to obtain good variance for statistical analysis. As a result, in this study only the descriptive statistics were analyzed.

Another limitation of this study was the research tool. Due to the time constraints in this research process, the questionnaire was not pretested for accuracy in obtaining the desired information. As a result, the measure needed to address psychosocial stressors was not fully obtained by this tool. Additionally, the language of the tool may have been misunderstood, thus, bringing into question the validity of the responses. Future research in this area

should ensure that validated measures be used in order to better assess the psychosocial variables under study.

Implications

The needs of adults living with SCA are complex and represent multi-faceted issues. Their lives are swayed by environmental and social stressors which complicate their daily lives. The implications for social work are influenced by the correlations found in this study.

Understanding the nature of SCA and the debilitating cycle of crises the illness manifests, the need for a more comprehensive treatment modality is palpable. Social workers should play key roles in developing and implementing a biopsychosocial framework in treatment alternatives for clients with SCA. The framework should be a social model that addresses the totality of the clients' needs including housing, employment, health, relationships and self-esteem.

The model of choice when working with clients who present with multi-problems is case management. Using a case management model, social workers are better able to meet the needs of the client while helping them lead productive lives within the limitations this illness brings. To improve the healthcare relationship, social workers can serve as advocates for the clients by educating healthcare

professionals in terms of understanding the nature of sickle cell disease absent of the acute pain crises.

Social workers should be sensitive to the sickle cell client's need for counseling and social stimulation. As the data have shown, there are strong correlations with self-esteem and relationships. This would suggest a greater need for ongoing counseling interventions as well as appropriate social activities. Strategies for integrating a biopsychosocial model should be developed to ensure effective interventions and positive outcomes that help control pain crises for adults who have SCA. The integration of the biopsychosocial model, aimed at promoting good health prevention, requires that social work practitioners act as primary providers of psychosocial services. The future treatment implications must include components of education, increased awareness, provisions for policy development, and advances in healthcare management that will generally improve the quality of life for our clients with SCA.

Appendix A

Questionnaire

Please complete the following information.

What is your age? _____ Gender? Male _____ Female _____

What is your marital status? _____

Do you have children? Yes _____ No _____

If yes, # or children _____ Age(s) of children _____

How many of your children live with you? _____

At what age were you diagnosed with Sickle Cell Anemia? ____

What is your monthly family income? _____

Do you pay monthly rent? Yes _____ No _____

Do you receive government subsidized housing? Yes ___ No ___

Are you employed? Yes _____ No _____
If yes, Full-time? _____ Part-time _____

Are you a student? Yes _____ No _____
If yes, Full-time? _____ Part-time _____

Do you have health insurance? Yes _____ No _____

Your health coverage is provided by _____

Do you have other health concerns? Yes _____ No _____
If yes, please list other health concerns

In the past two years, I have had _____sickle cell crises which have required hospitalization?

Please circle the answer which best fits you.

1. What is your approximate individual monthly income?

A). Less than $700
B). $701-1100
C). $1101-1300
D). More than $1300

2. My illness affects where I live?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

3. I need to live with a roommate because of my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

4. In spite of my illness, I do not worry about where I live?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

5. Because of my illness, I worry about where I will live in the future?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

6. My illness has no affect on my ability to work?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

7. I am unable to keep a job because of my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

8. I am not working because of reasons other than my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

9. My longest time on a job has been?

A). Less than 3 months
B). 3-6 months
C). 6-9 months
D). More than 9 months

For students only:

10. I am unable to stay in school because of my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

11. The longest I have been able to stay in school has been?

A). Less than 3 months
B). 3-6 months
C). 6-9 months
D). More than 9 months

12. My doctor openly shares information with me about my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

13. I think health care providers do not understand my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

14. I worry about my health?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

15. Having medical insurance coverage is not a worry for me?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

16. I enjoy intimate relationships despite my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

17. I do not have intimate relationships because of the additional stress my illness places on relationships?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

18. I do not need others to meet my daily needs?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

19. I have limited social activities because of my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

20. In spite of my illness, I enjoy social activities?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

21. My family/friends/social supports do not understand my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

22. I feel my family/friends/social supports prevent me from doing things myself?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

23. There are times when I do not think about my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

24. Who I am has nothing to do with my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

25. I rarely feel isolated from my family/friends/social supports because of my illness?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

26. Because of my illness, I see myself different than others my age?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

27. I rarely use my illness to get my way with my family/friends/social supports?

1	2	3	4	5	6
Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree

Appendix B

Informed Consent

This study in which you are about to participate is designed to explore whether or not environmental stressors are associated with the occurrences of sickle cell pain crises. This study is being conducted by Cynthia Alexander and Denita Grant, Master of Social Work students at California State University San Bernardino. This project is being supervised by Delia Lang and is approved by the Department of Social Work sub-committee of the CSUSB Institutional Review Board.

You will be a member of a small group of people involved in this study. As part of the research, you will be asked to participate in a 90-minute interview by the two above named researchers. You will be asked information about housing, employment, health management, interpersonal relationships and self-esteem. You will be given the opportunity to ask any questions you may have prior to the interview. At the conclusion of the interview, the two researchers will be available to discuss any questions you may have. You will also be given a list of resources in your community.

You can be assured that all information you provide will be held in strict confidence and at no time will your name or any personal information be revealed. At the conclusion of the project all data will be destroyed. The project's final results will be reported in group form only. Your participation in this study is strictly voluntary and you are free at any time to withdraw yourself and any information given without penalty. Should you have any questions or concerns throughout the research process, please contact Rosemary McCaslin, Coordinator of the Research Sequence in the Department of Social Work at (909) 880-5507 or the Sickle Cell Organization in Riverside, California at (909) 684-0420.

Your mark below indicates your willingness to participate in this study.

_____

Mark here

_____

Date signed

Appendix C

Resource List

This list contains some community organizations that may be useful to you.

Social Security Administration
1 (800) 772-1213

California State Department of Rehabilitation
Riverside: (909) 782-6650
San Bernardino: (909) 383-4401

DPSS-Department of Adult Services
In Home Supportive Services
San Bernardino Referrals:
(909) 945-3865
Riverside Referrals:
(909) 784-5222

Transportation- Both Counties
Health Link (909) 792-1105
Inland Empire Connection 1 (800) 800-7821
Medi-Van Southern California 1 (800) 794-4667

Counseling Referral Service
(909) 885-2200

San Bernardino County Behavioral Health
(909) 387-7171

Riverside County Mental Health
(909) 358-4500

Legal Aid
San Bernardino
(909) 889-7328
Riverside
(909) 684-0448

HUD Housing
1 (800) 569-4287

Sickle Cell Organization of the Inland Counties
(909) 684-0420

Appendix D

Tables

TABLE 1. Mean and Standard Deviation for Independent Variables

	CRISES	HOUSING	EMPLOY	HEALTH	RELATION	SELF-EST
MEAN	6.0	14.4	12.4	15.3	24.8	15.5
STD. DEV.	3.13	6.11	2.68	3.20	8.84	5.04

TABLE 2. Pearson r Correlations between number of crises and Independent Variables

	CRISES		HOUSING		EMPLOY		HEALTH		RELATION		SELF-EST	
	r	p	r	p	r	p	r	p	r	p	r	p
CRISES	1.0	--	.195	.272	-.141	.331	.508	*.046	.226	.202	.478	.058
HOUSING			1.0	--	.249	.217	.383	.110	.391	.105	.746	*.003
EMPLOY					1.0	--	.004	.496	.358	.127	.192	.275
HEALTH							1.0	--	.402	.098	.265	.203
RELATION									1.0	--	.707	*.005
SELF-EST											1.0	--

TABLE 3. Difference in number of crises based on gender

	NUMBER OF CRISES				
GENDER	N	MEAN	ST DEV	t	p
MALE	4	4	2.94	1.69	.122
FEMALE	8	7	2.88		

TABLE 4. Difference in number of crises based on children

	NUMBER OF CRISES				
CHILDREN	N	MEAN	ST DEV	t	p
NO	7	5.29	3.55	-.928	.375
YES	5	7	2.45		

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