The psychosocial adjustment of adolescents with Sickle Cell Anemia

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ABSTRACT

SOCIAL WORK

WINN, VANIETHIA R. B.A. CALIFORNIA STATE UNIVERSITY, FULLERTON, 1990

THE PSYCHOSOCIAL ADJUSTMENT OF ADOLESCENTS WITH SICKLE CELL ANEMIA

Advisor: Joanne V. Rhone

Thesis dated: March 1994

The overall objective of this study is to investigate the psychosocial problems experienced by adolescents with sickle cell anemia. To attain this objective, the following issues were addressed by the researcher: (a) peer relationships; (b) independence; (c) stress; and (d) self-concept. A descriptive research design was used in the study. A questionnaire developed by the researcher was utilized and administered via telephone conversation/interview to 13 adolescents with sickle cell anemia located in the Metropolitan Atlanta area. The results of the study indicated that the participants diagnosed with sickle cell anemia maintain good peer relationships, experienced high levels of stress, have low self-concept and, have not achieved an appropriate level of independence with regard to a sense of personal freedom.
THE PSYCHOSOCIAL ADJUSTMENT OF ADOLESCENTS
WITH SICKLE CELL ANEMIA

A THESIS
SUBMITTED TO THE FACULTY OF CLARK ATLANTA UNIVERSITY
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF SOCIAL WORK

BY
VANIETHIA R. WINN

SCHOOL OF SOCIAL WORK

ATLANTA, GEORGIA
MARCH 1994
ACKNOWLEDGEMENTS

Many have been instrumental in the evolution and preparation of this study. I would like to thank the almighty God for blessing me with knowledge and patience. I thank my parents, Daniel and Marie Foster for their continued love and support, and for teaching me that "I can do all things through Christ who strengthens me." My great appreciation is offered to Dr. Joanne Rhone for her insightful comments and consistent encouragement, and to Dr. Ajo for his statistical advisement. I thank Gerald Mansfield, of the Sickle Cell Foundation of Georgia, Inc., for allowing me to volunteer and learn. I wish to express my deepest gratitude to the adolescents in this study who have struggled with sickle cell anemia. I wish to thank my family, friends, and colleagues for their support. I thank all the contributors to this study who helped me to expand my knowledge.
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CHAPTER ONE
INTRODUCTION

The term "psychosocial" was introduced to social work literature by Frank Hankins, a faculty member at Smith College, in 1930.¹ Hankins believed that it is important for the social worker to understand the person's psychological and sociological framework. Therefore, the term "psychosocial" refers to one's mental state of mind, or psyche, and one's everyday social environment and interactions. Moreover, the psychosocial theme takes into account the person's total life situation. This theme builds from an understanding of individual development, interpersonal influence, influence of significant others, and influence of significant environments and systems on the development and maintenance of healthy living.²

Personality is drawn from the organization of biological, psychological, and sociological components that help create individual unique adjustments to society. These components are interrelated, in that, the personality develops its essential characteristics and

behaviors from the interaction that occurs among these components. Therefore, personality is changing and interdependent. Yet individuals experience a period of readjustment and imbalance as problems or changes occur within their biological, psychological, and/or sociological systems.

Although the purpose of social work is to improve social functioning and the coping with social problems, it is important that this profession acknowledge that the client's biological endowment can influence one's behavior as well as how one functions. The genetic and heredity process have a great affect on many individuals.

Indeed, some individuals inherit the propensity to some diseases. Their physical feelings of well-being or lack thereof impacts their self-image, dependency patterns, problem-solving activities, mobility, social-interactional patterns, access to alternatives and attitude toward life and the future. As one's reaction to one's health varies depending on the seriousness of the health situation and its length over time.

One particular disease that may affect a person's psychosocial adjustment is sickle cell anemia. During the

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early 1920's, Dr. V.R. Mason defined the term sickle cell anemia as a disease in which one's red blood cells become distorted from their shapes. In fact, sickle cell disease stems from an inherited abnormality in hemoglobin, which consists of molecules in each cell that carry oxygen to all parts of the body. In sickle cell the hemoglobin releases too much oxygen. Once oxygen is reduced enough, the cells become elongated, or "sickled," red blood cells that clog the small blood vessels.

When the cells cannot pass through the capillaries, they stop oxygen from reaching the bones and vital organs, causing intense pain. In its severe form, the disease can cause death. People with anemia often feel tired and lack energy. These feelings are due to sickle cells removed from the blood, and therefore, the body doesn't have enough red blood cells to supply the oxygen.

Sickle cell disease can be detected at birth. If both parents have the sickle cell trait, each time a child is born there is a 25% chance the child will have sickle cell anemia. 

\[^{4}\text{Afro-American Encyclopedia, 1974 ed., s.v., "Sickle Cell Anemia."}\]

\[^{5}\text{C.H. Whitten, Fact Sheet on Sickle Cell Anemia (Los Angeles: National Association for Sickle Cell Disease, 1973)}\]
have the trait for the disease. It is estimated that one in every four hundred African Americans inherit the disease from parents that have the trait.

As with many chronic illnesses, persons affected with sickle cell disease experience pain and other complications without notice. For many patients this is extremely frustrating, as their normal physical, psychological, familial, and social functioning is disrupted.

Physically, there are many signs and symptoms which usually appear after six months of age. The physiological effects of the disease may be pain, shortness of breath, poor health, constant colds, sore throats, jaundice, fatigue, and loss of appetite. Still some physical complications may appear for longer periods of time, such as surgical scars, dental deformities, impaired growth, leg ulcers, increased susceptibility to infections, tissue damage to vital organs, and swollen hands and feet.

The most common symptom is sickle cell "crisis." Patients with sickle cell anemia may suffer from periodic attacks of severe pain in the chest, abdomen, arms and legs. These episodes of pain vary in length from hours to weeks and may take place several times a year. Frequent pain crises can cause early death in some individuals and
shorten one’s life span if not treated properly.\textsuperscript{6} Persons having sickle cell anemia may experience psychological complications. Some individuals appear to have an emotional tolerance to the disease. The persons with sickle cell anemia may experience particular feelings of frustration, anxiety, anger, resentment, helplessness, depressed by the prospect of being ill for the rest of their life or having a potentially fatal disease, feelings of defectiveness, fear, and preoccupations with death.\textsuperscript{7}

Families with chronically ill members may be affected, also. Having a diseased child may lead to marital discord and inappropriate placement of blame, and it may cause feelings of guilt, helplessness, and dependency. Next, parents may feel they are bad parents and try to overindulge their child in order to compensate. Some parents become very over-protective, and in turn, over-nurture the child. In addition, siblings of chronically ill children may be jealous and feel rejected.


Moreover, persons with sickle cell anemia experience problems in social relationships. Due to absences from school and physical complications, sickle cell children are held back from normal grade advancement and have poor relationships with other children. Adolescents with sickle cell disease experience a longer period of conflict between dependency and independence. After reaching adulthood, frequent episodes of pain or disease-related problems may affect employment. Persons may be stigmatized because of this disease.\(^8\)

For adolescents, chronic illness imposes a direct challenge to their increasing independence, autonomy, and identity formation. Over-dependency on parents and medical personnel becomes a source of self-hatred often defended against by rejection of these authorities and their expertise.\(^9\) Persons with sickle cell anemia and other chronic illnesses share many stresses, such as academic

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failure and loss of school time, uncontrollable bouts of pain, fear of death, altered self-image, and social solitude and ineptness.\textsuperscript{11}

Given that there are extraordinary stresses involved with chronic diseases, persons with sickle cell anemia, particularly adolescents, may experience frustrating psychosocial adjustments in their normal physical, psychological, familial, and social functioning.

\textbf{Significance of the Problem}

This researcher was lead to explore the literature about sickle cell anemia due to personal experience with friends who have this disease, and lack of knowledge about this disease and its affect on psychosocial development. Adolescents with sickle cell anemia are at risk for psychosocial adjustment problems. It is quite difficult for chronically ill young people to adjust to the ups and downs of their ongoing illness as well as deal with everyday teenage concerns associated with the adolescent stage of life.

Moreover, delay in the onset of puberty may cause chronically ill adolescents to feel different and unattractive. In turn, they may withdraw from having

\textsuperscript{11}Ibid., 8.
social relationships; feel less attractive because of their underdeveloped body images; feel resentment about the physical limitations which deny them opportunity to participate in sport activities they enjoy; and may feel anger toward parents who gave them the disease as well as anger toward siblings who are not afflicted by the disease. Many persons within the social environment of a chronically ill person may never see him/her ill or experience a crisis. Since sickle cell anemia is not an observable disease, many peers of adolescents with this disease do not think of him/her as being ill. They may interpret behaviors as personality characteristics rather than adaptations to a chronic health problem.

In order for more comprehensive care to be provided more attention should be given to the psychosocial complications experienced by adolescents with sickle cell anemia. It is necessary for the social work profession to understand the way this disease affects daily living and social-emotional and physical development of this population. This is an important area for social workers to target with appropriate interventions and support, and to provide leadership in developing strategies for educating the general public about the illness in non-hospital
settings, like schools and neighborhood centers.

**Purpose of the Study**

When studying sickle cell disease, many researchers investigate the physical aspects of the disease and accompanying treatment interventions. Researchers give little attention to the psychological issues that affect people with sickle cell anemia. In fact, little is known about the emotional and social impact the disease has on ill adolescents. Adolescence is a period of readjustment of psychological, social, cognitive, and physical functioning. Although many adolescents pass through these years without much problem, some teenagers are constantly challenged. In fact, a chronic illness imposes an increase burden on the adolescent. What should be a normal period of development becomes disorganized, for the body is not dependable, comfortable, and well developed. In addition, the normal adolescent defenses of denial, avoidance, or acting-out may be exaggerated.

This researcher realizes that adolescents' with a chronic illness like sickle cell anemia are at risk for psychosocial adjustment. They struggle to maintain their goals and hopes for the future. Often times, a painful sickle cell "crisis" can interrupt the adolescents sense
of mastery and control in various areas of functioning. Also, a crisis can cause him/her to doubt his/her capacity to function independently.

The purpose of this research effort is to investigate the psychosocial problems experienced by adolescents with sickle cell anemia. This research will document the stress and psychosocial issues confronted in achieving independence from family, participating in peer group activities, and developing a healthy self-concept.
CHAPTER TWO

LITERATURE REVIEW

The Period of Adolescence

Adolescence may be defined as a critical period of human development manifested at the biological, psychological, and social integration, of variable onset and duration but marking the end of childhood and setting the foundations for maturity. For some teenagers this can be an exciting time of life as they develop a sound identity and achieve attitudes and beliefs needed for effective participation in society. Hall described adolescence as a period of "storm and stress." The emotional ups and downs, physical changes, and struggle to emancipate oneself from one's parents, indeed presents a unique and stormy developmental process.

Adolescence is heralded by pubescence, a stage of rapid growth when reproductive organs begin to mature. The physiological changes, having to do with growth spurt in height, weight, and muscle have important social meanings to adolescents. Due to the changes in size, build, and composition from preadolescence to adolescence, physical

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appearance becomes of great concern. A great number of adolescents experience anxiety, worry, and embarrassment associated with physical changes. The slightest physical change, such as breast development or increased height, can be frustrating to some teenagers. However, other adolescents view such changes as an enjoyable process of maturing. Furthermore, teenagers are very preoccupied with how they appear to others in their peer group as compared with what they feel they are.

According to Sigmund Freud a primary tasks of adolescence is ego development. Many of the behaviors that were once forbidden in childhood are available to adolescents. Once one establishes a sense of self, or ego ideal, one is able to alter one's superego, due to the fact that one has formed new thoughts and behaviors that previously did not exist. Through the ego ideal, one must incorporate new areas of morality and character, sense of sexual identity, and a total holistic formation of personal identity.2

Freud feels that one of the primary tasks of adolescence is to resolve the Electra or Oedipal conflicts revived at the phallic phase. According to Freud, boys

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encounter an Oedipus complex as they fall in love with their mothers, and girls undergo an Electra complex as they experience strong sexual feelings towards their fathers. Due to overwhelming sexual urges in which the ego cannot repress, fantasies and impulses re-emerge during puberty. To Freud, it's natural that these impulses are reawakened, for he is more concerned with adolescents that do not exhibit emotional conflict than adolescents which do.\(^3\)

Erik Erikson notes that "adolescence is a period of rapid change—physical, psychological, and social; a time when all sameness and continuities relied on earlier are more or less questioned again".\(^4\) According to Erikson, the most crucial stage for adolescents is identity versus identity (or role) diffusion. The adolescent is continuously trying to determine who he/she is and what he/she will become. He/She may choose to incorporate many of his/her new social experiences in school into his/her


sense of identity. Some teenagers' identity is uncertain and unclear, and as a result, they suffer from role confusion. Erikson feels that adolescence is the stage of the "identity crisis." The crisis between identity versus role confusion is indeed a struggle, yet it is best resolved through integrating earlier identifications, present values, and future goals into a consistent self-concept.\(^5\) Identity formation consists of factors, like changes in cognition or group affiliations, which help the adolescent develop a sense of self and understand what he/she wants out of life.

Adolescents may lean towards one peer group in order to obtain a sense of belonging. As the adolescent moves closer to the peer group, he/she struggles to become independent of his/her parents. Therefore, he/she may become rebellious to parents restrictions and controls and may resist dependence upon them for guidance or approval. As a result, conflict with parents may increase as adolescents adopt their peer group behavior, clothing, and mannerisms.

According to Albert Bandura because of the conflicting values and pressures to which the adolescent

is exposed, he/she is ambivalent, frightened, unpredictable, and often irresponsible in behavior.\textsuperscript{6} Since the adolescent is neither a child nor an adult, he/she is confused about his/her identity.

**Chronically Ill Adolescents**

Many theorists dispute whether adolescence may or may not be a turbulent period;\textsuperscript{7} however, evidence indicates that chronically ill adolescents are confronted with exacerbated biopsychosocial problems than the non-diseased adolescent. In fact, evidence shows that chronically ill adolescents have the potential for emotional difficulties.

With this in mind, it is important that the social worker gain an overall understanding of the adolescent and become aware of various biopsychosocial phenomenon that is peculiar to chronically ill adolescents. These adolescents may experience feeling helpless and dependent on parents and the health care professional; feel isolated from and rejected by the peer group; and feel vulnerable and insecure rather than power. Following weekly group meetings with nine Black adolescent girls, LePontois


discovered that various problems confront adolescents with sickle cell anemia, including dependence versus independence, peer group success versus isolation, competence and mastery versus failure, and limitation versus aspirations.⁸

According to Kumar, Powers, and Haywood, "there is no significant difference between sickle cell children and healthy children in personal, social, and total adjustments."⁹ Yet, children with sickle cell have a lower self-concept than the control group in this study. Contributing factors may be that unpredictable sickle cell crises interrupts social relationships, activities, and achievements in school. In turn, when adolescents feel healthy, they feel as if they can function independently and effectively, and when a crisis occurs they suddenly require dependent care. Special measures were recommended to enhance their self-concept. The medical and psychological care should include guidance and especially reassurance to strengthen self-confidence.


According to Robert Anyan chronic illness has a great effect on the adolescent's sense of achievement. Frequently ill patients appear to be more inner-directed, self-absorbed, and have problems with interpersonal relationships. In addition, frequently ill teens show more anxiety and more awareness of emotional problems than those who are less frequently ill. Clinicians should be sensitive to feelings displayed by these youngsters. They may wonder what they did wrong or why this illness happened to them.\textsuperscript{10} One clinical study (Conyard et al.) discovered that adolescents who frequently visit clinics and hospitals display a high degree of isolation, dependence, fear of illness, withdrawal, poor self-image, depression, anxiety, lack of verbalization, and concern with death.\textsuperscript{11}

The burden of a chronic disease may have a long-term psychological affect on ill adolescents. Jean Moise suggest that children with a higher level of adjustment have a positive self-concept, internal locus of control,


and are a part of more cohesive families.\textsuperscript{12} Moise investigated the psychosocial adjustments of sickle cell patients in relation to family environment, life stress, self-esteem, and locus of control. This particular study focused on sickle cell adolescents rather than compare them to their physically healthy peers.

Moise, Drotar, and Gross further investigated the interactive role of emotional factors with sickle cell anemia. Moise et al. were concerned about the degree to which family environment, self-esteem, and locus of control had on the adjustments in sickle cell children. In fact, self-esteem and locus of control correlated positively with personality and total adjustment. Therefore, a child who feels he/she has control over life events is better able to cope with his/her illness than one who feels life events are beyond his/her control.\textsuperscript{13}

The most frequent occurring psychosocial problems are treatment compliance difficulties, family/significant


\textsuperscript{13}J.R. Moise, D. Drotar, & S. Gross, "Correlates of Psychological Adjustment of Children and Adolescents with Sickle Cell Anemia." Unpublished manuscript at Case Western Reserve University, (1982).
other relationship impairment, relationship impairment with health care providers, mood disturbance, and financial difficulties. After evaluating the psychological adjustments of thirty Black children with sickle cell anemia, it was discovered that there is no difference in psychological problems between ill children and healthy children. It is possible that low socioeconomic status (SES), rather than the illness, can contribute to the maladjustment of children with sickle cell anemia.

Morgan and Jackson study compared body satisfaction, depression, and social withdrawal in twenty-four Black adolescents with sickle cell anemia to healthy adolescents. Ill teenagers, as a result, were less satisfied with their bodies, more depressed, spent less time in social and nonsocial activities, and tended to be less successful in school than their healthy peers. The results suggest that adolescents with sickle cell are confronted with psychosocial adjustment problems, such as

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depression, social involvement, and body satisfaction.\textsuperscript{16}

In addition to physiological and psychological adjustments, adolescents with sickle cell may experience social and familial adjustments as well. Moise believes there is a significant relationship between life stress and school performance; therefore, children from a highly stressed environment may have poorer school performance.\textsuperscript{17}

According to Williams, absences from school may prevent academic advancement and may effect social status. One's self-esteem may be hampered due to a limited motivation to succeed. Peer pressure for the adolescent with sickle cell may be painful. As far as physical appearance, adolescents may self-consciously compare their bodies to their peers. As a result of over-protective parents, some ill teens may remain dependent and withdraw from normal social relationships. Still, the adolescent may place him/herself in daring situations just to prove


his/her courage.\textsuperscript{18}

Fowler and his colleagues examined neuropsychologic tests results and academic functioning of patients with sickle cell anemia. The ill patients had lower reading and spelling scores than healthy children. According to research, sickle cell anemia may be associated with neuropsychological and learning deficits which may interfere with school performance and lead to academic problems.\textsuperscript{19}

Gaston states that "familial relations may be a point of stress for the adolescent as well as for other family members."\textsuperscript{20} According to Treiber, Mabe, and Wilson, during a non-crises period, healthy siblings are at risk of psychological adjustment problems when compared to their ill siblings.\textsuperscript{21} The healthy siblings may


\textsuperscript{21}F.A. Treiber, P.A. Mabe, & G. Wilson, "Psychological Adjustment of Sickle Cell Children and Their Siblings," Children's Health Care, 16(2) (1987): 82.
experience rejection from parents, depression, and anxiety. Also, parents view the children with the disease as having more behavior problems than the healthy children.22

To Kazak it is not uncommon to see mild to moderate levels of distress within the family system of chronically ill adolescents. Several variables can affect psychological distress, such as the nature and course of the illness, individual coping resources, family structure and function, and medical, psychosocial, and educational resources.23

Hauenstein reviewed studies of distress in parents with chronically ill children. Both mothers and fathers of ill children have significant emotional distress more so than parents of healthy children. The majority of parental distress is due to having few social resources and more problems with ill children than healthy children.24

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Furthermore, the family environment may have an effect on the behavior problems of chronically ill children. Researchers have determined that chronically ill children with more behavioral problems have less supportive and more conflicted families. In turn, children with less supportive and more controlling families are more likely to have behavior problems in school.\(^{25}\)

Clearly the literature establishes a relationship between sickle cell anemia and psychosocial issues, noting several areas of adjustment. During this review it was shown that adolescents experience many physical and emotional changes. However, adolescents with a chronic disease are confronted with more biopsychosocial problems than their non-diseased counterparts. In fact, evidence suggests that adolescents with sickle cell anemia experience stress on several levels: physiological, psychological, social, and familial.

Literature about adolescents with sickle cell anemia primarily addresses self-esteem, locus of control, parental involvement and dependency issues. Furthermore,

research focuses on how parents, teachers, and physicians view persons with sickle cell anemia. Yet research is limited to ill adolescents' descriptions of their own experience; therefore, the voices of adolescents with the disease as well as their healthy peers are rarely heard.

**Theoretical Framework**

Biopsychosocial theories that encompass stress and anxiety are most appropriate theories for this study. These theoretical foundations are supportive of the information presented in the review of literature.

**Theories on Stress and Anxiety**

Stress consists of several different meanings. It seems to apply equally to a form of stimulus (or stressor), a force requiring change of adaptation (strain), a mental state (distress), and a form of bodily reaction or response. More than any other developmental period, theorists have characterized adolescence as a stressful period in which they face a variety of stressors.

Hans Seyle was the first to come upon the term "stress." Selye's concept of stress is considered a

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"general adaptation syndrome," in which we psychologically react to adverse environmental stimuli. Therefore, as stress confronts us, our bodies will react in patterned ways, such as an increase heart rate, gastric, and respiratory changes occur. According to Selye, an important feature is how we cope with stressful events, for our attitude determines how a stressor is perceived.

Anxiety is a feeling of fear and apprehension. Karen Horney makes a distinction between fears and anxiety. To Horney, a fear is a reaction to a certain danger, to which the individual can make a specific adjustment, whereas anxiety is a reaction to a threat to any pattern which the individual has developed which he/she feels his/her safety to depend. Horney states that "conflict leading to anxiety in a child is between dependency on the parents and hostile impulses against the parents." Hostility directed towards the parents has to be repressed because of the child's dependency on the parents. Repression

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creates an inner unconscious conflict, and in turn, the child feels defenseless and helpless. According to Horney, anxiety develops early in life due to disturbed relationships between the child and significant individuals in his/her environment.

After reviewing the various theories of anxiety, Rollo May came to the conclusion that anxiety is more than an intense fear, yet it is a threat to an individual's self-esteem, personality, sense of worth as a person, physical life, or psychological existence. May cites Freud and Sullivan who both believe that anxiety is a "cosmic" experience. It is "cosmic" in that it invades us totally, and we cannot see it separately from ourselves. According to May anxiety arises from the fact that the security base of the individual is threatened, and since it is in terms of this security base that the individual has been able to experience himself/herself as a self in relation to objects, the distinction between subject and object also breaks down.29

Several theorists have described adolescence as a period of "turmoil," "storm and stress," and a vulnerable

period. Many traditional psychoanalytic theorists focus on the traumatic features of adolescence, as well. Nixon refers to the "shock of puberty" as a stage of anxiety. According to psychoanalytic theory, any age may be confronted with problems or the inability to handle impulses, but the maturation of sexual impulses makes adolescence especially stressful. In addition, a few theorists suggest that adolescence is a very emotional period, yet hardly enough to justify calling it a period of storm or stress. Shuster and Asburn explain normal behavior in the context of time, culture, and specific situations that change in our complex society. The authors suggest that there may be no "normal" teenagers in our society. Rather, there may be several unique individuals who have their own, distinct way of getting through adolescence.

Statement of the Hypothesis

Considering the relationship between health and psychosocial development, the literature and theoretical framework have led the researcher to make the following


hypotheses for study:

(1) Adolescents diagnosed with sickle cell anemia will experience undue amounts of personal and social adjustments.

(2) Sickle cell anemia will effect the adolescents self-concept.
CHAPTER THREE

METHODOLOGY

Research Design

This study is a descriptive study aimed at identifying and evaluating the psychosocial issues that adolescents with sickle cell anemia are confronted with in the Metropolitan Atlanta area. A descriptive study seeks to discover the truth with respect to the present situation. This method is a structured attempt to obtain information about the psychosocial issues associated with sickle cell anemia among adolescents.

Descriptive research is concerned with the prevailing condition at the time of the study. This particular design is utilized because it permits exploration and correlation between certain variables.

Sampling

Purposive or judgmental sampling is the sampling technique used in this study. This sampling was chosen because it is a non-probability sampling technique that is simple, inexpensive, and convenient. This particular sampling is one in which the researcher uses his/her judgement and prior knowledge related to the research
problem to select people who would best serve the purposes of the study.

All participants in the study were identified as adolescents, ranging from 12 to 17 years of age, and who have been diagnosed as having sickle cell anemia. The researcher obtained a list of 19 adolescents who participated in the Sickle Cell Summer Retreat program sponsored by the Sickle Cell Foundation of Georgia, Inc. The study consisted of 13 participants.

**Data Collection Procedure**

The instrument utilized in this study was a questionnaire, developed by the researcher in order to examine the relevant variables that concern the research question. The questionnaire consisted of twenty questions designed to evaluate the existing psychosocial factors that adolescents with sickle cell anemia are confronted. The questionnaire was a self-rating Likert scale in which subjects answered the statements by stating whether they strongly agree, agree, not sure, disagree, or strongly disagree. The subjects were asked to respond to statements like "I feel very good when I am with my friends," "I think I need more self-confidence," "I believe I am an independent person," and "I worry about getting sick."
Questions with regards to peer relationships, self-esteem, independence, and stress were examined in this study. The items on the questionnaire were designed to obtain information from the respondents regarding their feelings and attitudes about the problems and issues they experience. Each question was designed to effectively explore only those variables that relate to the overall study.

The initial contact with the participant and his/her parent(s) was via telephone conversation/interview. During the interview the researcher identified herself and her relationship with the Sickle Cell Foundation of Georgia, Inc., and purpose of the study was explained. Once the parent(s) and adolescents agreed to participate, the researcher administered the questionnaire via telephone. During the weeks of January and February of 1994 the data was collected.

**Data Analysis**

Simple descriptive statistics were used to evaluate the data. Descriptive statistics consists of a form of reporting the major characteristics of a group of known size, where the focus of interest is primarily on the group itself. It also permits the researcher to describe
several scores. Actual statistics used to measure each participants response on the questionnaire were percentages and frequencies. Tables and graphs were used to demonstrate the frequency distribution of the data. Demographic variables used in the analysis were age, gender, number of siblings, rank order in the family, and parent's yearly income.

Psychosocial adjustment is measured with four measures. The first measure is peer-relationship. Responses were summed to form a scale which ranges from 6 to 30. Scores from 6 to 21 indicated poor peer-relationship. Moderate peer-relationship scores ranged from 22 to 24. High scores of 25 and above indicated good peer-relationship. The second measure is a measure of self-concept. The items were summed to form a scale which ranges from 5 to 25. Low scores from 5 to 17 demonstrate low self-concept. Moderate self-concept scores ranged from 18 to 20. High scores of 21 and above demonstrate high self-concept. Third, the independence items were summed to form a scale which also ranged from 5 to 25. Respondents who score from 5 to 17 show somewhat independence. Moderately independent scores range from 18 to 20. Very independent scores range from 21 and above. Stress was the final measure. Responses were summed to form a scale which
ranged from 4 to 20. Low stress scores ranged from 4 to 14. Moderate stress scores ranged from 15 to 16. Scores from 17 to 20 demonstrate high stress.
CHAPTER FOUR
PRESENTATION OF RESULTS

Demographic Information

This study consisted of 13 black participants. The population group ranged in age from 12 to 17 (Table 1). Five respondents (38.5%) were fourteen years old; three respondents (23.1%) were seventeen years old; two respondents (15.4%) were twelve years old; another two respondents (15.4%) were fifteen years old, and one respondent (7.7%) was thirteen years of age. The data showed that eight respondents (61.5%) were male, whereas five respondents (38.5%) were female.

Table 1
Age and Gender of Respondents
(N=13)

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<td>23.1</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>8</td>
<td>61.5</td>
</tr>
<tr>
<td>female</td>
<td>5</td>
<td>38.5</td>
</tr>
</tbody>
</table>
The findings further revealed that 12 of the 13 respondents had siblings (Table 2). Five respondents (38.5%) had one sibling; four respondents (30.8%) had three siblings; three respondents (23.1%) had two siblings; and one respondent (7.7%) had no siblings. Concerning the subjects rank order in their families, 38.5% of respondents are the youngest child, 30.8% of respondents are the middle child, 23.1% of respondents are the oldest child, and 7.7% of respondents are only child.

Table 2
Number of Siblings and Rank Order in Family (N=13)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Siblings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>7.7</td>
</tr>
<tr>
<td>1</td>
<td>5</td>
<td>38.5</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>23.1</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>30.8</td>
</tr>
<tr>
<td>Rank Order in Family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>oldest child</td>
<td>3</td>
<td>23.1</td>
</tr>
<tr>
<td>middle child</td>
<td>4</td>
<td>30.8</td>
</tr>
<tr>
<td>youngest child</td>
<td>5</td>
<td>38.7</td>
</tr>
<tr>
<td>only child</td>
<td>1</td>
<td>7.7</td>
</tr>
</tbody>
</table>

In table 3, the majority of the respondent's (53.8%)
parent's yearly income fell among the medium income level between $15,000 and $25,000. Four (30.8%) of the parent's yearly income was considered within the low income range between $0 and $15,000. Two (15.4%) of the parent's yearly income was considered among the high income range from $25,000 and above.

Table 3
Respondent's Parent's Yearly Income (N=13)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>low ($0 - $15,000)</td>
<td>4</td>
<td>30.8</td>
</tr>
<tr>
<td>medium ($15,000 - 25,000)</td>
<td>7</td>
<td>53.8</td>
</tr>
<tr>
<td>high ($25,000 and above)</td>
<td>2</td>
<td>15.4</td>
</tr>
</tbody>
</table>
Peer Relationship

Figure 1

Figure 1 reveals that only 1 respondent (7.7%) had a poor peer relationship; 4 respondents (30.8%) had moderate peer relationships; and 8 respondents (61.5%) had good peer relationships. Therefore, the majority of respondents have a good relationship with their peers and get along with their peers.
Self-Concept

Figure 2

Figure 2 shows that 5 out of 13 respondents (38.5%) had a low self-concept, whereas 4 respondents (30.8%) had a moderate self-concept; and another 4 respondents (30.8%) had a high self-concept. Overall, a marginal number of respondents lack self-confidence and are self-conscious.
Figure 3 shows that 5 out of 13 respondents (38.5%) viewed themselves as being somewhat independent; 4 respondents (30.8%) believed they were moderately independent; and 4 respondents (30.8%) stated they were very independent. Hence, a marginal amount of respondents have no sense of personal freedom.
Concerning the respondents' stress level (Figure 4), the findings demonstrated that only 1 respondent (7.7%) had a low level of stress; 2 respondents (15.4%) had a moderate stress level; and 10 respondents (76.9%) had a high stress level. As a result, a significant number of respondents reported experiencing extreme amounts of stress.
The present results support the hypothesis that adolescent respondents diagnosed with sickle cell anemia experienced undue amounts of personal and social adjustments. Although some of the respondents maintain good relationships with their peers, a marginal amount of respondents believed that they were not independent and a significant number of them had high stress levels. In addition, the results further supported the hypothesis that sickle cell anemia will effect the adolescent's self-concept. Though marginal, many of the respondents feel they need more self-confidence.

The results of this study suggest that adolescents with sickle cell disease are likely to be affected by the disease. These participants are not severely maladjusted; however, they appear vulnerable to emotional and social problems. They may experience relationships that are vulnerable to feelings of inadequacy or fear of being alone. These participants may function independently and effectively until an unpredictable sickle cell "crises" requires dependent care at home or in the hospital. Since sickle cell anemia is a chronic disease which is not curable, these individuals may always struggle between independence and dependence. These challenges and
difficulties suggest that sickle cell anemia may alter the adolescent's capacities and competencies to take on certain life roles.

One interpretation of the present findings might be that adolescents with sickle cell anemia may feel some sense of freedom and feel more in control of their lives when they are with their peers. Perhaps, through the peer group, these adolescents can develop a sense of self and move away from dependency on parents. Yet, while at home, if the parents respond as if their well-adolescent is still ill, the adolescent may have the experience of feeling helpless and dependent. One may also consider that unpredictable sickle cell "crises," which may interrupt social relationships, activities, and academic achievements, may cause adolescents with the disease to feel less confident in self. These adolescents may feel unable to maintain a high level of performance in school and social areas, and as a result, they may have difficulty maintaining a positive self-concept.
CHAPTER FIVE
SUMMARY AND CONCLUSION

This study has attempted to investigate the psychosocial problems experienced by adolescents with sickle cell anemia. When studying sickle cell disease, many researchers investigate the physical aspects of the disease and accompanying treatment interventions. It is the understanding of this researcher that stress, emotional, and social issues may impact the illness. Consideration of these factors is essential if problems regarding research and clinical issues are to be remedied and future progress realized.

The results of this study reveal that adolescent participants between the ages of 12 and 17 with sickle cell anemia maintain good peer relationships, in which they find pleasure in their friends and feel "part of the group." However, it appears that these adolescents have a low self-concept and high stress level. The results further suggest that this group of adolescents have not achieved an appropriate level of independence with regard to a sense of personal freedom.

Limitation of the Study

This study was limited to a sample utilizing only a
group of adolescents associated with the Sickle Cell Summer Retreat at the Sickle Cell Foundation of Georgia, Inc. Hence, the sample is not necessarily representative of all adolescents with the disease in the Metropolitan Atlanta area. As a result, one cannot generalize these findings to the total population of sickle cell adolescents in Atlanta, or in other parts of the country. This group of adolescents was appropriate for the purpose of this study; however, additional studies will need to be conducted with other adolescents suffering with sickle cell anemia for more detailed information.

Another limitation of this study was that the only contact with the participants was via telephone conversation/interview. It is possible that when the researcher called, some of the participants were preoccupied and might have hurried through the questionnaire or their attention might have been elsewhere. Moreover, the study's sample size was limited, in that, many of the subjects could not be reached by telephone because they either were not available, had moved to another address, or their telephone was disconnected.

**Suggested Research**

Further research is needed to evaluate and
investigate the relationship between sickle cell disease and psychosocial development. Future research might examine whether the frequency of crises have an impact on the psychological and social adjustment of adolescents. Perhaps the adolescent feels more in control of his/her life when he/she feels healthy. However, after a painful crisis the adolescent who once felt independent may be forced to depend on his/her parents and the physician, or may withdraw from his/her peer group.

Another area of concern might be to compare the psychosocial adjustment of sickle cell adolescents to other chronically ill adolescents. It would be interesting to note if all chronically ill teenagers are confronted with similar adjustment issues, or if one group of ill adolescents is able to psychologically and/or socially adjust more so than sickle cell adolescents.

Implications for Social Work Practice

Social workers can play a significant role in meeting the psychosocial needs of adolescents with sickle cell anemia. Through increasing educational and counseling techniques, the social work profession might help teenagers cope with their feelings, anxiety, self-esteem, personal and social adjustments.
In health care settings, social workers can advocate for support services which address psychosocial effects of the disease. They can also educate the patients and their families about the physical and emotional effects of sickle cell anemia. Social workers are the primary psychosocial professionals who have contact with the patient and the family; therefore, they may also serve as a liaison between the physician and the parents. Furthermore, social workers are needed in schools and communities to educate the general public about the extent and problems of sickle cell disease as well as the importance of testing for the sickle cell trait. Through these efforts, the social work profession can significantly help those who suffer from sickle cell disease to live less stressful lives, to develop greater self-confidence, and to become more independent.
APPENDICES
Mr. Gerald Mansfield
Patient Service Coordinator
The Sickle Cell Foundation of Georgia, Inc.
2391 Benjamin E. Mays Drive, S.W.
Atlanta, Georgia 30311-3291

Dear Mr. Mansfield,

I am a graduate student in the Master of Clinical Social Work program at Clark Atlanta University. In order to receive the MSW degree in May of 1994, I am required to complete an acceptable thesis or research project. I am writing to you because I am particularly interested in obtaining subjects from the Sickle Cell Foundation of Georgia, Inc., in order to research the psychosocial adjustments of adolescents with sickle cell anemia. I have enclosed my proposal and questionnaire for your consideration.

It is with sincere hope that your agency will allow me to research this important topic and gain valuable information from adolescents with the disease. If you have any questions regarding my proposal or questionnaire or would like to further discuss this study, you may contact me at (404)221-5099.

Thank you in advance for your time and consideration.

Sincerely,

Vaniethia R. Winn

Enclosure
APPENDIX II

QUESTIONNAIRE FOR ADOLESCENTS WITH SICKLE CELL ANEMIA

PART I

Personal Data

Age:______

Sex (circle one):  male    female

Race:______________________

Number of Siblings:  brothers_____  sisters_____

What order in the family best describes you? (check one):

   oldest child  ____
   middle child  ____
   youngest child  ____
   only child  ____

Parents Yearly Social Economic Status (check one):

   $0 - 5,000  ____
   $5,000 - 10,000  ____
   $10,000 - 15,000  ____
   $15,000 - 20,000  ____
   $20,000 - 25,000  ____
   $25,000 - 30,000  ____
   $Above 30,000  ____

PART II

Instructions: Read each of the following statements and
decide whether you agree or disagree by circling the number that best describes your response. Complete all statements using the key below:

1  Strongly disagree
2  disagree
3  not sure
4  agree
5  strongly agree

Please begin.

1. I feel very good when I'm with my friends. 1 2 3 4 5
2. I get along with my friends. 1 2 3 4 5
3. My friends enjoy having me around. 1 2 3 4 5
4. My friends are a real source of pleasure to me. 1 2 3 4 5
5. I don't feel like I am "part of the group." 1 2 3 4 5
6. I really feel like I am disliked by my friends. 1 2 3 4 5
7. I think I am a rather nice person. 1 2 3 4 5
8. I feel very self-conscious when I am with strangers. 1 2 3 4 5
9. I think I am a beautiful person. 1 2 3 4 5
10. I think other people have more fun than I do. 1 2 3 4 5
11. I think I need more self-confidence. 1 2 3 4 5
12. I think I am able to participate in every day activities. 1 2 3 4 5
13. I believe I am an independent person. 1 2 3 4 5
14. I am treated like a child because of my illness. 1 2 3 4 5
15. My parents are overprotective of me.
16. I believe I have control over my life.
17. I worry about getting sick.
18. I worry that people hate me because I'm always sick.
19. I am concerned about my bodily changes.
20. Thoughts of the future are always on my mind.
APPENDIX III

Explanation of and Agreement to Participate in the Survey Study

I am a graduate student in the School of Social Work at Clark Atlanta University. As part of the fulfillment of requirements for the Masters degree, I am conducting a study on the psychosocial issues faced by adolescents with sickle cell anemia. Your participation is important and appreciated.

You are asked to complete a questionnaire that has been approved by my advisor at Clark Atlanta University. It will take approximately 20 minutes of your time. Please answer each question as carefully and accurately as you can. However, if you think a question is too personal, you may choose to skip it.

Please be assured that I will take all necessary precautions to ensure your anonymity. Thank you very much for your time and your cooperation.
BIBLIOGRAPHY


Hurtig, A.L. and Park, K.P. "Adjustment and Coping in


